APPENDIX B

NHS England

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

Public Consultation Mid-Point Review

South East London JHOSC – Informal discussion/briefing -21 November 2023

Purpose of paper

- This paper has been shared with the South East London Health and Overview Scrutiny Committee ahead of the informal meeting/briefing on 21st November 2023 as background briefing material. NHS England will present a summary of this information at the meeting.

- If further detail is sought, we would like to encourage Committee members to visit our website that includes our consultation document; pre-consultation business case; pre-consultation feedback report; and detailed information on a range of topics.

Background and Context

Overview

- Specialist children’s cancer services in England are led and coordinated by Principal Treatment Centres.
- The Principal Treatment Centre for children living in Brighton and Hove, East Sussex, Kent, Medway, south London and most of Surrey is provided in partnership between The Royal Marsden NHS Foundation Trust at its site in Sutton, and St George’s Hospital in Tooting, south west London.
- The service they provide is safe and high quality. But the very specialist cancer treatment services at The Royal Marsden are not on the same site as the children’s intensive care unit, which is at St George’s Hospital.
- National clinical requirements for Principal Treatment Centres are set by NHS England. They mandate very specialist cancer treatment services for children – like those at The Royal Marsden – MUST be on the same site as a level 3 children’s intensive care unit and other specialist children’s services. This is non-negotiable.
- The current Principal Treatment Centre does not and cannot comply which means very specialist cancer services currently provided on The Royal Marsden site need to move.
- The purpose of the consultation is to understand the impact of implementing either option for the future location of the Principal Treatment Centre, to test and update our plans to mitigate impacts and to understand the impact of moving conventional radiotherapy from The Royal Marsden to University College Hospital.

Why things need to change (1)

The five main reasons why specialist children's cancer services at The Royal Marsden need to move are:

Hospital transfers of very sick children for intensive care add risks and stress

- Every year, a small number of very sick children who need intensive care are transferred eight miles from the specialist children's unit at The Royal Marsden's Sutton site to St George's children's intensive care unit at Tooting.

- This is done safely. But urgent transfers of very sick children to another hospital for level 3 intensive care services that can give life support, even in a special children's ambulance with an expert team on board, add risks to what is already a very difficult situation. These risks can only ever be managed. Transfers of very sick children also put added stress on patients, parents, and the staff involved.

The intensive care team is not currently able to provide face to face advice on the care of children on the cancer ward

- Currently, the Principal Treatment Centre's intensive care specialists are at St George's Hospital while most specialist care for children with cancer is at The Royal Marsden. Some children every year have to be transferred by ambulance from The Royal Marsden to the cancer ward at St George's Hospital as a precaution, in case they suddenly get worse and need intensive care. It can be disruptive and stressful for them.

- Intensive care specialists can't work closely with specialist cancer teams to help children stay well enough to avoid intensive care if they are not all on the same site.

Why things need to change (2)

The five main reasons why specialist children's cancer services at The Royal Marsden need to move are:

There is a need to improve children and families' experience when patients require intensive care and other specialist children's services

- Some specialist children's services needed by children with cancer are not on site at The Royal Marsden. Staff at The Royal Marsden arrange for children to attend or be safely transferred to other hospitals as needed.
- Parents and staff say having to get to know new members of staff at different locations, especially at a time of crisis, can increase families' anxiety and distress.

As already described, the current Principal Treatment Centre does not and cannot meet national requirements

- The national service specification for Principal Treatment Centres was approved by NHS England in 2021 after being developed by patients, parents and professionals, and must now be implemented.

Although it offers a wide range of innovative treatments, the current Principal Treatment Centre is excluded from giving a specific type of new treatment, and others expected in the future

- Innovative cancer treatments are bringing new hope for children and families. Some have a greater risk of complications – such as too big a response from a child's immune system – that could require urgent support from an on-site intensive care team. As a result, they can only be given at children's cancer centre's on the same site as a children's intensive care unit. The current Principal Treatment Centre is excluded from giving a specific type of new treatment because it does not have an intensive care unit. Other similar treatments are expected in the future.

Why things need to change – conventional radiotherapy

While The Royal Marsden currently provides high quality conventional radiotherapy treatment (using high energy x-rays) for children as part of their care, the proposed move of specialist children's cancer services to either Evelina London or St George's Hospital, alongside advances in radiotherapy, means we propose this service is provided differently in the future.

This is because:

- It would be difficult to sustain the conventional radiotherapy service for children at The Royal Marsden without the staff and facilities of the Principal Treatment Centre on site (and which it is an integral part of)
- Radiotherapy services for children are changing. More children will be treated with proton beam therapy in the future; this means we expect the number of children requiring conventional radiotherapy services to fall making a high-quality service at The Royal Marsden even harder to sustain.

This means that:

- Both options in our consultation propose that children's conventional radiotherapy moves from The Royal Marsden to University College Hospital in central London.
- Proton beam therapy is already provided at University College Hospital. Bringing all radiotherapy services together in a larger centre would create opportunities to improve outcomes for children in the future.
- Our proposals do not affect radiotherapy services for teenagers and young adults or adults provided at The Royal Marsden.

Who the changes would affect

Around 1,400 children, aged one to 15, are under the care of the Principal Treatment Centre. In 2019/20, 35 children were transferred from The Royal Marsden to St George's because they needed or might need intensive care.

In 2019/20, the Principal Treatment Centre treated 536 children as inpatients. Children also receive some of their care closer to home in local shared care units. More than 60% of the center's patients are from outside London.

1,373 children were treated by the Principal Treatment Centre in 2019/20

536 had inpatient care (they were admitted to The Royal Marsden or St George's for day care or a stay of at least one night)

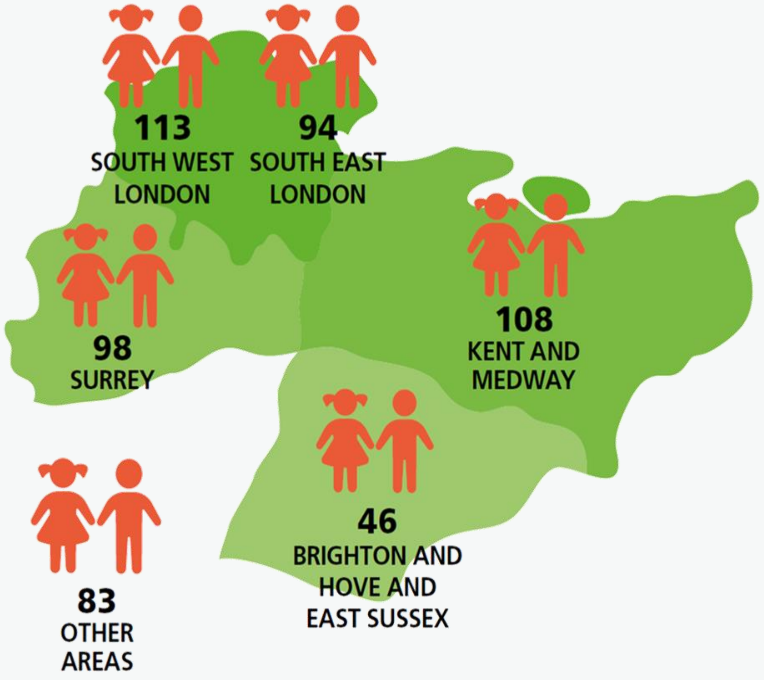
1,367 had outpatient care (they came to The Royal Marsden or St George's for an appointment)

84 had intensive care (15 came from The Royal Marsden, others were at St George's or transferred from their local shared care unit)

41 had conventional radiotherapy at The Royal Marsden.

- **113** children from south west London
- **108** children from Kent and Medway
- **98** children from Surrey
- **94** children from south east London
- **46** children from East Sussex and Brighton and Hove
- **83** children from other areas.

The number of children attending for outpatient care followed a similar pattern.



There are 15 shared care units across the catchment area which provide supportive care working closely with the children's cancer centre. These are not impacted by this consultation.

**Further detail available on pages 15 to 17 of consultation document*

The process we’re following

Where we’ve been and where we are now

Develop a Case for Change

Develop the clinical models

Development of fixed points

Development of hurdle criteria

Identify long list of options

Application of hurdle criteria to produce a shortlist of options

Evaluation of shortlist of options

Development of a Pre-Consultation-Business Case (PCBC)

Pre-consultation engagement

Advice from Clinical Senate, and assurance from NHS England

We are here

Public consultation

26 September to 18 December 2023

Evaluation of consultation responses and other relevant information

Final decision taken by NHSE leaders

Early 2024

A formal reconfiguration process is required when moving a significant service from one site to another to ensure all stakeholders have the opportunity to review and comment on the case for change, clinical model and proposals.

**There is lots more detail on our website; including our pre-consultation business case; Clinical Senate Review and our response to it; and information on our options development process.*

An overview of the options appraisal process

We have already run an option appraisal process which concluded in January 2023 – consisting of four elements:

Longlist to shortlist

In line with NHS formal reconfiguration guidance, a short list of options was developed from a long list of all potential options by first applying **fixed points** (things that cannot be changed) and then **hurdle criteria** (things that need to be delivered by any option).

Following this stage, **two options remained**: the trusts running St George's and Evelina London Children's hospitals. Both were asked to complete a formal proposal document outlining how they would deliver the service using set criteria.

Evaluation Criteria

Evaluation criteria were developed over 2020/2022, reflecting the requirements of the service specification and incorporating research, patient and carer experience, capacity and resilience.

This resulted in four domains for evaluation: clinical, research, enabling requirements, and patient and carer experience. Measurable sub-criteria were developed for each domain, drawing on expertise from clinicians, parents, and managers from in London and outside London.

Weighting the evaluation criteria

Four expert panels comprised of patient and carer representatives, charities, researchers from outside London, clinicians (medical and nursing) from in and outside London, managers, and experts in various specific fields (e.g. emergency preparedness, human resources) were established to weight and score the criteria within each domain.

In September 2022, the Programme Board finalised the high-level weighting given to each of the domains. Between October and November 2022, the identified panels for each domain undertook a virtual, two-stage exercise to establish the sub-weights for the criteria within their domain.

Scoring the proposals

In November 2022 both Trusts submitted their proposals, aligned with the domains and sub-criteria. During December 2022, the topic-specific expert panels scored the submissions against each of the sub-criteria for their specific domain.

Final scores were calculated for each option using the pre-agreed weighting.

**There is lots more detail on* How we identified the options *and* developed the evaluation criteria *available on our website*

The shortlisted options (options we are consulting on)

Shortlisted options (1)

Over the past three years, we have engaged widely with patients, families, staff, cancer charities, patient groups, cancer specialists and health and care partners across the catchment area, to find out what is important to them about these services and to get their input into our process.

We followed a best practice approach to identifying the possible ways the Principal Treatment Centre could be provided in the future. We identified ‘fixed points’ and ‘hurdle criteria’ which were applied to a long list of eight possible solutions. This resulted in two potential locations for the future centre:

- **Evelina London Children’s Hospital in Lambeth, south east London, run by Guy’s and St Thomas’ NHS Foundation Trust** with conventional radiotherapy services at University College Hospital

- **St George’s Hospital, in Tooting, south west London, run by St George’s University Hospitals NHS Foundation Trust** with conventional radiotherapy services at University College Hospital

Both locations deliver outstanding rated children’s services, and both could deliver a future Principal Treatment Centre that meets the service specification.

- Both propose that conventional radiotherapy services for children currently provided at The Royal Marsden move to University College Hospital, central London, meaning that all radiotherapy services for children in south London would be provided there in the future, instead of only some, as now.

**Further detail available in our consultation document*

Shortlisted options (2)

Four advisory groups and an independent clinical review group helped us develop evaluation criteria to compare and assess the two options for the future Principal Treatment Centre.

Four panels of experts – cancer specialists and other doctors and nurses, parents, representatives of children's cancer charities, researchers and other experts – reviewed the two options against key areas. Both options scored highly but Evelina London Children's Hospital scored higher. On this basis, at this stage in the process, Evelina London is the site we prefer for the future Principal Treatment Centre.

However, we are open-minded about both options and open to any other evidence the public may share.

No decision will be made until the public consultation has concluded, the feedback analysed, and all relevant data, evidence and other factors, including the consultation responses, have been carefully considered.

**There is further detail on the scoring outcome in our consultation document (p55-57) with further detail on* how the options were assessed and scored *on the consultation website.*

The options

Both Evelina London and St George's would provide all the services that must be on the same site as the Principal Treatment Centre, including a Level 3 children's intensive care unit. They both have the facilities to provide the service and flexibility to cope with more demand, if needed.

Would make sure the future Principal Treatment Centre has:

- ✓ good facilities for children with cancer and parents
- ✓ beds for parents to stay next to their children and nearby
- ✓ play specialists to support children, spaces for young children and teenagers, outdoor space, parents' lounges, cafes, self-catering options and rooms for parents to stay.
- ✓ involvement of children, parents and staff in the design of the future centre if it was at their hospital.
- ✓ a range of ways to support travel and access, including dedicated parking; patient-transport services (see next slide).
- ✓ high quality children's healthcare and education services which are already rated outstanding at both locations.

Neither Evelina London nor St. George's

- currently delivers the specific specialist cancer services that are based at The Royal Marsden
- would provide all 'readily available' services listed in the national service specification – these are services which do not need to be on site but must be available at all times. Most would be on site. However, for radiotherapy, patients would go to University College Hospital. In addition:
    - neurosurgery would not be on site if the future centre was at Evelina London - *patients would go to King's or St George's Hospital*
    - specialist cardiology and nephrology (heart and kidney services) would not be on site if the future centre was at St George's Hospital – *patients would go to Evelina London.*

**Further detail available in our consultation document, from page 41*

Evelina London proposal

- Purpose-built specialist children's hospital. All staff are experts in children's healthcare
- Is a specialist children's heart and kidney centre
- Runs the retrieval service which transfers seriously ill children, including those with cancer
- A children's intensive care unit with capacity for 30 beds. Two of these beds are expected to be needed for children with cancer
- In 2019/20, treated almost 120,000 young patients living in Kent, Medway, south London, Surrey and Sussex
- Does not currently provide the Principal Treatment Centre or surgery to remove tumours. It has a team of 54 surgeons with wide ranging expertise and would work with them, and others to create a team to undertake this surgery if it became the future centre
- Has more than 70 staff working on more than 180 national or international research projects in child health
- Guy's and St Thomas NHS Foundation Trust, which runs Evelina London, attracted more than £25 million of funding for research staff in 2019/20.

If the future Principal Treatment Centre was at Evelina London, it would have:

- A new children's cancer inpatient ward in Evelina London's main children's hospital building
- A dedicated children's cancer day-case unit and a dedicated outpatient space for children with cancer next to other facilities for children. Diagnostic services in the children's hospital building
- Outdoor spaces on site and at a park directly opposite the hospital
- Intensive care, cancer surgery and all other expert care provided on-site, other than services which are not changing, radiotherapy (proposed to be provided at University College Hospital) and neurosurgery which would continue to be at King's College Hospital and St George's Hospital.

**Further detail is available in our consultation document, page 44-45*

St George’s Hospital proposal

- A large teaching hospital. Provides specialist services for adults and children
- Provides all the intensive care, most cancer surgery, and other specialist children’s services for the current Principal Treatment Centre, which it provides in partnership with The Royal Marsden
- Has a 14-bed children’s intensive care unit. Two of these beds, like now, are expected to be needed for children with cancer
- In 2019/20 treated almost 60,000 young patients mainly living in south west London, Surrey and Sussex
- 25 years experience of caring for children with cancer
- All children’s service staff are experts in children’s healthcare
- Provides neurosurgery alongside King’s College Hospital
- Has 25 children’s researchers and a good track record in national and international research
- St George’s University Hospitals NHS Foundation Trust, which runs St George’s Hospital, attracted £8.2 million of funding for research staff in 2019/20.

If the future Principal Treatment Centre was at St George’s Hospital, it would have:

- A new children’s cancer centre in a converted wing of the hospital with its own entrance
- Dedicated outpatient clinics and day case treatments including chemotherapy and minor operations in the cancer centre, with diagnostic services close by
- Dedicated garden space which could be closed off to other patients and visitors.
- Intensive care, cancer surgery and all other expert care provided on-site, other than services which are not changing, radiotherapy (proposed to be provided at University College Hospital), and specialist heart and kidney services which would continue to be at Evelina London.

**Further detail is available in our consultation document, page 46-47*

Support with travel and access

Through engagement with families and J/HOSCs, we have heard that travel times and access to the future Principal Treatment Centre are important. Many travel more than an hour to the current service and also by car.

An independent travel analysis looked at journey times and found:

Public transport

Both options are very similar, or faster, to get to by public transport than to The Royal Marsden now, for the vast majority of people

Car

By road, for <u>many</u> going to St George's Hospital and <u>most</u> going to Evelina London, the journey time would be longer

For University College Hospital it is a similar picture.

There would be a range of measures to support people with increased travel including:

- help to plan journeys to hospital
- financial support to help with travel costs – such as, the ability to reclaim ULEZ charges and congestion charges (if applicable)
- non-emergency transport services
- space for families to stay
- easy arrangements at the site, including for dedicated parking and drop-off
- convenient appointment times
- more care closer to home

Both potential providers of the future Principal Treatment Centre have committed to developing action plans to ensure effective delivery of these measures.

We are keen to hear more from families during consultation about this important issue and to work with them on measures to support with travel and access.

**Further detail available on pages 28 – 29 and 48 – 51 of consultation document; also see our dedicated information sheet on* <u>how travel times were assessed</u> and on <u>getting there</u>

Engagement

Our approach is informed by ongoing engagement

Engagement phase	How engagement is influencing the process
Early engagement and options appraisal (March 2020 - January 2023)	Fed into the development of the case for change and options appraisal process.
Pre-consultation (March 2023 – August 2023)	Helped us to plan the consultation and understand what some of the key issues may be.
Consultation (September – December 2023)	Will help us understand the impact of implementing either proposal and consider mitigations.
Decision-making (early 2024)	Feedback considered, alongside other evidence, to support the decision-making process.

We are here ⇨ Consultation

Stakeholders who have been involved in this process to date:

- Parents/carers, children and young people
- Trust staff
- Researchers
- Stakeholder Group
- Joint/Health Overview Scrutiny Committees (J/HOSCs)
- Greater London Authority (GLA)
- Members of Parliament (MPs)
- Clinical Advisory Group and other leading clinicians
- Senior managers and experts in specific fields (such as HR)
- Voluntary and community organisations including specialist children's cancer charities
- Independent experts.

Pre-consultation engagement

Pre-consultation (April to August 2023) helped us to refine and update our consultation materials, inform our consultation plan and build our understanding of the key issues.

We mostly spoke to those with direct experience of receiving or providing the service as well as voluntary and community organisations including specialist children's cancer charities.

We visited the South East London JHOSC and gathered feedback from members on our consultation plan and document.

We also heard from a range of people from across the catchment area including

- from a range of ages (both of children, young people and parents/carers)
- people who have physical or mental health conditions, disabilities, or illnesses other than their cancer
- people from black, Asian and other ethnic minority communities
- people who do not speak English as their first language

	739 **responses, in total, to the engagement**		**27** **engagement sessions** (including events, focus groups and meetings)
	313 **responses to online surveys**		**7** **visits to wards on the different sites to speak to staff and families**
	44 **direct responses via email**		**Over 2,015** **organisations and individuals directly**[2] **contacted to encourage responses**

**Further detail available in our consultation document (pages 34-28) and pre-consultation engagement report on our website*

Some of the ways we have responded to your feedback

You said*:

- You wanted to know more about parking spaces available at Evelina Children's Hospital.
- You wanted to be assured on arrangements for supporting staff from current service to transfer; including plans for retention, and where needed, recruitment.
- You enquired whether both potential providers were adequately prepared to meet the 2.5-year implementation timeline of this service change

We did/have*:

- The interim Equality and Health Inequality Impact Assessment (EHIA) includes a range of draft recommendations to support access to the future PTC. Recognising the importance of this, both Evelina London and St George's have set out their commitment to the development of detail plans to implement these. Both would provide dedicated parking for patients of the children's cancer centre. We have included more details in their consultation materials and want to gather more feedback in consultation.
- Through our pre-consultation engagement and ongoing consultation we want to continue to hear from staff about things which are important to them and are working with trusts to encourage this. This is allowing us to draw on their experience and understand their needs to explore ways to help ensure as many staff as possible transfer to the future service. Throughout the implementation phase we will have a dedicated focus on workforce. We plan to make a joint appointment between NHSE and current service to support this.
- Both potential providers have shared plans for transitioning the PTC over a 2.5 year period. Once a decision has been made, the implementation phase will involve work by a number of stakeholders to do detailed implementation planning for the service change. An Implementation Board will be established to oversee/help ensure a smooth transfer. We know from families and staff that continuity of care will be really important.

**in our meeting with the JHOSC, July 2023*

**Further detail available in our pre-consultation engagement report on our website*

Our public consultation

There are opportunities open to everyone to get involved and share their views – all feedback is sent directly to the independent agency analysing the consultation and will not be directly attributable to individuals. **The consultation runs from 26 September to 18 December.**

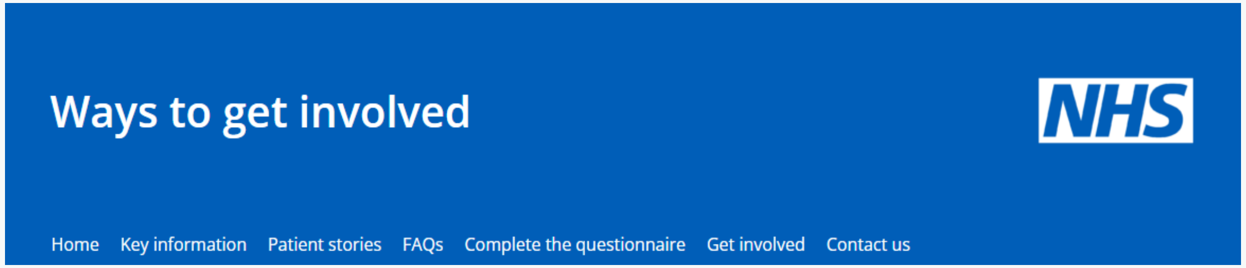
How you can contact us during consultation:

Email: england.childrenscancercentre@nhs.net

Phone: 0800 135 7971

Toys used by play specialists to talk to children being treated for cancer about the children's cancer centre consultation, and hear their views.

Full details and consultation documents are available on our website: **www.transformationpartnersinhealthandcare.nhs.uk/childrenscancercentre**



Ways to get involved

Ways to feedback:

- Public listening events – sign up here
- Online full and easy read survey, printed easy read survey
- Email, phone and written responses (free to call and post)
- On-demand briefings/inviting us to join existing meetings
- Visits to both sites to see the hospital sites
- Useful resources for professionals - communications toolkit here

How we are hearing from parents and young people who currently use the service through our public consultation

The Royal Marsden, St George’s, University College London Hospitals are helping us to hear from parents, families and carers who have children impacted by cancer. We also want to hear from staff who work for the current service; or related services such as POSCUs.

We continue to work closely with national and local charities to share information and encourage responses. Activities to reach current parents, to ensure they have their voice, include:

- Letters to current and recent families (shared by Trusts on our behalf)
- Posters and materials physically on site that link to the questionnaire and consultation website
- Information shared by clinical colleagues to patients on wards and in outpatient areas
- Information shared with The Royal Marsden Parents Facebook Group
- Emails and telephone calls to 36 local and national specialist children's cancer charities to promote/raise awareness and encourage participation
- Arranging parent focus groups with those who attend the current PTC and/or use POSCU services
- Emails to parents who we engaged with during pre-consultation to encourage responses
- Play specialists are undertaking sessions to gather direct feedback from children with cancer – 6 sessions already completed

South East London: Communications and engagement activity

Communications

An example of organisations we have contacted across each south east London boroughs include:

- Healthwatch
- MPs
- Maternity Voice Partnership meetings
- Children and young people’s forums
- Individual borough level Healthwatch organisations
- Ethnic minority communities
- Disability and advocacy groups
- Carers and young carers organisations
- Specialist children’s cancer charities
- South East Cancer Centre
- Charities connected to the Trusts: Evelina London
- SEL ICB colleagues have shared information borough level networks

Engagement already undertaken in south east London

- Personal calls to over 50 organisations in the area supporting equalities groups to raise awareness of the consultation and to book in sessions
- Parent/carer group in Bromley
- Cancer Alliances, Operational Delivery Networks and Paediatric Networks
- Community focus group in south east London with children and families

Consultation: Mid-point review

Purpose of the mid-point

As set out in our consultation plan, the purpose of this mid-point review is to:

- Document the consultation and communication activities that have happened to date
- Review the overview response rate to the consultation and the response rate from specific stakeholder groups and geographical areas
- Identify any gaps in representation
- Consider the appropriateness of planned activity to address any gaps identified
- Provide an overview of key findings emerging from the consultation feedback
- Suggest next steps to address any gaps or other issues identified.

Explain Market Research have undertaken a desktop review of consultation feedback to produce an independent mid-point review document, including recommendations. This report is shared separately.

Next steps following the mid-point

- The independent mid-point report has been reviewed by the programme team and communications and engagement leads; it will also be shared with the Programme Stakeholder Group (including parents and local and national charities), Programme Board (including Trust, Integrated Care Board (ICB) and patient representatives), and Joint Overview & Scrutiny Committees (JOSCs).

- Following these meetings, our action plan, drafted in response to the mid-point document, will be updated and finalised.

- Based on feedback from Explain, the data shows we have made good progress with the consultation. **Our current and future plans for the remaining engagement period put us in a good position to close the consultation, as planned, on the 18th of December 2023.**

Communications and engagement activity to date

Communications activities have included:

These activities have been supported by our partners including the trusts involved and Integrated Care System colleagues.

- Letters directly to patients
- Sharing information and toolkits with partners to cascade through networks
- Media release and media interviews
- Sharing content on social media
- Joining meetings to brief stakeholders about the consultation
- Proactive phone calls to organisations
- Hard copy documents in hospital departments
- Staff periodically handing out information to families currently using services

Engagement activities have included:

Some of these activities have been supported by specialist organisations commissioned by NHS England.

- Community focus groups
- Play specialist sessions on wards
- Public listening event
- Joining community events with people representing equalities groups
- Meetings with wider clinical colleagues, MPs, Overview and Scrutiny Committee leads

You can read more about the communications and engagement work undertaken, to date, in Explain's independent mid-point report

Overview of uptake of the consultation

Key figures

- Over 680 responses have been received to the consultation so far*
- Over 450 online and hard copy survey responses
- 232 people engaged face to face/virtually
- Nearly 2200 people have visited the consultation website
- Over 270 documents have been downloaded from the website
- Over 410 views of our animation
- 27 meetings held – a mix of briefing and feedback sessions

**As of the 9th of November 2023*

You can read more about the uptake of the consultation to date in Explain's independent mid-point report

Overview of uptake of the consultation

We are hearing most from:

- Stakeholders in south west London
- Families who do not have direct experience of cancer services

We are hearing least from:

- Children, young people and families currently experiencing the service
- Staff working in the current service
- People from ethnic minority groups; people experiencing financial difficulties or who live in the most deprived areas; refugees, asylum seekers or those experiencing homelessness; families with poor literacy or language barriers;
- People outside London, specifically Kent & Medway and Sussex.

Our action plan, outlines planned activities are already in place to reach the groups identified.

You can read more about the groups responding to the consultation in Explain's independent mid-point report

Key themes

Below is a high - level summary of key themes, as reported by Explain, that are emerging from the survey and qualitative feedback received to date.

- Objections to the case for change
- Evelina London: challenges in travelling into central London
- St. Georges Hospital: challenges of travelling to the hospital
- Evelina London: perception that specialist services are lacking
- Evelina London: has the advantage of already being a specialist children’s hospital
- St. George’s Hospital: feedback about the quality of the existing estate
- St George’s: already an established provider of very specialist children’s cancer services

NHS England response to the mid-point review

We welcome the findings shared by Explain (set out in detail in their report), as part of our mid-point review, and can report that many of the recommendations made are already in the process of being actioned, through pre-existing planned work. Further actions have also been identified.

We have prepared a detailed action plan, together with these slides to respond to the recommendations.

As our mid-point review is still in progress, these documents are ‘living’ documents which we expect to continue to refine as we get further input from stakeholders. We continue to welcome feedback from JHOSC members on areas we can focus activity. We look forward to discussing our planned actions and adding to these in conversation with key stakeholders in the coming weeks.

NHS England high-level response to the recommendations

Explain Market Research have provided six high-level recommendations. Our response is outlined below. Further actions were also suggested and are contained within our detailed action plan.

Recommendation	NHS England action/ response
1. Addressing gaps in representation from specific target groups and geographical reach	We already have some meetings planned with the specific target groups (including patients, families and staff) identified as part of future engagement work. We are exploring further ways to reach these groups through funding sessions provided by external partners, where appropriate. We are working closely with partners in ICBs to consider how best to encourage uptake from outer London areas – as well as going to hospital sites, where possible.
2. Maximising reach from communications activity	We will be reviewing opportunities to refine our communications approach to ensure it is tailored appropriately to different stakeholders. As an example, with learning disability groups, making it explicit that, even though individuals may not have experiences of using cancer services, we want to understand their experiences of change and how this may affect people with learning disabilities. We continue to audit where and how information is being shared so that we can maximise partner networks and seek to bridge any gaps.
3. Objections to the proposals	We are reviewing opportunities to make the scope of the consultation even clearer, including the case for change, and to encourage more feedback on the options so that this can be captured and inform decision-making.
4. Comprehension of the proposals	We are going to produce audio versions of the proposals to support accessibility as well as embedding information about the proposals within the online survey itself. We will continue to discuss both proposals during face-to-face engagement sessions.
5. Support to complete the survey, particularly for specific target groups	Some organisations have already indicated that they are supporting target groups to complete the survey. we will continue to explore other alternative ways to support people to complete the survey.
6. Focus of children and young people play specialist sessions	We have already worked with the play specialists conducting these sessions to review the approach, to make sure we are getting the best possible feedback about the proposals through this method of engagement.

**Our detailed action plan can be shared with more detail*

Next steps and timings

What happens once the consultation closes?

- The public consultation is planned to close at midnight on 18th December.
- The consultation responses will be analysed by an external organisation and written up in a report which will be made publicly available. We will share this with the JHOSC also.
- No decision will be made until the public consultation has concluded, the feedback analysed, and all relevant data, evidence and other factors, including the consultation responses, have been carefully considered.
- Indicatively, NHS England are planning to take the decision on the future location of the Principal Treatment Centre in early 2024.
- Services would not move until at least 2026. We expect all the preparations for the future Principal Treatment Centre to take place within two and a half years.

**Further detail available in our consultation document*

Ensuring a smooth transition

Wherever the future Principal Treatment Centre is located, it will be important that the move of the service is as smooth as possible.

Following consultation, and once a location is decided, detailed planning will be undertaken. Some of the things this will focus on are:

- planning and undertaking building work to refurbish existing space for the future centre
- supporting as many staff as possible from the current service to move to the future centre and feel part of the new organisation
- maintaining the current levels of research activity and funding
- ensuring there are strong plans for the The Royal Marsden to continue to provide the teenage and young adult services and that arrangements for transitioning patients from the children’s service to this service continue to go smoothly
- putting everything in place for a safe, smooth transfer of patient care.

With any service change, we recognise it is also important to consider its impact on other NHS services and patient care.

For more information see our consultation document – page 52 - 54.

Benefits

Whether the future Principal Treatment Centre were at Evelina Children's Hospital or St George's, it would:

- end hospital transfers of very sick children with cancer from the specialist centre, who need or might need intensive care, eliminating the added risks and stress these transfers bring
- enable children to get more of their care on the specialist cancer ward and minimise the number of children admitted to intensive care, which can be stressful for children and families
- have more services on the same site than now, improving experience for many children and families
- meet the national requirements and be capable of offering cutting-edge treatments that need intensive care on site
- make it easier for different specialist teams treating the same child to work closely together, improving care for children and supporting new kinds of research
- make it easier for cancer and non-cancer specialists to learn from each other and share learning, and support future recruitment and retention of staff.

Raising further awareness of our consultation

Please continue to promote the consultation with your local communities – our website contains a comms toolkit with pre-written information that can be lifted.   We also have a range of materials to support patient engagement. Please get in touch if we can provide support or you have questions.

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

How you can contact us during consultation:

Email: england.childrenscancercentre@nhs.net
Phone: 0800 135 7971

Full details and consultation documents are available on our website:
www.transformationpartnersinhealthandcare.nhs.uk/childrenscancercentre

Appendices

Pre-consultation engagement

Early engagement

Early public engagement (March 2020 - March 2023)

Purpose: Seek early feedback about experiences of the current service and understand important features for a future service.

Activities:

- **2 surveys –** online and via staff on wards
- **9 Meetings with our Stakeholder Group** – of parents and charities
- **Over 60 contacts** (through our independent Chair of the Stakeholder Group) with parents/carers /caregivers – a combination of meetings, individual conversations with parents (telephone or virtual) and email contacts - to support their participation and engagement
- **Panel of parents** participated in the options appraisal process – scoring aspects of the patient experience domain
- **2 parent representatives** involved in reviewing the Equality and Health Inequalities Impact Assessment

Impact of engagement: Fed into the development of the case for change and influenced options appraisal criteria and weightings

Reach and representativeness

Through our early engagement work, **we heard from over 250 children, young people and families** through our surveys from:

- a broad range of geographies across the PTC catchment area, including in south east London
- a range of ages of parents and children
- 33% of survey respondents were from Mixed/Multi Ethnic, Asian, Black Ethnic Groups or other Ethnic groups

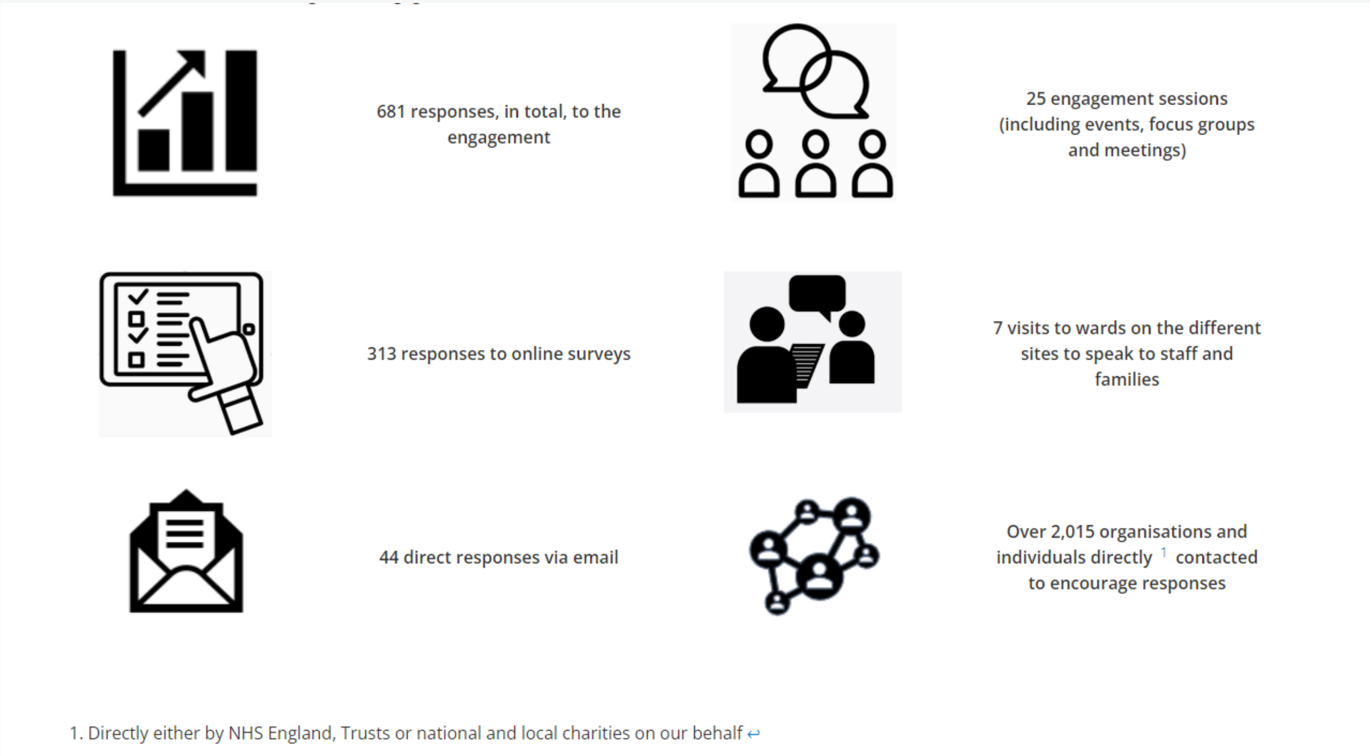
Our future focus has been on reaching a wide range of views – many currently in the service may not be affected in the future. Conversely, some families who currently know nothing about the service may be impacted if they need to use the service in future.

Pre-consultation engagement

Pre-consultation (April to August 2023) helped us to refine and update our consultation materials, inform our consultation plan and build our understanding.

We engaged on a 1:1 basis, via email, through surveys or at meetings – mostly with those with direct experience of receiving or providing the service as well as voluntary and community organisations and specialist children's cancer charities. Including people:

- from a range of ages (both of children, young people and parents/carers)
- who have physical or mental health conditions, disabilities, or illnesses other than their cancer
- are from black, Asian and other ethnic minority communities
- who do not speak English as their first language
- who have had experiences of receiving treatment at, or working for, the current Principal Treatment Centre



681 responses, in total, to the engagement

25 engagement sessions (including events, focus groups and meetings)

313 responses to online surveys

7 visits to wards on the different sites to speak to staff and families

44 direct responses via email

Over 2,015 organisations and individuals directly[1] contacted to encourage responses

1. Directly either by NHS England, Trusts or national and local charities on our behalf ↩

Equalities groups

Organisations contacted during pre-consultation engagement, identified in our Integrated Impact Assessment:

- Specialist children and young people (CYP) cancer charities/groups (including parent-led organisations)
- Youth Forums/Councils/Parliaments
- Healthwatch organisations
- Maternity Voice Partnerships
- Mental health umbrella organisations
- Black and minority ethnic forums/ groups
- Pan-geography organisations supporting refugees or asylum seekers, people with addiction and/or substance misuse issues, people involved in the criminal justice system, people experiencing homelessness, and gypsies or travellers
- Learning disability and autism groups
- Groups supporting people with physical impairments
- Carers (young and adult)
- Community groups in the most deprived areas within the catchment area.

Equality and Health Inequality Impact Assessment: high-level summary

Equality and Health Inequality Impact Assessment: Process

Purpose of the EHIA

To support meeting legal duties including the Public Sector Equality Duty (Equality Act 2010) and the Health and Social Care Act (*to have regard to the need to reduce inequalities between persons in access to, and outcomes from healthcare services*)

What changes are we assessing the impact of?

A change in location of the current Principal Treatment Centre and the implications of this change on patient travel arrangements including travel time, complexity of journey (including parking arrangements) and cost.

Additional considerations:

- the prospect of the service change process itself
- the prospect of a new environment and aspects of onsite accessibility
- other potential benefits

The EHIA takes a non-comparative, population-based approach.

Plus other groups who face health inequalities

Which population groups were considered in terms of experiencing differential impacts?

Those with a protected characteristic as specified in the Equality Act 2010, or who typically face health inequalities, <u>including those living in deprived areas or families on low incomes</u> (EHIA document contains full list).

For each group, using the information referenced below, plus professional and personal experience, the sub-group assessed any potential <u>differential</u> impacts of the proposed changes in relation to both the Public Sector Equality Duty and inequalities in access to, and outcomes from the service.

Sources of information used:

1. An equalities profile for the Principal Treatment Centre catchment population
2. A travel time analysis report
3. Qualitative insight collected through patient engagement activities

Equality and Health Inequality Impact Assessment: Overall findings

Impacts of travel time differences on health inequalities (access)
When comparing travel times to the current Principal Treatment Centre main site (The Royal Marsden) to either future option, travel time analysis shows:

- there are differential positive impacts for children living in the most deprived areas and rural areas when travelling by public transport.
- there are differential negative impacts for children living outside London or in rural areas when driving.

Other impacts Several population groups (full list in EHIA) may experience a differential impact in terms of:

- complexity or cost of their journey
- uncertainty brought on by the prospect of the service change process itself
- on-site accessibility

For example, patients and/or families:

- where a family member is disabled (or has a spectrum disorder)
- who are on a low income/living in more deprived areas
- with poor literacy and/or language barriers
- who experience digital exclusion

The Equalities profile document includes an estimated quantification of the size of each population group within the PTC catchment area.

Benefits for improving outcomes and reducing inequalities:
Compliance with the service specification will mean that healthcare related outcomes (in terms of patient experience and safety) are likely to be enhanced through receipt of co-ordinated, holistic care with a reduced requirement for treatment transfers at a time of crisis and the risk that certain types of transfers involve.

While this will benefit all children attending the Principal Treatment Centre, the EHIA sub-group concluded that there may be a differential positive benefit for certain groups who may have a higher need for additional paediatric specialties (e.g. those with complex cancer care needs, co-morbidities, who are disabled or have or other conditions) or with communication difficulties (e.g. language barriers or poor literacy) where the reduced need for treatment transfers/multi-site appointments may be beneficial.

Equality and Health Inequality Impact Assessment: Public transport and driving times (South East London)

On average, the residents of most boroughs within South East London would see a reduction in travel time to either Evelina London or St George’s via public transport, compared to travelling to The Royal Marsden.

Travel times to Evelina London would reduce by 34 minutes on average.

Travel times to St George’s would reduce by 23 minutes on average.

For context, the estimated current public transport travel time to The Royal Marsden for South East London residents is on average 1 hour 24 minutes.

On average, many residents of most boroughs within South East London would see a decrease in travel time for driving compared to travelling to The Royal Marsden.

However, residents of Bromley and Bexley would see an increase in travel time for driving to both potential future PTC sites and residents of Bexley would see an increase in travel time for driving to St. George’s.

Meanwhile, residents of Bexley would be likely to experience an increase of around 15 minutes travel time to St. George’s.

For context, the estimated current drive time to The Royal Marsden for South East London residents is on average 54 minutes.

Lots more information on our work in this area, including consideration of travel to University College Hospital is available in our consultation materials.

Equality and Health Inequality Impact Assessment: mitigation & next steps

It is important to note that the travel analysis can only capture impacts in terms of travel time. It is not possible to systematically quantify impact in terms of complexity of journey, reliability of transport services and costs. **The most important aspect of the EHIA is the recommendations for mitigation**. The EHIA sub-group has put forward a range of potential systems, processes or programmes that could serve to mitigate the adverse impacts of a longer, more complex, more costly journey.

The main themes include:

1. Systems and processes aimed at helping patients and families plan their journeys to hospital, including provision of inclusive and accessible information and translation services.
2. Systems and processes aimed at reducing the financial impact of travel, such as reimbursement schemes for travel costs (including ULEZ charges and congestion charges where applicable) or supporting patients to access other financial support.
3. Transport services provided directly to patients and their families (with clear eligibility criteria) and family accommodation.
4. High quality onsite accessibility arrangements, including parking and drop-off facilities.
5. Other aspects of care planning including flexibility for appointment times, shared care closer to home, strong communication systems between different health and social care teams, and remote (non face to face) appointments (that take into account aspects of digital capability)
6. An excellent implementation plan for the service change process, to support patients through the transfer period, with high quality continuity of care. Implementation plans should consider meeting NHS duties around health inequalities and take a Core20Plus5 approach.

Next steps

The Interim EHIA

Public consultation and further stakeholder engagement

Final EHIA