

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

Pre-consultation engagement activity and stakeholder feedback

‘You said, we did’ report

4 October 2023



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1. Background and introduction

When a child is ill with cancer it's a hugely stressful time for them, their parents and families. The NHS England leaders for London and for South East region want children to get the best care in the best way. To provide the very best care for children with cancer, specialist children's cancer services currently provided by The Royal Marsden NHS Foundation Trust need to move to be on the same site as a children's intensive care unit. This service looks after children and young people from Brighton and Hove, East Sussex, Kent, Medway, south London and most of Surrey.

Children's cancer centres (known as Principal Treatment Centres) are responsible for making sure every child with cancer gets the expert care they need. They are mainly for children aged 15 and under with cancer. (They can carry on caring for older children if that is best for individual patients). The Principal Treatment Centre for south London and much of the south east is currently provided in partnership between The Royal Marsden NHS Foundation Trust and St George's University Hospitals NHS Foundation Trust.

Very specialist cancer treatment services for children – like those at The Royal Marsden's site in Sutton – are now required to be on the same site as a children's intensive care unit that can give life support. With the experience and expertise of specialist children's cancer teams on the same site as children's intensive care specialists, surgical teams and other children's specialties, the future Principal Treatment Centre will minimise risk to children and be capable of giving innovative treatments that require intensive care support on site.

The current service for children with cancer who live in south London and much of south east England does not and cannot meet this requirement. As a specialist cancer hospital, The Royal Marsden does not have a level 3 children's intensive care unit (which can give life support) on site. Children's intensive care units are always on sites used by tens of thousands of children every year because intensive care teams need to see high volumes of very sick children to maintain their specialist skills and expertise. This wouldn't be possible at The Royal Marsden due to the smaller number of children who need treatment there.

As the children's cancer services currently at The Royal Marsden need to move, NHS England will be consulting on two options for the proposed future children's cancer centre – that it is either at Evelina London Children's Hospital in Lambeth or at St George's Hospital in Tooting. We (NHS England London and South East regions) propose that, under both options, all radiotherapy services for the future children's cancer centre (instead of some, as now) would be provided by University College London Hospitals NHS Foundation Trust in central London.

Evelina London is part of Guy's and St Thomas' NHS Foundation Trust, which is referred to as Guy's and St Thomas' in this document. St George's Hospital is part of St George's University Hospitals NHS Foundation Trust which is referred to as St George's in this document.



Engagement with people and communities has been and will continue to be an essential part of NHS England’s process. As part of the 12-week consultation launched on 26 September 2023, we would like to hear from a wide range of people with an interest in the service. This includes those with direct experience of providing or receiving the service to understand their experience of the current model, future service requirements, opportunities, challenges and mitigations for the impact of moving the service. We also want to hear from patient groups and community representatives, from cancer specialists and those working in children’s cancer research, from health and care system partners, from those from across the catchment geography and their elected representatives. We will be engaging and formally consulting with the local authorities in south London and south east England through health overview and scrutiny committees. Following the consultation and then a decision-making period, we will be working closely with whichever provider is selected as the future Principal Treatment Centre, so that they can continue the conversation about how the service moves to its future location and is co-designed with children, families and staff.

2. Executive summary and key findings

This report summarises feedback received from pre-consultation engagement undertaken by NHS England between mid-April 2023 and the end of August 2023.

This engagement followed previous early engagement activity undertaken since 2020. Engagement during previous phases of the programme helped us understand what was important to children who receive the services and their parents/carers, and to the staff who deliver the service. This helped shape the questions we asked the trusts submitting proposals for the future centre and informed the development of the options we are consulting on. These questions were then used as evaluation criteria for our pre-consultation options appraisal. A wide range of experts were involved in different stages of developing the criteria and assessing the options.

The primary purpose of more recent engagement, reflected in this feedback report was to understand:

- how the consultation could best reach affected patients and staff as well as wider communities who may be future users of services
- what the opportunities, challenges, mitigations, and solutions might be, in terms of relocating the service.

This engagement has helped to shape our approach to consultation and the types and content of information we are providing to help people respond to the consultation. It has also informed our approach to mitigating potential negative impacts of our proposals and enhancing positive ones, and how this is reflected in our documentation.

The NHS England programme team leading this reconfiguration process has regularly reviewed all the comments received and has already taken action on many of them, incorporating several ideas and suggested solutions as part of its plans. For example, in response to feedback, this document includes “you said, we did” summaries to demonstrate how feedback has influenced the programme. These are set out in section 5 of this report.

This document is accompanied by several appendices outlining anonymised data used to compile the report including survey data, demographic and respondent information, data collected about current staff and family journeys to both The Royal Marsden and St. George’s sites, and information about the engagement activities listed and organisations and groups that responded.

The programme team has had ongoing conversations with children and young people, families, carers, clinical and research staff, staff from children’s cancer shared care units (which provide specific types of cancer care in more local hospitals), Joint Overview and Scrutiny Committees and Overview and Scrutiny Committees, and MPs throughout this process to inform the development of the case for change, options appraisal criteria and assessment.

While most of the feedback received focused on sharing insights to help us prepare for consultation, we also received feedback which will be helpful once a decision about the future location of very specialist cancer treatment services for children has been made, and planning for implementation begins. This information has been captured and will be shared with the future provider of the service to ensure they are aware of people’s desire to understand what happens next and how children, families and staff can co-design the future children’s cancer centre.

This section highlights response rates and reach of engagement activities, as well as summarising the overall feedback and key themes across all respondent types and feedback methods.

Later sections of the report draw out key themes from different audiences and demographics, to highlight similarities and differences, if and where they were present.

2.1 Early engagement

To help inform the development of different options for where the future Principal Treatment Centre could be located, and to shape the criteria being used to score those options, we undertook some early engagement work. This, together with parents from our stakeholder group who helped to weight and score aspects of the patient experience domain, helped us understand the priorities for a future service.







We undertook two surveys – one conducted face to face by staff with patients and families on wards (seeking feedback on aspects of the patient experience criteria), and one conducted online by The Association of Young People’s Health – reaching over 250 children, young people and families and seeking feedback on experiences of current services and priorities should the service be relocated.

For information on ‘How we identified the options’ and ‘How the evaluation criteria were developed’ please see more detailed information on our website.

2.2 Pre-consultation engagement

2.2.2 How did people engage?

Table 1: Engagement Response over the period April 2023 – August 2023¹

	<p>739 responses, in total, to the engagement</p>		<p>27 engagement sessions (including events, focus groups and meetings)</p>
	<p>313 responses to online surveys</p>		<p>7 visits to wards on the different sites to speak to staff and families</p>
	<p>44 direct responses via email</p>		<p>Over 2,015 organisations and individuals directly² contacted to encourage responses</p>

A mixed approach was taken to engagement to ensure accessibility.

2.2.3 Who responded?

Overview

Around 46% of responses received were via our surveys (completed online or in person in outpatient/ward settings), the remainder were received through face to face meetings (online or in person). Further detailed breakdown of this data can be found in the appendices.

- The vast majority of respondents had experience of providing or receiving the current service (including 69% of survey respondents).

¹ The Programme has also conducted early engagement activities over the period since 2020 – these activities helped to inform the evaluation criteria and development of the options.

² Directly either by NHS England, Trusts or national and local charities on our behalf

- They included 149 **members of staff** from The Royal Marsden and 119 **members of staff** from St George’s Hospital³. We also heard from 44 staff at Evelina London.
- Staff we heard from included nurses, doctors (both consultants and more junior doctors), play therapists and other allied health professionals, radiologists, neurosurgeons, radiographers, clinical researchers, psychologists, pharmacists, social workers, pathologists, and admin and support staff. We also heard from staff expert in research from the Institute of Cancer Research and The Royal Marsden.
- We heard from over 120 **families** - including more than 30 **children and young people - with direct experience of the current service** as well as wider cancer services in children’s cancer shared care units.
- We also heard from 46 families with no direct experience of the current service – whose feedback closely aligned with feedback from families with direct experience
- And we heard from 26 organisations, including those supporting families of children with cancer; and more general community advocacy and engagement services. These included Healthwatch organisations as well as local authority Overview and Scrutiny Committees within the geography.

2.2.4 Children, young people and families with direct experience – including communities identified in our Integrated Impact Assessment

From our survey on wards, with those who had direct experience of receiving the current service (based on demographic information from survey data), we have been able to reach a range of children, young people and families:

- from all geographical regions within the PTC catchment area
- from a range of ages
- who have physical or mental health conditions, disabilities, or illnesses other than their cancer – 23% of those who engaged with us
- who were from Black, Asian and other minority ethnic communities – 29% of those who engaged with us
- who do not speak English as their first language – 15% of those who engaged with us
- who had had experience of The Royal Marsden Hospital, St. George’s Hospital and other wider cancer services. Many had experienced treatment at both sites

³ Respondents were asked about their primary site of employment and therefore does not account for roles that may cover both sites.

While engagement was successful in reaching all of the key groups identified in the Integrated Impact Assessment, we did face some challenges. We found that many organisations supporting equalities groups did not respond to requests to engage with us. We also heard less from people with learning disabilities, who, through our Integrated Impact Assessment, were highlighted as being potentially at higher risk of being affected. To address this during public consultation, NHS England will be reaching out to organisations providing advocacy support to this community to emphasise why feedback from this group is needed to enable us to fully understand the impacts. We are also contacting Healthwatch organisations asking for their support to reach these groups.

2.2.5 Clinical and research staff

From our work with staff with direct experience of providing the current service, (based on information the respondents to our surveys supplied) we have been able to reach:

- a range of job roles: nurses, doctors (both consultants and more junior doctors), play therapists, radiographers and other allied health professionals, radiologists, neurosurgeons, colleagues from the Institute of Cancer Research, psychologists, pharmacists, social workers, pathologists, admin and support staff
- a range of grades of staff: from more junior to more senior
- both those working full-time and those working part-time in the service
- staff who have physical or mental health conditions, disabilities, or illnesses (13%)
- staff from Black, Asian and other minority ethnic communities (23%)
- staff who do not speak English as their first language (3%).

2.2.6 Wider stakeholder engagement

We have engaged with local councillors from across the geographical catchment area and have met with Overview and Scrutiny Committees meetings (and Joint Overview and Scrutiny Committees (JOSCs) for committees in south London and Surrey) to share our case for change and early proposals to address it, and determine if those committees see our proposals as ‘substantial variation’ to current services for their population, if so triggering the duty to formally consult with them. We have attended meetings and provided informal briefing sessions, supported by email correspondence, to seek feedback on our consultation plan and documentation.

MPs have been briefed by letter, at their ongoing meetings with partners, and were offered online briefings prior to the consultation launch which some took up. For those MPs from whom we did not receive a response to our invitation, we also sought to contact them by phone and, where possible, left voicemails.

Communications and engagement leads from Integrated Care Boards have helped shape the planning of the consultation and the delivery of engagement. This is via NHS England’s

Communications and Engagement Group for this programme, which also includes communications and engagement leads from the three Trusts and the two NHS England regions. The Group plans communications and engagement activities, ensuring alignment with local activities and working through existing networks.

During the pre-consultation period, we strengthened our working with Integrated Care Board communications and engagement leads from across the area covered by the Principal Treatment Centre to ensure we make the most of all opportunities to reach patients and their families as well as other interested stakeholders, using established channels where possible.

Integrated Care Boards are more widely engaged through representation from south London Integrated Care Boards on the Programme Board, representation on the Equality and Health Inequalities Impact sub-group; and engagement as part of activities undertaken with Overview and Scrutiny Committees. They have provided letters of support to the consultation and have received communications updates at key points in the programme.

2.3 Key findings

The primary purpose of the pre-consultation period was to share our case for change and to gather insights about how we should be engaging, who we should be engaging with, and to understand the types of content and format of information we should be providing through consultation. We also asked people for their initial thoughts about the potential opportunities and challenges that the two shortlisted options for the proposed future Principal Treatment Centre could present. Those conversations developed further to discuss potential mitigations for the challenges, and views on travel times and modes of transport (for those currently accessing the service).

The views and feedback we received helped to shape the information provided for the consultation, making sure it helps people to make informed responses to the consultation. It is expected that the themes emerging from this early stage of engagement will be explored much more fully during consultation, particularly as more information about the options is made available to inform feedback.

The pre-consultation feedback we received helped to shape and support the communications and engagement approach set out in our consultation plan – offering a range of ways to feedback including digital and non-digital means, where possible, producing short documents with links to more information as well as short videos to make information accessible. Suggestions around additional stakeholders to add to mapping were adopted and the engagement approach was developed in response to the feedback we received.

While there was generally a broad understanding for the need to locate the future service alongside intensive care, some raised questions about the case for change, particularly in relation to current and future demand for children’s intensive care. There were also questions around the future of radiotherapy and what a proposed move of services to University College Hospital could mean for hospital transfers and patient experience.

People told us that that the current service is of high quality and that every attempt should be made to retain the good things about how the service currently works - staff, the clinical and operating model, research model, ward environment and facilities. We endorse this and have made sure to emphasise this ambition in our consultation proposals.

Alongside benefits associated with delivering the proposed change; feedback also identified potential opportunities from relocating specialist children’s cancer services to a site with a children’s intensive care unit. These included opportunities for children, families and staff to be involved in the creation of the future service (bringing learning from what currently works well) and in designing the space and opportunities for closer multidisciplinary working.

Solutions and mitigations collected will inform and strengthen ongoing work as part of the Integrated Impact Assessment, communications and engagement strategies, and in time, detailed implementation plans for whichever site is chosen as the future location of the Principal Treatment Centre. Most suggestions centred on providing clear timely information to ensure stakeholders are updated in a variety of ways at key milestones within the programme. A key theme was around providing reassurance and confidence in the process and supporting people to understand the benefits that would be delivered by implementation of NHS England’s proposals. Our engagement will continue through all phases of the programme, initially in the options development and pre-consultation phase, then in consultation, and afterwards in planning for and implementing the change, including designing the space for the future Principal Treatment Centre to ensure it meets requirements.

Many of the initial solutions put forward in pre-consultation engagement, focused on mitigating travel impacts, by providing free or subsidised transport, parking and considering what care could be provided closer to home (for children and young people) as well as more streamlined hospital transport and sufficient family accommodation. For staff, mitigating travel impacts centred more on considering flexible/remote working options, where possible, as well as financial incentives.

Our surveys with children, young people and families who have direct experience of the service showed:

- 81% travelled to their treatment site (either The Royal Marsden or St George’s Hospital) by car (own vehicle or taxi)
- 11% travelled by public transport (bus, train, hospital transport etc.).
- 35% of journeys took over an hour (some families suggested this could be up to two hours)
- 54% of journeys took 45 minutes or less.

- Families using Principal Treatment Centre services at St George’s Hospital were more likely than families going to The Royal Marsden to have shorter travel times and live close by, with most journey times for these families taking less than 30 minutes (77%)⁴.

This shows us that many families are already making lengthy journeys to receive their care, particularly to The Royal Marsden which provides the majority of care for the current service.

The majority of staff at The Royal Marsden travel by car to work (65%), whereas the most used form of transport for staff at St. George’s is public transport (42%). For both staff groups, the majority of journeys to work take less than 30 minutes (this is the case for 57% of staff at The Royal Marsden and 58% of staff at St. George’s Hospital). This indicates that, currently, journeys are relatively short for staff to get to and from work.

Staff, understandably, raised many queries about the impact on their roles and how the proposed change would affect them. Feedback on this topic, which is summarised in section 5.7 will be addressed as early as possible. The Royal Marsden and St George’s are working to support staff during this time. Further organisational development work would be important during the implementation period.

⁴ The number of families NHS England were able to speak to at St. George’s Hospital specifically were very small, therefore this data cannot be considered representative

3. Engagement methodology

Following a period of early engagement which ran from March 2020 until early 2023, NHS England launched wider pre-consultation engagement to speak to people about the case for change and to understand key issues and opportunities. This began on 27 April 2023 and ran for 18 weeks until 31 August 2023. Initially, the pre-consultation period was due to end in June. However, in response to feedback, including about running a consultation over summer, launch of the consultation was postponed until early autumn. This gave us the opportunity to undertake a mid-point review of work undertaken to date and to undertake pre-consultation engagement for longer. The mid-point review helped shape subsequent activities to ensure we reached a good sample of current users and of staff providing the service.

3.2 How the communications and engagement programme was designed

In planning our pre-consultation engagement, we worked with key stakeholders including our Communications and Engagement Group (comprised of leads from both regions, Trusts and integrated care boards), Stakeholder Group (comprised of parents, local and national charities), the Programme Board (comprised of senior doctors and managers from NHS England (London and South East regions), the chief executives from the four Trusts which provide specialist children’s services in south London and the other Principal Treatment Centre in London, two national charities and two external expert advisers), and clinical colleagues to test our plans, ensuring they would reach and hear from as many people who may be affected or interested as possible.

Ahead of the pre-consultation period, in early 2023, NHS England attended Overview and Scrutiny Committee meetings in each geographical area within the service catchment area. Three committees originally deemed the change substantial and requested NHS England formally consult on the programme – both South East London, and South West London and Surrey Joint Overview and Scrutiny Committees, and Brighton and Hove Overview and Scrutiny Committee⁵. NHS England consulted with Overview and Scrutiny Committees during the pre-consultation period, including to test the consultation plan, document and to provide additional information and updates.

Work was undertaken with Trusts and Integrated Care Boards to confirm key stakeholder groups who should be engaged, as well as opportunities to use existing, trusted, relationships to reach people.

⁵ Through the formal consultation process with Brighton and Hove Overview and Scrutiny Committee, they took the decision, during the pre-consultation period, that they did not consider the service change to be detrimental to the health of their city’s residents. As such, they did not wish to undertake further formal scrutiny of these plans. However they indicated that they wished to be kept informed of progress as did the other Overview and Scrutiny Committees which did not regard it as a substantial change for their residents..

Feedback received helped shape plans and offered contacts and opportunities to be utilised during the engagement period.

3.3 Target audiences

The early Integrated Impact Assessment (IIA) set out groups likely to be most directly affected by changing the location of the service, and groups that have an interest because the change affects communities they support or represent. We mapped and contacted voluntary and community organisations and networks connected to or representing the communities identified in the Integrated Impact Assessment for each geographical area to ensure the most appropriate groups were reached to meet our equalities duties. These communities included:

- current and recent service users and their families/carers (more specifically those from Black and other ethnic groups, families from deprived areas, children with physical and/or learning disabilities and autism)
- staff
- specialist children’s charities and donors
- public representatives (councillors and MPs)
- health and care partners
- scrutiny and assurance bodies.

3.4 Engagement methods

A mixed approach was taken to engagement to ensure accessibility – offering online and face-to-face engagement.

People could feedback through:

- **targeted online surveys** – tailored to specific groups with specific questions on travel and access for those directly providing or experiencing the current service
- **on the ward surveys** – speaking to patients and families in clinical settings, with support from clinical staff
- face to face events and focus groups for staff
- online on-demand briefing sessions
- attendance at meetings (by invitation)
- dedicated engagement email address
- **meetings with Overview and Scrutiny Committees** which deemed this change as substantial for their populations – formal meetings open to members of the public

- **meetings with MPs** whose constituents may be affected.

3.5 Promotion

Due to the types of stakeholders we were predominantly seeking feedback from (outlined in section 3.2) promotion was targeted. Our main aim was to gather insights from children, families and staff via surveys or to arrange structured face to face discussions with stakeholders to explain the programme, reduce concern and enable direct dialogue with NHS England. Some of our activity included:

- **targeted emails from NHS England** – to voluntary and community organisations and individuals working with communities likely to be most impacted by any changes – resharing information multiple times throughout the pre-consultation period to encourage responses on the best ways to reach their communities
- **targeted emails from partners through their channels** – content was provided for Trusts and national charities to share with key groups they engage with routinely, signposting them to contact us to help shape our consultation plan to help shape our consultation plan
- **posters and fliers** – placed around The Royal Marsden site and sent directly to the families of children with cancer being treated at St George's Hospital encouraging responses to surveys
- **letters to key stakeholders** like MPs and wider NHS organisations within the geographical catchment area, to keep them informed
- **web story** – live on the NHS England website giving information about the proposals change and directing people to the team contact details
- **direct proactive contact** – with Chairs of Overview and Scrutiny Committees, MPs and other elected officials, research organisations and specialist children’s cancer charities.

3.6 How the engagement approach adapted during the engagement period

Taking a best practice approach to this engagement work, NHS England undertook a mid-point review of engagement in June 2023 – around six weeks into the pre-consultation engagement period. This mid-point review aimed to:

- understand activities that had been completed to date
- review the response rate overall and from specific target groups
- understand key themes from feedback and how this was influencing thinking

- review upcoming planned activities to ensure they were fit for purpose
- consider additional activities that might be required to reach communities that were not being reached.

Additional work undertaken as a result of the mid-point review, included:

- further visits to wards to hear more from families with direct experience of the current service
- additional “drop in” sessions with Royal Marsden staff to reach more junior colleagues and wider supporting teams who had not been able to join the in-person event
- further meetings with Overview and Scrutiny Committees to talk through our approach to specific aspects of the work, like our options appraisal, travel times, engagement and seeking feedback on our consultation plans
- meetings with research organisations to undertake further scoping work to understand the current service
- facilitating both Evelina London and St George’s Hospital to meet with colleagues from the Institute of Cancer Research and The Royal Marsden to hold discussions on management of potential risks and also to tour their sites
- clinical workshops to share information on how specific aspects of children’s cancer services currently work, with a particular focus on working across sites and between multidisciplinary teams
- proactive telephone calls to Healthwatch organisations to make them aware of the changes
- a Healthwatch specific workshop
- meetings with key national charities such as Young Lives vs Cancer, Children’s Cancer and Leukaemia Group, and Children with Cancer UK to seek their support to reach children from a broader geography through their networks
- seeking feedback from young people in the Teenage and Young Adults cancer service within Evelina London who may have experienced the current Principal Treatment Centre service
- conversations with children’s cancer shared care units about how best to reach their staff and patients during consultation
- emails to stakeholder groups not originally contacted, such as primary care staff, a Royal College, and community service providers.

4. Approach to analysis

Due to the very specialist nature of the services being discussed, individual topics were raised by very small numbers of respondents. There were also topics that were raised by multiple stakeholders within our stakeholder groups, such as staff or families, presenting more of a consensus view. Section 5 presents the full analysis of all the feedback received. This section includes a summary of the themes which were most commonly mentioned first, followed by single issues or topics less frequently mentioned. This aims to provide a structure to the way in which feedback is presented and is not intended to suggest that topics less frequently mentioned are less valid or important.

We recognise that this proposed service change is extremely emotive for those receiving and providing the service. Those with strong feelings are more likely to take the time to provide their views robustly. The responses we have received reflect this. We have therefore oriented the report to focus on the issues that are to be resolved and information/reassurance to be provided as well as understanding how we can best consult all stakeholder groups.

Open questions and free text responses were analysed using a qualitative data analysis approach. All text comments have been coded thematically to organise data. To do this, a code frame was developed to identify common responses then refined throughout the analysis process, and as more information was received, to ensure that each response could be categorised accurately and could be analysed in context.

Points to note regarding data

- Some respondents may have fed back on the engagement exercise through more than one method, for example they may have completed the online survey and participated in a face-to-face session, giving mirrored responses. This may mean that the number of responses to the engagement exercise we received may be different from the number of people who participated.
- Not all survey respondents completed every question.
- Not all survey respondents completed demographic information. We have therefore only used feedback that can be identified by stakeholder group for sections where we are comparing views.
- Feedback presented is from the perspective of the respondent – no adjustments have been made to correct any factual inaccuracies in statements.
- When seeking to understand how views from specific groups may differ from others, we have used demographic data provided to us by respondents for the purposes of this report.



Pre-consultation engagement activity and stakeholder feedback – ‘You said, we did’ report

- When working with percentages, these have been rounded up or down from two decimal points.

5. Key themes – you said

This section focuses on exploring the key themes raised in our pre-consultation engagement activity, which were identified above in the executive summary, in more detail. This section also identifies differences and similarities, where present, in feedback from different stakeholders.

Examples of how we have used this feedback to inform our plans are included below.

5.2 How we communicate and engage during consultation

5.2.2 How we engage

What people told us

- Discussion groups were, overall, supportive of our engagement approach.
- People with experience of providing or receiving the current service who responded to our survey preferred more indirect forms of engagement – such as filling in surveys and replying via email.
- Online events were more popular than face to face events.
- Families felt that being asked questions in waiting rooms while they were already waiting for treatment was preferable to events or interviews.
- One to one interviews were the least popular method for engagement. This was echoed across all stakeholder groups.

Additional feedback to consider is listed below.

Considerations about digital engagement

- Multiple respondents felt having online events is helpful as they are easy for families to attend and there is no travelling involved. While face to face events are a nice idea, they can be logistically tricky given the small number of children with cancer in each geographical area.
- Social media and emails are useful for sharing messaging and promoting the consultation.
- Online forums are a good way to collect feedback.
- There is a need for non-digital feedback routes.
- Multiple respondents suggested that using a poster with a QR code that links to the website/ways for patients to give their feedback could be effective.

Feedback on types of engagement activities

- Having a number of different ways to feedback will be important.
- Face to face engagement is important, be that via video call or in person.
- Meeting people on wards is a good way to seek feedback.
- Multiple respondents suggested that focus groups may be intimidating but smaller sessions could work well.
- Activities should be designed and delivered in a way that is engaging, accessible and understood by the intended audience.
- Engagement should consider individual needs to ensure it is accessible.
- A 24/7 event where the information is recorded so people can review and comment flexibly, in their own time when it suits them, could be a useful approach.
- We should learn from past consultations to shape our plans.

Consideration of disabilities

- Attention span (as a result of treatment) can be an issue, therefore keeping things concise is essential.
- Further work is required to agree how to engage children with learning disabilities or autism, working with Trusts who have experience of doing this.

Reaching into diverse communities

- Working through community leaders can be helpful to reach a diverse range of people.
- Flexible engagement is required to ensure inclusion of people who cannot read or write.
- Children’s cancer might be quite a sensitive topic for some people to engage with, for example, pregnant mothers; there are also cultural reactions to talking about cancer.

Engagement with staff

- There should be opportunities for teams at both Evelina London and St George’s Hospital to share more information about the two options being consulted on with staff from The Royal Marsden– either through online or in-person meetings.
- Staff engagement may be most effective if it is available where staff work.

Engaging with children and young people

- We should consider how engagement is incentivised – for example, pizza has worked well with young people in the past – and ensure that young people are not out of pocket as a result of their participation.
- We should find an organisation that specialises in engaging young people to partner with.

- For younger children and those with additional needs, engagement should involve play and work with hospital play specialists.
- Collaboration with children’s clinicians could be useful to identify other patient groups that have similar concerns about accessing care and how this is addressed. Children and young people with other serious, chronic, and rare conditions and their carers may have invaluable insights that are transferrable to the experience of children’s cancer.
- Multiple respondents suggested asking children and young people with cancer from outside our area about their experiences, to get a wider view.

Engaging with other hospitals and community-based partners

- In selecting hospital and community-based organisations to engage with, we should consider which organisations could help recruit people with lived experience, either of cancer or other, similarly long-term and severe conditions, or work with people with lived experience to co-design mediation strategies. An example of a strategy might be one that reassures parents and reduces their concerns about travelling with immunocompromised children for care. Further engagement in this area could also be included in implementation planning.

Timing of engagement

- Consulting over the summer period (as was originally planned) was raised as a concern by people due to summer holidays and absences which could mean reduced opportunities for engaging with the consultation.

You said, we are doing

Concerns were raised with us about consulting over the summer holidays

One of the reasons that we took the decision to postpone the public consultation was to reflect feedback we’d heard about the consultation timing. We also postponed the consultation to allow more time for NHS England to consider feedback that we received in the early phase of the pre-consultation engagement period including on draft documents we shared.

Having a number of different ways to feedback will be important

Feedback methods we are planning for the consultation range from large scale events to more individual conversations. They include “going to people where they are” by targeted engagement with different stakeholder groups. We are working with The Royal Marsden and St George’s Hospital to reach families currently receiving treatment so they have the

chance to comment. Our plans will be kept under review throughout the consultation to be responsive to feedback.

Activities should be designed and delivered in a way that is engaging, accessible and understood by the intended audience. For younger children and children with additional needs, engagement should involve play

We have commissioned two organisations with specific expertise in engaging with children and young people. Starlight, a play specialist organisation, will run creative sessions with children and young people currently in treatment/who may be isolating on wards. Participation People will reach as many people identified in our Integrated Impact Assessment (IIA) as possible.

There is a need for non-digital feedback routes. Flexible engagement is needed to ensure inclusion of people who cannot read or write. Children’s cancer might be a sensitive topic for some people to engage with. Attention span (as a result of treatment) can be an issue

- We have prepared a range of documents of different lengths and formats. They include a short animation and easy read versions of the summary document and consultation questions.
- We have a freepost address and freephone telephone number for people to contact us or respond to the consultation.
- Work is underway with Trusts and children’s cancer shared care units to put printed documents, which comply with infection control guidance, in clinics. Printed documents will also be available from us on request.
- Advocacy groups will be approached so we can reach children and adults with learning disabilities in an effective way.
- In-person focus groups will be held in more deprived areas, identified from Census data. Participation People will recruit people with specific characteristics to join in-person and online focus groups. This is so that we can make sure we get views and feedback from a representative group of people from across the catchment population, as well as making sure we hear from those who will be particularly impacted or proportionally impacted by the proposals compared to other groups. Participation People will consider how best to describe the topic and test this with young people to ensure it is treated sensitively.

Online events are easy for families to attend and no travelling is involved

Three large scale online events for the public, as well as focus groups and interviews, are planned.

Posters with a QR code that links to the website could be effective

Printed posters with a QR code (and which comply with infection control guidance) will be displayed at Evelina London, St George’s Hospital and The Royal Marsden and at many children’s cancer shared care units.

Focus groups may be intimidating but smaller groups could work well. Staff engagement may be most effective if it is available where they work

Smaller group conversations for staff are being organised so people can come together in an environment where they feel comfortable about providing feedback.

Social media and emails are useful for sharing information and promoting the consultation

We are sharing information through NHS England social media channels and our website has a communications toolkit for partners, including voluntary and community organisations, so they can encourage people to respond to the consultation. It includes graphics and suggested messaging.

We should consider how engagement is incentivised and ensure that young people are not out of pocket as the result of taking part

To ensure people can participate, and to thank people for their contributions, appropriate incentivisation will be offered. For the work specifically conducted by NHS England to reach those groups we are targeting based on the Integrated Impact Assessment, this will be in line with the NHS England Reward and Recognition Policy.

We should ask children and young people with cancer from outside our area about their experiences, to get a wider view

We have been working with national charities to share opportunities for engagement through their existing channels, for example, the Young Lives vs Cancer Youth Board, Children’s Cancer and Leukaemia Group parents’ forum, and Children with Cancer UK’s mailing list. Plans include continuing to work through these channels to reach these families during consultation.

5.2.3 The information we need to provide during consultation

We asked staff, parents and Overview and Scrutiny Committees to validate (or otherwise) which types of information we thought would be essential to provide during consultation, such as:

- why the service needs to move and the benefits
- a description of the two options for the future location of the Principal Treatment Centre
- what might be different about your children’s care in the future
- what the wards would be like in the different hospitals

- what support might be available to help with travel
- what other services are already available on the site for each option
- how we would make the transition smooth, once a decision has been made
- what we’ve already heard from children and young people
- the process we’ve been through to get us here.

Our survey data showed that those with experience of providing or receiving the current service were most keen to understand more about where services might move to and how we would make the transition smooth once a decision has been made. These trends were echoed across all stakeholder groups.

Staff within the current service also felt understanding the feedback we had previously received was a priority. Families currently receiving services were keen to understand if/how care might be different as well as what support might be available to help with travel. Overview and Scrutiny Committees were also keen that information was shared on travel costs and logistics, the feedback we’ve received, and the evaluation/scoring work.

In addition to these, many respondents agreed that the following information was also felt to be important.

- Reassurance that there would be continuity of staff at the proposed future Principal Treatment Centre as far as possible.
- Reassurance that any new staff would be appropriately trained and have the relevant experience.
- Reassurance around future-proofing the service for future demand.
- Understanding whether there would be an impact on waiting times for treatment.
- How we would make the future service work for children with brain tumours who had their surgery on a different site from the Principal Treatment Centre⁶.
- How to travel to the service safely (for example, how to be safe if travelling on public transport, parking arrangements for driving).
- Information about the different ward environments, including physically seeing what it might be like.
- How any move would be managed so that the impact on treatment is minimised.
- How research would be impacted/continue once a decision is made.
- Funding for the service reconfiguration and costs of both proposals.

⁶ Neurosurgery, for brain, nervous system and spinal problems in children with cancer, is provided by King’s College Hospital and St George’s Hospital. In 2019/20 around 20% of children had their neurosurgery at St George’s Hospital. Although numbers do vary year on year, the proportion of neurosurgery that both sites do is expected to remain similar under both options for the proposed future Principal Treatment Centre.

- How the changes would fit with the wider context of children’s services, such as the Principal Treatment Centre’s relationship with children’s cancer shared care units.
- Being clear about what services children and young people would have to travel for under our proposals, including radiotherapy.
- The HR process for staff and how they would transfer to the future service.
- Many staff at The Royal Marsden were already familiar with the services at/ connections between The Royal Marsden and St George’s Hospital, and expressed a desire to understand more information about what Evelina London would offer.
- Information about how Evelina London and St George’s Hospital proposed to remodel their existing sites to accommodate these services.
- Impact on wider services – how these would be affected, including those at The Royal Marsden, St George’s Hospital and Evelina London.
- What support would be/is available to help with costs of childcare and travel.
- Findings of the Integrated Impact Assessment and how these have shaped the Programme’s approach to engagement and informed the groups it plans to target.
- In terms of the options appraisal; having information about the detailed scoring and criteria used for the options appraisal, understanding feedback from stakeholders about the process, and how the preferred option was arrived at as part of the options appraisal.
- Numbers and types of beds that would be available.
- Each provider's experience and the key features of their proposals.
- A summary of feedback heard through the pre-consultation period.
- How journeys would change depending on the location chosen for the future Principal Treatment Centre, following consultation.
- Key messages and (up to date) information for staff so that, if approached by patients, they could answer questions.

You said, we are doing

People want to understand more about where services could move to and to have information about the different ward environments, including physically seeing what it might be like.

Accessible information on both options is included in our consultation document and summary. Very detailed information is available in our pre-consultation business case. People who want to visit both sites to look at the space can contact us so this can be arranged. Opportunities for people to learn more about the proposals will be kept under review to meet demand.

People want to understand more about many aspects of the options, including travel.

As a result of this feedback, we have added to the information in our consultation document, pre-consultation business case and Integrated Impact Assessment. Where people have expressed particular interest, such as in travel, evaluation and scoring, we have created standalone information (drawn from the pre-consultation business case) and added it to our website -

<https://www.transformationpartnersinhealthandcare.nhs.uk/childrenscancercentre/> - so it is more easily accessible.

To ensure staff have the information they need to answer families’ questions, they have been provided with a few simple factual points and guidance on where to find out more.

NHS England will continue to work in partnership with Trust clinical and communication leads to be responsive to feedback about what is working well and where we need to adjust our approach. All feedback pertinent to the Implementation Phase of this Programme has been captured and will be shared with the teams working on the move to the future Principal Treatment Centre, once the decision on its future location has been taken.

5.2.4 How we present complex information

We asked the people we engaged with how we can simplify information about this complex change. Survey respondents with experience of providing or receiving the current service preferred short documents with links to more information and short videos (less than a minute) to present complex information. Longer videos (more than a minute) were the least popular way to present complex information. Across all stakeholder groups, these trends were echoed.

Additionally, through discussions, additional considerations were identified, these are listed below.

- We heard Gypsy, Roma and Traveller families may need non-jargon, clear explanation and information. This is our aim for all our materials for all audiences.
- Asylum seeking families will need materials in their own language.
- No acronyms.
- Simple information in straightforward language.
- Complex issues should be broken down, noting that families going through treatment likely won’t have time to go through complex documents.
- Providing visuals of proposals so that people don’t have to imagine the offering.
- Charts or bullet points.



Pre-consultation engagement activity and stakeholder feedback – ‘You said, we did’ report

- Identify some of the major languages beforehand and prepare translations.
- Provision needs to be made for people for whom English is not their first language, given the complexity of the service.

You said, we are doing

The materials should be short, simple and use visuals

We have endeavoured to produce material in as clear and plain English as possible, given the complexity of the programme.

The website for the consultation includes an easy read page for children, young people and other people who prefer short text and lots of pictures. An easy read version of the summary consultation document and the questionnaire are available online and in print. We have also produced a short animation which explains why things need to change and encourages people to take part. It is subtitled, ensuring it is accessible by people with hearing impairments, and can be easily followed on social media.

We have worked very hard to make the materials and messages as simple as possible, without losing vital detail. We have tried to ensure there are no acronyms in any of the public documents and to avoid NHS jargon.

Where possible, we have varied how information is presented e.g., using infographics, tables, bullet points and charts. We have used pictures and colours to make information more engaging and have tested these materials with a range of different stakeholders, including young people and people from racially minoritised communities, to make sure they are fit for purpose.

We have also created detailed information on specific topics which is available on our website – so that information on topics people have asked about specifically is easy to find and more digestible.

We could not create our full consultation document or summary as very short documents with lots of links because we need to make sure there is equity of access to information for people who are not online.

Participation People and Starlight, which have been commissioned to deliver certain engagement activities with children and young people, will be designing activities and materials specifically for them.

Identify some of the major languages beforehand and prepare translations.

We recognise that we have a diverse population and need to ensure consultation materials can be made available in various languages. We have identified the main languages spoken across the catchment area for these services.

The subtitles for our animation are being translated. Lines in each of these languages, signposting to how people can request our materials in translation, are also in both the full and summary consultation documents.

We have taken this approach because we recognise that individuals who do not speak English may not have a high standard of literacy in their first language. Conversations

may meet their needs better than asking them to read lengthy documents. This is being taken into consideration in our focus group work, and we will assess the need during consultation.

5.2.5 Priority engagement groups

As part of pre-consultation activity, a stakeholder mapping exercise was undertaken to identify organisations which could support the consultation to reach people with lived experience and communities identified by the Integrated Impact Assessment as potentially at higher risk of being affected.

We also asked partners and stakeholders for their views on groups or organisations we should prioritise.

Groups highlighted stakeholders that are already on our stakeholder mapping, these include:

- those who will be directly affected by these changes - children (aged one to 15), their parents/carers, siblings and families in south London and much of south east England using the current Principal Treatment Centre children’s cancer services at The Royal Marsden and at St George’s Hospital
- teenagers (aged 15 and 16) using children’s cancer services at The Royal Marsden who are about to transition to teenage and young adult (TYA) cancer services
- staff members of specialist, multidisciplinary teams working with children and teenagers in both the children’s and teenage and young adult cancer services at The Royal Marsden and at the other service providers in the children’s cancer network
- individuals/organisations who provide funding for the children’s cancer service.
- third sector partners who provide workforce/infrastructure for the children’s cancer service.
- people with learning disabilities, autism or dyslexia
- people from socio-economically deprived areas
- people with sensory impairments
- children, young people and families with lived experience of Principal Treatment Centre children’s cancer services in other geographical areas or accessing other cancer services locally via children’s cancer shared care units
- research staff and organisations.

New groups identified to be added to our stakeholder mapping include:

- teenagers whose cancer treatment and support needs require input from children’s services due to their specific cancer (cancers unique to children) or the nature of their need or cognitive development
- children, teenagers, and their families in the UK using the Experimental Cancer Medicines Centre based at The Royal Marsden’s children’s cancer centre
- children and their families who come from abroad as private patients to access cancer care not available to children/teenagers in their home country.

Many of the people we engaged with felt that engaging more broadly with families who had no experience of the service (providing a view from a proxy group who may be affected in the future) would be valuable. It was suggested this could be done via pre-school families and pregnancy and maternity groups, local toddler groups and nurseries. However, notably, south west London Healthwatch organisations disagreed with this approach, feeling it more important to prioritise voices of those with lived experience.

You said, we are doing

Suggestions for additional groups to engage with made during pre-consultation engagement have been added to our existing stakeholder map to ensure we capture views from these communities. We will continue to be responsive to feedback on any new groups to engage with during consultation.

Through our pre-consultation engagement work, we spoke to a small number of families who did not have lived experience of the current service. The feedback they shared was in line with those who did have lived experience.

We will continue to approach “future” service users, especially if they are from communities identified within our Integrated Impact Assessment. We will be clear in the feedback report where this feedback has come from, so that any differences between those with/without lived experience can be understood.

5.2.6 How we feedback during and after consultation

Staff from St. George’s and some voluntary organisations we spoke to were keen that we:

- publish feedback themes at the mid-point of consultation, to support a two-way dialogue
- share more information about whether different views received during consultation will subsequently be weighted (e.g. clinicians/those with direct experience versus the general public, for example) and how the options appraisal criteria may be used.

- share how we think having a preferred option will impact on consultation responses and how we will make sure the information we provided is balanced
- share how feedback will influence the consultation and subsequent decision-making processes.

You said, we are doing

Publish feedback themes at the mid-point of consultation

We anticipate sharing a summary of feedback themes through our website and at meetings when our mid-point review has been completed (there is more about this in section 5.1.6).

Approach to views expressed by different stakeholders

The external organisation which will be undertaking the independent consultation analysis has advised us that best practice is to include chapters on feedback from different stakeholder groups so that views from different perspectives can be captured, reflected, and understood. We have facilitated this through the design of our consultation questions. Once the public consultation is complete a report on consultation responses will include information on who responded and what issues were raised by different stakeholders.

Information about preferred option

Whilst both options are consulting on scored highly and are viable options for the future location of the Principal Treatment Centre, one part of the information that is being shared as part of the consultation is that there is a preferred option. This is due to the fact that one option scored more highly than the other in the pre-consultation evaluation. This information is presented as part of consultation documentation alongside a wide range of other information. We have sought to ensure consultation materials are balanced. Information about the initial options evaluation process is included so that people who read the document are able to understand what types of things were evaluated as part of this process. We worked with patient and public representatives as well as cancer experts to develop the criteria used in our evaluation process.

Information about impact of feedback on the consultation and decision-making processes

Information about how feedback will influence the consultation and subsequent decision-making processes is included in our consultation document, summary document and pre-consultation business case.

We want to gather feedback from all key stakeholders to understand the potential impacts of implementing either option. We will consider all feedback received during the consultation period. We will set out how we have taken account of feedback in our decision-making business case. Alongside feedback from the consultation, information from the evaluation (conducted before consultation), alongside other relevant information

(such as the Integrated Impact Assessment) will form part of the information that we consider when we take our decision.

5.2.7 Running an effective consultation

Feedback from some staff highlighted the importance of:

- ensuring all partners involved work together to run an effective consultation
- ensuring that messaging shared is factually accurate and that we are mitigating/managing inaccurate information
- having one agreed set of messages that are shared for consistency

Additionally some felt it was important to provide assurance that a decision has not already been made and that feedback can influence the decision.

Healthwatch organisations in south west London were particularly keen we consider how there can be assurance that we are doing a good job of engaging, to ensure we are allaying concerns raised by a group of stakeholders around not feeling heard in the process.

You said, we are doing

Assurance of our consultation plan, questions and materials

The Consultation Institute, a leading organisation in consultation best practice, reviewed our consultation documentation, including the consultation plan and questions, to ensure they would support us to run a fair and robust consultation.

To make sure we do a good job of engaging throughout the consultation we have developed and widely tested our consultation plan, with a range of activity and different methodologies to reach people and enable them to have their say. In addition, we will hold a mid-point review to understand which communities and stakeholders we have heard from, and what we might need to do to further extend our reach, particularly to fill any specific geographic or demographic gaps in responses.

This will involve a review of responses received to date, demographic information, communications activities, and engagement work undertaken and planned.

We will talk through the findings of this review with several different stakeholders. These may include the Programme Board, Overview and Scrutiny Committees, the Stakeholder Group and The Consultation Institute.

Where needed, feedback from these conversations will inform further work to reach identified priority groups either through commissioned activity or by providing information

differently or additionally to support people to respond in the second half of the consultation.

We are likely to publish key themes and include this in presentations at meetings so that people understand what feedback has been given so far.

Working together to run an effective consultation

Our Communications and Engagement Group for this programme continues to meet to share information about the consultation and coordinate engagement activities. It brings together communications and engagement leads for Evelina London, St George's Hospital and The Royal Marsden, Integrated Care Boards for the catchment area, and NHS England (London and South East) regions. The Trusts, Integrated Care Boards, parents from the Stakeholder Group, independent experts and others have contributed to the development of the consultation document and other official consultation materials, which constitute the approved documentation for the consultation. Feedback relevant to communications or engagement is taken to this group and helps shape our communications.

The teams at The Royal Marsden, St George's Hospital and Evelina London have worked with us to design and share communications for patients, families and staff to mark the launch of the consultation, and have agreed to signpost people to the NHS England consultation materials and website within their own communications cascade. Materials have also been shared with many other stakeholders, including voluntary and community groups, and individuals who have signed up to find out more.

Ensuring messaging shared is factually accurate

Our website has the approved documentation for the consultation. Printed copies of key documents will also be available. We will seek to correct misinformation, and to ensure that people understand that our website is the primary source of trusted information they can use to understand our proposals and to provide feedback to the consultation.

Keeping people informed and engaged

We are exploring how the consultation website can provide regular updates on engagement activity and other news. Our consultation materials provide indicative timelines for decision-making, which depend on a range of factors. Updates will be provided on timelines and the approach to decision-making as the process continues. We understand that providing certainty for people about where the future centre will be is important. We are also keen to identify how people can be involved after consultation and after the decision has been made, so that the conversation can continue.

5.3 General feedback about the current service

Many families with direct experience of the current service shared how positive their experiences of care are, in particular at The Royal Marsden. This included not only staff directly providing care but also supporting services and facilities. The Royal Marsden is felt to be a welcoming and friendly environment for children and young people, and parents told us it feels more like a ‘clinic’ than a hospital, which makes having treatment seem less daunting and more comfortable.

You said, we are doing

Feedback has shown that many aspects of the current service are important to retain; this has informed the vision for the future service.

NHS England and the wider Programme Board recognise the importance of seeking to retain the strengths of the current service while making the most of opportunities that would be provided by co-locating very specialist children’s cancer treatment services on the same site as a children’s intensive care unit and other specialist children’s services.

Retaining the expertise and experience of staff from the current service is a priority for all organisations involved. We will need to work closely and collaboratively with partner Trusts and staff to do this.

5.4 Case for change

There was generally a broad understanding across stakeholder groups that having very specialist cancer treatment services for children on the same site as a children’s intensive care unit will generate benefits for the future Principal Treatment Centre. While this fact was recognised, people also told us that the current service is highly regarded.

We received a few comments and questions in relation to the national service specification which is out of scope of this piece of work.

You said, we did

In response to feedback, more information has been added to consultation materials to clearly communicate the reasons why services at The Royal Marsden need to move; and to provide some background to the national service specification which has already been consulted on and approved by the NHS England Board in 2021.

As well as the case for change, the consultation document and the pre-consultation business case set out the benefits for children with cancer that would be achieved by co-locating the children’s cancer service currently provided at The Royal Marsden on the same site as a children’s intensive care unit. Some of the benefits of the move that we list

in our consultation materials are informed by what people told us during the pre-consultation engagement phase, including clinical staff and some patients we spoke to.

5.5 Opportunities arising from relocating services

A number of opportunities of co-location were identified by people we spoke to. Staff and families frequently mentioned potential opportunities that could come from designing the future Principal Treatment Centre (including clinical and recreational facilities) to support patient, family and staff experience. Examples of what they felt might be possible included more space in general, different ward environments (enabling single ensuite rooms and space for parents to sleep), enhanced play facilities and if possible, access to outdoor space. The quality of food (currently provided at The Royal Marsden) was highlighted as something people would be keen to see in the future service.

Having greater access to (and support from) other specialist services for children – both those needed urgently and less urgently – was also a frequently mentioned benefit.

Many patients accessing services at The Royal Marsden felt that there was the potential for services to be closer to home for some, including through children’s cancer shared care units.

These early views have fed into our work to date, including the two options for consultation.

Some people felt they needed more information through consultation to understand the benefits and opportunities.

Other, less frequently mentioned opportunities can be found in Appendix 1.

You said, we are doing

Interest from children, families and staff in co-designing services has been noted and supports existing plans that both potential future providers have for co-design during the implementation phase. This feedback has also helped shape content in the consultation document and pre-consultation business case. Feedback received in our early engagement phase on things that people value also informed the options development.

5.6 Things to explore further

Lots of people gave us feedback which raised questions for us to explore. Many respondents recognised that any kind of change for this cohort of patients would have an impact and present some challenges that would need to be carefully considered and managed as well as potential benefits.

The remainder of this section explores the most frequently mentioned themes in greater detail. Other, less frequently mentioned, issues can be found in Appendix 2

During the pre-consultation phase, many of the issues highlighted in this section have been explored, acted on, and/or incorporated into our consultation materials. We look forward to receiving further feedback through the public consultation.

5.6.2 Impacts on families – including travel and access

Travel and access

As with any move of service, some people would have faster journeys and others slower ones compared to now as the result of the change. For this proposed service change, the mode of transport would be significant, in that journeys by public transport would be very similar to or faster for most people than travelling to The Royal Marsden, but journeys by car would take longer for many people going to St George’s Hospital and most going to Evelina London than to The Royal Marsden.

- Significant numbers of respondents commented on the potential impact that relocating the service could have on travel times, costs and access to parking – both for service users and staff. There was mixed feedback about which of the two potential options would be easier to access for families.
- Many families told us they prefer to use a car to travel to the Principal Treatment Centre. Some parents told us they do not have access to a car or prefer to be physically close to their child on the journey to their treatment, which was echoed by some voluntary organisations we spoke to.
- Accessibility of the future site in general was frequently mentioned. Many highlighted that travel into London (as compared to the current site in Sutton) would be more challenging and less practical with a sick child. For some, it might also mean changing transport mode (from car to public transport) which could add further stress to both parent/caregiver and child as well as increasing infection control concerns.
- Although The Royal Marsden, in collaboration with Great Ormond Street Hospital and University College Hospital (which also provide specialist cancer services), has guidance which advises that it is safe to travel on public transport for children with cancer, even with a weakened immune system, many parents told us they prefer to take their children by car due to concerns around infection prevention. They told us about their concerns for those who face longer journeys by car into London, with driving becoming more problematic due to congestion and lack of parking availability (and planning for these issues) adding to stress.

- They also highlighted the likelihood of increased stress for parents/caregivers caused by being late for appointments – due to being unable to park close by or due to unreliable public transport.
- Given high preference rates for travel by car, many families and staff told us the availability of parking would be important.
- Some respondents told us they would have worries about the additional costs of travel, including the congestion charge, Ultra Low Emissions Zone (ULEZ) charge, and parking costs⁷.
- They said longer journeys by road for some patients and families could also increase the carbon footprint of families travelling to the service.
- Parents also expressed concerns for asylum seeking children and their families, and their ability to get to or from appointments.
- Parents and carers told us they currently need to make arrangements for childcare, their own jobs and taking time off to support their child through treatment. Increased travel times could mean longer periods away from school or work.
- Some people suggested visitors from children’s wider families might have more expensive and longer journeys. This could mean less frequent visits which could have an impact on both patients and parents.

Other concerns

- The cost of accommodation for parents staying near the hospital (if they were not eligible for or able to access supported accommodation) was queried, with concern that costs may be higher further into London.
- The Royal Marsden memorial garden was highlighted, with questions about how to preserve past memories for donors and for bereaved parents.
- Many families felt that The Royal Marsden site is generally quiet and The Oak Centre quite contained, whereas being on the same site as a bigger hospital could mean a different experience.

Many of the above points were echoed by members of staff and some members of NHS England’s Stakeholder Group.

⁷ As of 31 August 2023 The Royal Marsden Hospital now falls into ULEZ restrictions, meaning current families have to pay these charges.

You said, we are doing

Concerns about travel

NHS England carried out an initial equality and health inequalities impact assessment (EHIA) to help in understanding how the decision to change services may affect different groups of people in different ways. National and local data as well as feedback from children, young people and families was used to shape this document.

The impact assessment made recommendations for things that could make the change easier for children and families. These include:

- help for patients and families to plan their journeys to the future Principal Treatment Centre, including easy to understand information in different languages
- getting their travel costs paid quickly. Help to access other financial support
- improving non-emergency transport services for patients and their families
- space for families to stay
- easy arrangements at the future centre, including for dedicated parking and drop-off
- convenient appointment times, more care closer to home, strong communication between different health and social care teams, and online or phone appointments
- an excellent plan to support patients during the move, with a named care coordinator (such as a specialist cancer nurse) for each child and family.

In response to feedback, representatives from across the catchment area have been invited to review the impact assessment and add further detail to recommendations on accommodation, family facilities, parking arrangements and consideration of prospective funding of travel costs.

Recommendations will continue to be developed, including in response to consultation feedback and suggestions. The team running the future centre will need to act on these recommendations. Everyone is committed to doing so.

Memorials at The Royal Marsden

The need to work in a sensitive way to consider plans for the memorial garden and associated tributes has been recognised by all three Trusts. The Royal Marsden and the future Principal Treatment Centre would work with families on preserving memorials for children in line with families’ wishes.

More information is available on our consultation website about areas where people have raised questions and/or expressed concerns, and we invite further feedback as part of the public consultation. We will supply printed versions of detailed information on our website

to those who contact us by phone or email to request it, on their own or someone else’s behalf.

5.6.3 Impact on the workforce and their wellbeing

Staff shared a range of feedback with us as part of pre-consultation engagement.

- Some highlighted the importance of strategic workforce planning to support the proposed service transfer and ensure the future service had the staff it would need.
- Concerns were raised about recruitment and retention both during the current period of uncertainty and when services moved to the future Principal Treatment Centre, noting the specialist nature of the workforce and the importance of retaining their skills and expertise.
- The importance of ongoing investment in the current service, including staff training, during the proposed change process was emphasised.
- While it is hoped that all eligible staff would move with the service, some said they may choose not to because of the increased length and cost of their journeys to either of the two options for the future centre, and the impact on their work/life balance and childcare arrangements, including their cost. In this scenario, some staff noted they were uncertain what types of alternative roles would be a good match for their skillsets.
- Staff also want to understand the training and education opportunities and other benefits that could be available to them.

You said, we are doing

Support through change

We recognise that it is really important to support families and staff through the change process. Hearing from families and staff in the pre-consultation period has helped reinforce this. In recognition of this, our consultation questions specifically ask patients and staff about different types of support to make the move easier.

We are working closely with the Trusts who have an important role in ensuring that current staff are supported through this process. As part of this, and in response to feedback and suggestions received, we propose to establish a joint leadership role with The Royal Marsden to support the change process. The role would evolve once the future Principal Treatment Centre is decided.

The retention of the expertise and experience of staff within the current service is a key priority for everyone concerned. During the pre-consultation engagement period there has

been close working with the current service to build relationships with their staff and understand their concerns about the change process. In response to feedback, more staff sessions were held, in smaller groups. This will continue during consultation and help gather feedback to inform our decision-making. Relevant feedback to the consultation will also be shared with the future provider after a decision has been made on the location of the future centre, to help them identify how they can best support existing staff to transfer with the service as part of their implementation planning.

The implementation plan will draw very significantly on the experience, expertise and insight of the current Principal Treatment Centre teams at The Royal Marsden and St George’s Hospital, patients and their families, and the children’s cancer network. Feedback gathered to date and through the consultation will help inform the plan’s development.

5.6.4 Interdependent services

We received feedback on a number of areas of significance for cancer care for children. Alongside the areas below, people told us it was important that the chosen site has the available capacity, space and experience to take on the service. They said careful planning to support the transfer would be needed to mitigate potential service impacts that were mentioned.

5.6.4.1 Research

We heard that there are significant benefits for research trials, drug development and drug discovery teams, as well as academic staff, from having children’s cancer services at The Royal Marsden very close to the Institute of Cancer Research, which undertakes laboratory-based research to develop new drugs. Consideration needs to be given to how these benefits could be maintained in both potential options.

There were a number of questions about the future of research and how patients would maintain access to clinical trials as they do now at The Royal Marsden:

- Concerns were raised that early access to clinical trials at The Royal Marsden could be difficult to replicate elsewhere
- Staff were concerned that patient access and enrolment to clinical trials (regardless of future location of the Principal Treatment Centre) could be negatively impacted. Clear plans would be needed to ensure these issues are addressed.
- Teenagers and adults with paediatric types of cancer, and children with adult types of cancer are currently able to access clinical trials and new therapies at The Royal Marsden because the Trust provides cancer care for children, teenagers and young adults, and other adults. Staff raised concerns this may be difficult to maintain in the

future with the future Principal Treatment Centre at a different site and provided by a different Trust

- They also highlighted concerns about access to clinical trials for teenagers and young adults: staff told us that clinical trials giving access to new therapies often include patients up to the age of 25. We heard how this could be difficult to maintain if children’s cancer services and teenage and young adult cancer services were no longer on the same site. The need to retain expertise across the age range was also emphasised.

On research we also heard:

- It is important to recognise the part that parent-run charities play in funding children’s cancer research and understand how this may be impacted
- Concerns that research won’t maintain its current profile if the services move
- Questions about how the research portfolio would be maintained - currently there is a team to manage the large number of clinical trials.

You said, we are doing

Engaging with research staff

Prior to and during the pre-consultation engagement period, NHS England met with research staff at The Royal Marsden and the Institute of Cancer Research to understand their current needs and concerns for the future. What they told us has helped the programme consider what needs to be done to safeguard research up to and during the move and for the future, to be more aware of the risks, and to build mitigations. It has also helped build relationships that will be helpful as this programme moves forward. The consultation documentation, particularly the pre-consultation business case, reflects information about risks that have been identified and potential mitigations for these.

In early September 2023, we organised site visits for research staff from the Institute of Cancer Research and The Royal Marsden to Guy’s and St Thomas’ and St George’s Hospital to discuss concerns that they have and to tour the facilities.

We recognise how important research is and will continue to work with stakeholders to maintain a focus on managing potential risks as the programme progresses, this will also be shaped by feedback we received through the public consultation.

5.6.4.2 Radiotherapy

- More information was sought about our proposal under both options for conventional radiotherapy services (mostly using high energy x-rays known as photon beams) to

transfer from The Royal Marsden to University College Hospital. Staff told us that some children would continue to require photon beam radiotherapy, and that some types of patients would have to be transferred from the future Principal Treatment Centre to receive this. Staff told us it would be important to determine the best pathway for these patients in the future.

- Given the requirement for the service, many wanted more reassurance about capacity at University College Hospital and its ability to cope with increased activity to ensure that patients could be seen quickly enough.
- Staff told us that there is a need to ensure there would be enough staff (clinical oncologists, anaesthetists, and radiographers) to cope with increased demand.
- People told us that proposals for radiotherapy needed to be highlighted more clearly in our consultation materials, including the reasons for change and the impact of the change.

5.6.4.3 Neurosurgery

- Cancer-related neurosurgery is for problems affecting patients’ brains, nervous systems or spines.
- Both King’s College Hospital and St George’s Hospital provide neurosurgery, people asked for clarity on arrangements for future neurosurgery provision in the proposals and the impact on the existing service.
- They wanted to understand how Evelina London (which doesn’t provide neurosurgery) would provide and manage this service.

You said, we are doing

More information on radiotherapy and neurosurgery

As a result of feedback, we have worked closely with those who provide the current services at different sites and other stakeholders to add more detail into our consultation materials. As well as summary information on these clinical services in our consultation document, there is detailed information in our pre-consultation business case. This has been extracted to be separately available on the consultation website for ease of access.

For our proposals on radiotherapy, this includes the drivers for change, proposed arrangements, benefits and potential impacts. For neurosurgery, this includes a description of how the service is currently provided and how it would work if the future Principal Treatment Centre was at Evelina London.

We are working with Trusts to design focus groups with staff for the consultation. This will be one of several ways that clinical and non-clinical staff can share their views, including on these aspects of our proposals.

Once a decision has been made, much more detailed discussions will be needed between partners to make plans for the transition. Feedback received from the public consultation can be used to help inform these.

5.6.5 Options appraisal process

Several stakeholder groups (including staff, some Overview and Scrutiny Committees and our Stakeholder Group) wanted more information to be available about the options appraisal process undertaken in the pre-consultation phase and scores, specifically about the process itself and the other options considered, including whether we had explored keeping services on The Royal Marsden site (for instance, by building a children’s intensive care unit). Additionally, there was interest in understanding the scoring and development of the travel time analysis.

Some staff and some members of the Stakeholder Group had more specific questions regarding the options appraisal process that was identified during the pre-consultation process. Some asked for more information on how a decision on having a preferred option was reached and how consideration of current expertise and knowledge in children’s cancer services was weighted within the scoring. Some parents in our Stakeholder Group raised questions about the approach used to assess travel impact.

In addition, some raised questions about how interdependent services (such as neurosurgery and radiology) featured in our evaluation process.

You said, we are doing

More information on options appraisal process

As a result of this feedback, we have added more detail to our descriptions of how we identified the options, how the evaluation criteria were developed, how the options were assessed and scored (which also has information on our preferred option), and how travel times were assessed and scored. This includes views that different stakeholders have expressed about aspects of these processes.

Detailed information on all of these is in our pre-consultation business case. For ease of access, it has been extracted to be separately available as information pages on the consultation website. This information is signposted from our consultation document.

There is also now more information in our consultation materials about why The Royal Marsden cannot be the site of a children’s intensive care unit.

We are providing very detailed information in this way to facilitate public consultation with patients, families, staff and other stakeholders. It will enable everyone interested in the detail to have access to the information they require to give an informed response.

5.6.6 Decision-making process

- Staff told us reassurance was needed that the final decision would be implemented and that the relocation of services would happen.
- People told us that moving the timeline for change or decision-making is unsettling for both staff and patients.
- Some felt that the time it will take from decision-making to ‘go live’ of the future Principal Treatment Centre feels relatively short – reassurance is needed that this would be achievable, but equally that the change process would be well managed so there would be no unwarranted slippage.
- Further information about the decision-making process was sought, including on how decisions would be made.
- Staff told us they want to have involvement in decision-making and subsequent implementation process.

You said, we are doing

Timelines and decision-making

Information about the decision-making process is included in the pre-consultation business case. The business case also sets out more information about the timelines for transferring the future centre, including plans that both Trusts have put together for this, and risks that will need to be managed.

NHS England (London and South East regions) recognises that people will be interested in the decision-making process and its outcome. We will be transparent about this and keep stakeholders informed, sharing relevant information at key milestones.

Implementation

Once a decision is made, it will be important that it is implemented in a timely fashion to ensure safe transition that provides continuity of care and to relieve uncertainty among staff and patients. We envisage establishing an Implementation Board to oversee the process, supporting delivery of its priorities and benefits, and collaboration between stakeholders including staff, and ensuring risks related to the service transfer are managed.

5.7 Solutions and mitigations to reduce concerns and support the change

Many respondents discussed the importance of providing clear information about both options during consultation, including things like estate plans, the affordability and cost of both options, workforce plans, and risk mitigation plans for clinical research activity. We heard that, once a decision is made, it will be important to have detailed transition plans including timelines, plans for the transfer of patients, training plans for staff; recruitment plans, and facilities plans.

Staff at The Royal Marsden were also keen to have information about the benefits and opportunities both options would offer for staff, for example information about support with travel costs, any flexible working arrangements, study leave arrangements and nursery care provision.

On more general communication, many stakeholders felt regular and clear updates about progress on the project, particularly at key milestones, would help to alleviate fears and misinformation. Having as much advanced notice of the change as possible would also be helpful for staff and families. People asked for clear, direct answers to questions that they have.

Listening to concerns from staff and patients and being open to receiving new information were also raised as important principles, together with being transparent, honest and fair.

Suggested solutions around travel and access included offering information about support for families with parking and travel costs, especially when children are being regularly admitted for care. Even better would be the provision of free or significantly subsidised parking costs with ring-fenced, accessible, spaces. Some families discussed the importance of providing enough family accommodation on site to meet the demand.

Key mitigations that families asked for were reassurance around current staff transferring to the future Principal Treatment Centre, ensuring the quality of care would be the same or better than it currently is, and that benefits of the move to patients were realised.

Other less frequently mentioned solutions and mitigations are explored in Appendix 3.

You said, we are doing

Clear information

As set out in section 5.1.3 above, we have worked hard to provide clear information on the options and on other aspects of our proposals. As a result of feedback from staff at The Royal Marsden, we specifically included impact on staff travel times and the benefits and opportunities both options would offer for staff as part of the criteria for the pre-consultation evaluation that was undertaken by expert panels. Information on the outcome of this is included in our consultation materials.

Listening to concerns

We are listening to concerns raised with us and will continue to do so throughout this process. We may not always be able to take the actions people want, but we are specifically asking people for their views on support that might help with the move as part of the consultation questions. Through this, we hope to receive more views on mitigations that would help and potential solutions to challenges people foresee. We will listen to and consider all the feedback we receive through the consultation, and are continuing to follow up feedback received through pre-consultation engagement too.

Travel and access

Many of the solutions and mitigations suggested are already in our Integrated Impact Assessment, which is shaped and informed by a group of stakeholders from the catchment area, including parents. We have worked with Evelina London and St George’s Hospital on the recommendations. They are both committed to developing them as part of the implementation planning phase, if they were to become the location for the future Principal Treatment Centre.

Keeping people informed and engaged

We are exploring how the consultation website can provide regular updates on engagement activity and other news. Our consultation materials provide indicative timelines for decision-making, which depend on a range of factors. Updates will be provided on timelines and the approach to decision-making as the process continues. We understand that providing certainty for people about where the future centre will be is important. We are also keen to identify how people can be involved after consultation and after the decision has been made, so that the conversation can continue.

5.8 Feedback received outside the scope of this engagement work

Some of the feedback received was outside the scope of this period of pre-consultation engagement work. Examples are questions about how the change would be implemented and the impact on individual staff members’ employment contracts (the latter will be subject to a formal Human Resources consultation once a decision on the future site has been reached). It has been presented here for transparency.

Issues set out in this section will help to inform the implementation phase and plans for service transition which will start once a decision has been made about where the proposed future Principal Treatment Centre will be. NHS England will support discussions between organisations to consider what human resources support for staff is needed between now and implementation.

5.8.2 HR questions regarding employment contracts

Concerns about pay and bandings

- It was noted that the uplift in salary of going from outer-London to inner-London weighting may not cover incremental costs of travel especially among more junior staff, there could be impacts on work/life balance.
- Staff wanted confirmation around whether they would transfer across under the same job description and pay grade.

Impact on roles

- There was a desire for more information about which roles are expected to move, who this would include, and how they would fit in with the future location.
- Some raised concerns that, as part of a broader children’s service, the future service may not be ring-fenced and they could be asked to cover other areas of work.
- There was a desire to understand if/how roles and the structure of the service would be impacted by transition to the future Principal Treatment Centre, and how staff who work for both children’s cancer services and teenage and young adult cancer services would be impacted by the change.

5.8.3 Implementation planning and transition

- There were questions over how services on the current site would transition to the future site and whether they would run concurrently or stop on one site and begin on the other.
- It was noted that during the transition and implementation phases of the service move, there should be continued high level involvement from key clinicians and advisors.

6. Next steps

We are grateful for all the feedback we have received during pre-consultation engagement and for the time that people have given to provide this. Many of the issues raised with us have been considered and explored, with additional information added to consultation materials and frequently asked questions ahead of the launch of consultation. Much more information is available to people as part of the consultation. We would ask people to read this material and to respond to our consultation questions to give us their feedback and inform decision-making.

A summary of this report was shared with the Programme Board in September, and was discussed with NHS England’s Stakeholder Group. The report will be published on our consultation website.

Appendix 1: Additional opportunities as a result of the change

Presented here are the less frequently mentioned opportunities, collected from surveys and qualitative conversations across all stakeholder groups. As mentioned above, these reflect what people told us and are their perceptions of what might be possible.

Potential opportunities for care

- A more holistic service.
- Access to additional expertise/support services.
- Access to tertiary children’s teams on site, to provide their expertise.
- Access to a wider range of resources/facilities as part of bigger children’s departments.
- Access to high quality imaging capability.
- Good wifi connectivity for older children to enjoy gaming, social media and watching TV.
- Increased support for older children moving to teenager and young adult services.
- Increased use of interventional radiology for simple procedures (as an alternative to surgery).
- Opportunities to grow and develop the service.
- Opportunities to develop new models of care and, possibly, treatment by harnessing expertise within the hospital such as interventional radiology.
- Opportunities for children, families and staff to be involved in/collaborate on the design of the future Principal Treatment Centre.
- Opportunities for staff to develop their expertise.
- Opportunities for staff to transfer into/become familiar with a new specialty
- Opportunities to use clear understanding of what the future Principal Treatment Centre will need/ways of working to recreate the good things in the existing service.
- Increased capacity.
- Expansion of the department (and others).
- Providing oncology services to a wider group of children.

Opportunities for access

- Access to family accommodation such as Ronald McDonald house (there is one at both future location options).
- Learning from the Principal Treatment Centre at Great Ormond Street Hospital to understand how they support travel and access to their site in central London.
- Future Principal Treatment Centre may have better transport links.

Research

- Increased opportunities for research, including new sub-specialties
- Increased capacity to collect tissue for tissue studies and increase translational research

Opportunities for the children’s cancer workforce

- Development opportunities within a bigger organisation.
- Greater stability and certainty for the future.
- Access to new learning opportunities.
- Opportunity to develop culture.
- Collaborative working across different teams.
- Improved utilisation of skills and resources within larger setting.
- Opportunity to increase the workforce size.
- Opportunities to meet with new staff and other young people
- Working physically, more closely with colleagues who provide more children’s services to share experience and knowledge.

Opportunities for the workforce in the receiving organisation

- Development of skills such as chemo competencies.
- Learning from the experience and expertise of the staff transferring into the service and developing skills.

Appendix 2: Additional issues to explore and consider

Presented here are the less frequently mentioned things to explore and consider, collected from surveys and qualitative conversations across all stakeholder groups. All feedback received has been captured and will be kept under review so that it can continue to inform our work.

Service reputation and identity

- Perceptions that the service could lose its identity in becoming part of a larger hospital offering a range of other services.
- Concerns over the loss of The Royal Marsden identity and culture
- Questions over whether an RMH@ model could be employed to help minimise the impact of the move.

Teenage and young adult services

Staff at The Royal Marsden in particular shared the following feedback:

- It will be harder to make transition arrangements between children and young people’s services to teenage and young adult services as seamless as they are currently, when children’s services and teenage and young adult services are delivered on different sites in the future. For example, some 16 to 17-year-olds – who may have a learning disability or whose weight may be more similar to a younger child – still require input from children’s cancer services
- It will be important to continue to be flexible with the ages that children move to teenage and young adult services – allowing this to be determined on a case-by-case basis
- There is a level of shared services, workforce and interdependencies between children’s services and teenage and young adult services at The Royal Marsden which benefit children and teenagers in and across these services. Concern was raised that a change in location of one of these services could have a direct impact.

Future capacity

- Importance of ensuring there are enough children’s intensive care unit beds to cope with demand, given there are shortages of these beds every winter and potential for patient transfers.
- Importance of ensuring there is enough theatre capacity to cope with demand.
- Importance of ensuring pathology labs have the capacity to manage activity.

Children’s cancer shared care units

Although there are no planned changes to these services, it will be important to make clear which services are in and out of scope for our proposals, so children with cancer and their families are clear.

Impacts on other clinical services

Some people raised concerns that there could be a potential impact on other related services including children’s non-cancer surgery at St. George’s Hospital that would need to be mitigated.

The London Cancer Hub is due to open next to The Royal Marsden and moving children’s cancer services could risk losing important links into the Hub.

Consideration of arrangements for children’s palliative care.

Perception that there will be a loss of the pharmacy service where drugs currently are brought to you on the ward at The Royal Marsden.

Questions over how existing therapies teams would integrate into either of the other hospitals.

General challenges of moving the service

Much of the feedback received has been about the very specialist clinical interventions provided and how these would translate to a future location. However, some of the feedback received was around the general challenges that would need to be managed when re-locating the service. These include:

- engaging staff to get them ‘on board’ with the proposed service transfer
- the ability of the future Principal treatment Centre to cope with demand
- the ability of the future Principal treatment Centre to cope with demand for radiology activity including specialist scans
- the work involved in establishing the service in a future location, including the learning curve that this could entail; ensuring the quality of patient care is not impacted
- ensuring future services continue to be high-quality
- uncertainty around the impact of potential changes to the way in which the service is managed
- management of the change process including management of identified risks and new risks that emerge
- questions about how medical records would be transferred



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- the need to establish new relationships between teams, and concern about the loss of existing interactions, including those between children’s and adult cancer services, research and radiology.
- management of patients in an environment where there were patients who did not have cancer; arrangements for infection prevention and control.
- ensuring facilities of the site are high quality and up to standard (with similar, if not better, facilities plus space for supporting services).

Appendix 3: Additional mitigations and solutions to support the change

Presented here are the less frequently mentioned suggestions around mitigations and solutions, collected from surveys and qualitative conversations across all stakeholder groups. All feedback received has been captured and will be kept under review so that it can continue to inform our work.

Potential solutions and/or mitigations

Ways of working

- Explore remote working for specialist teams to reduce the impact of increased travel
- Develop satellite hubs to enable staff who work in the community to have a base to undertake home visits from
- Remote working/remote hubs to continue to provide good palliative care

Staff support

- Support to integrate teams from different organisations
- Support with funding to help build/establish the future service
- Support from HR for staff with the change process
- Regular communications including frequently asked questions documents
- Consider potential incentives for staff to stay through the transition to be part of the future Principal Treatment Centre – suggested solutions included parking, support with Ultra Low Emissions Zone (ULEZ) costs and flexibility in shift patterns

Patient and family support

- Give information about the change to patients and their families again and again and in multiple ways – once will not be enough to take it in if you’re in the middle of treatment
- Extra time during appointments to discuss concerns (or maybe people in waiting room on clinic days/designated clinical nurse specialist to answer questions)
- Provide information about patient choice so parents can make choices that suit their child’s circumstances
- Raise awareness of the support already available to families as well as any new support that can be offered
- The future Principal Treatment Centre should ensure it has enough home from home accommodation to cope with the increased demand
- It should consider partnering with local hotels as well
- It should provide visual information about how to get to its site

- It should provide ways for children and families to get to know new staff
- It needs to be aware of local voluntary and community organisations and how they can support families
- It should offer flexibility in patient transport arrangements in terms of the number of people able to travel with the child
- For asylum seeking children and their families, and Gypsy Roma and Traveller communities, where the services are actually located will be of little interest. Making them welcoming, accessible and having the services that they need there (like interpreters and culturally trained staff to understand their needs) is more important to their actual experience and whether or not they will want to visit that site and engage with services in the future.

Planning and decision-making

- Timely decision making on the location of the future centre to provide certainty
- Openness and transparency about the decision-making process, and communicating this proactively
- Decision-makers taking into account feedback that is received
- Ensuring planning takes account of demand for children’s intensive care beds
- Ensuring there are detailed implementation plans and there is accountability for delivering proposals to achieve a smooth transition
- Demonstrate that we are taking into account other changes in the NHS system
- Demonstrate that the change will mean value for money and improve outcomes
- Support for ongoing links with other teams remaining at The Royal Marsden

Proposed future Principal Treatment Centre – building and accessibility

- Ensure the future site is physically accessible with wheelchair/pram access
- Share information about how disabled children will be supported to access the future Principal Treatment Centre through wheelchair access/ dedicated blue-badge parking
- Ensure the service has a separate space from the main hospital to reduce associated disruption and risk of infection
- Involve patients, families and staff to help shape the future service/plan the space and environment as part of the implementation plan
- Involve them in the design and build process to ensure it is inclusive and complementary to other services in the hospital
- Maintain links with existing charities

Stakeholder engagement

- Further engagement with professional groups/allied health professionals separately for more detailed and in-depth discussions about roles to understand the current service and develop solutions
- Provide information about how children’s cancer shared care units might be improving their service provision
- Ensure children’s cancer shared care units are engaged in the process and are supported to enhance their services for instance, so more chemotherapy can be provided closer to home
- Get feedback from community nursing teams to ensure issues around community provision of palliative care have been fully scoped
- Plan the implementation with all relevant providers
- Understand and retain the good things about the current site at The Royal Marsden
- Detailed workforce planning to manage the transition process
- Involve those with lived experience and staff in the decision-making process
- Share information about how either option would prepare for the future Principal Treatment Centre.

Appendix 4: Communications and engagement preferences during consultation

Presented here are quantitative findings from survey questions relating to communications and engagement preferences during the consultation. These are drawn from surveys conducted with families and staff with direct experience of the current service as well as staff and families with no experience of the current service. This information supports feedback from qualitative discussion groups, discussed in the main body of the report.

A4.1 Important information to include as part of the consultation

Topic	Number of staff (working full or part time in the current service at The Royal Marsden and St George’s Hospital)	Number of Evelina London Children’s Hospital staff	Number of families with experience of the current services	Number of families with no experience of cancer services
Where the service might be moving to	78	24	94	18
Why the service needs to move	55	17	67	10
What might be different about your care	39	18	78	28
What the wards are like in the different hospitals	38	16	52	13
What support might be available to help with travel	51	11	73	14
What other services are already available on the site	58	13	46	10

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How we would make the transition smooth, once a decision has been made	71	29	66	23
What we’ve already heard from children and young people	72	28	36	12
The process we’ve been through to get us here	43	16	33	10
If you would see the same consultant	0	0	2	0
Would it be big enough/ have enough capacity to cope with future demand	0	0	0	1
Any impacts on waiting times	0	0	0	1
How we intend to make the service work for children with brain tumours who also have care and surgery at King’s College Hospital	0	0	1	0

A4.2 Preferred methods of engagement

Method	Number of staff (working full or part time in the current service at The Royal Marsden and St George’s Hospital)	Number of Evelina London staff	Number of families with experience of the current services	Number of families with no experience of cancer services
Joining an event – in person	49	10	20	7
Joining an event – online	61	27	30	10
Interview – over the phone or online	26	7	12	6
Filling in a survey	72	35	76	22
Replying by email	41	16	62	12
Being asked while in a waiting room/ already at the hospital for treatment	8	1	42	16
Total⁸	257	96	180	64

⁸ Total exceeds number of people who responded as individuals identified more than one preference

A4.3 Presenting complex information

Method	Number of staff (working full or part time in the current service at The Royal Marsden and St George’s Hospital)	Number of Evelina London staff	Number of families with experience of the current services	Number of families with no experience of cancer services
Short videos (less than a minute)	53	22	57	26
Longer videos (more than a minute)	39	10	29	4
Pictures or diagrams	59	21	36	19
Short documents with links to more information	73	25	64	17
Presentations	64	24	27	7
Emailing info with links				1

Appendix 5: Information about respondents

Those completing surveys were given the opportunity to provide voluntary demographic data and information about what kinds of stakeholder they are, to help us understand who our pre-consultation engagement activities had reached. As this request was voluntary, not all respondents chose to complete this information. Qualitative discussions did not capture demographic information, meaning the information in this section can only be considered an indication of our reach. All data was anonymised.

A5.1 Respondent type

Respondent type	Number
Child or young person currently having treatment for cancer at The Royal Marsden/St George’s Hospital	18
Child or young person previously treated for cancer at The Royal Marsden/St George’s Hospital	12
Parent, carer or advocate for a child or young person who has/had cancer and received their main treatment at The Royal Marsden/St George’s Hospital	82
Parent, carer or advocate for a child or young person who has/had cancer but received their treatment somewhere other than at The Royal Marsden/St George’s Hospital	5
Parent, carer or advocate for a child or young person who has not had cancer	42
Sibling or other relative of a child or young person who has/had cancer	0
Sibling or other relative of a child or young person who has not had cancer	4
Friend of a child or young person who has/had cancer	0
Children’s cancer charity	2

Pre-consultation engagement activity and stakeholder feedback – ‘You said, we did’ report

Respondent type	Number
Member of the public	0
Voluntary organisation	0
Staff who currently work for the Principal Treatment Centre at The Royal Marsden and St George’s, either directly (they are employed by the current Principal Treatment Centre service) or indirectly (they spend some of their time supporting the Principal Treatment Centre service, for example the radiology team at St George’s Hospital)	88
Staff who currently work for the Principal Treatment Centre at The Royal Marsden and St George’s Hospital but are not directly employed by the NHS	3
Staff from other Trusts that provide children’s cancer services	1
Staff who currently work in children’s services at Evelina London	38
Staff who provide admin/clerical support at Evelina London	4
Member of the Clinical Network hosted by Evelina London	1
Other public body/stakeholder/political representative	1
Prefer not to say	1

A5.2 Professional role

As part of the survey, staff were asked to indicate what kind of role they perform and if/ how this connects to the current service. Qualitative discussions also captured professional roles, where possible. This has supported us to understand which staff groups we have reached and has enabled us to do further work to reach under-represented staff groups. As this information

Pre-consultation engagement activity and stakeholder feedback – ‘You said, we did’ report

request was voluntary, not all staff chose to complete this information, meaning the information in this section can only be considered an indication of our reach.

Title	Number of staff (working full or part time in the current service) from The Royal Marsden*	Number of staff (working full or part time in the current service) from St George’s Hospital	Number of Evelina London staff
Nurse	10	12	16
Doctor (including speciality doctor, consultants and junior doctors)	7	10	15
Play therapists, radiology and radiotherapy, and other allied health professionals	10	10	2
Management and administrative/research staff	9	3	5
Other (psychology, pharmacy, social worker, pathology)	2	12	2
Educational staff	3	0	0
Communications/media team	0	1	0
Prefer not to say	1	8	4

* During staff focus groups, we also spoke to nursing colleagues including children’s nurses and members of the late effects teams, research colleagues including nursing, assistant practitioners, consultants, governance staff, administrative and clerical staff, psychology team members, radiology team members, radiotherapy team members, team leads, ward matron.

A5.3 Geographic coverage

Areas shaded in show families that are technically coming from outside of the physical catchment area, but, for a number of reasons, these patients are accessing the Principal Treatment Centre for their treatment.

Area	Number of staff (working full or part time in the current service at The Royal Marsden and St George’s Hospital)	Number of families with experience of the current services	Number of families with no experience of cancer services
Bexley	0	2	0
Brighton and Hove	0	2	0
Bromley	1	5	1
Croydon	5	4	8
East Sussex	0	5	0
Greenwich	0	3	0
Kent	0	17	3
Kingston	5	3	0
Medway	0	2	0
Lambeth	9	5	5
Lewisham	0	3	6
Merton	9	1	5
Richmond	2	1	1
Southwark	2	5	4
Surrey	30	23	1
Sutton	15	10	1
Wandsworth	17	13	7
West Sussex	2	10	0

Pre-consultation engagement activity and stakeholder feedback – ‘You said, we did’ report

Area	Number of staff (working full or part time in the current service at The Royal Marsden and St George’s Hospital)	Number of families with experience of the current services	Number of families with no experience of cancer services
Barnet	0	0	1
Hammersmith and Fulham	2	0	0
Hampshire	1	0	0
Hertfordshire	1	0	0
Essex	1	1	1
Middlesex	0	2	0
Falkland Islands	0	1	0
Southampton	0	1	0
Buckinghamshire	0	1	0
Ipswich	0	0	1
West Hampstead	0	0	1

A5.4 Sex

What is your sex?	Number of staff (working full or part time in the current service at The Royal Marsden and St George's Hospital)	Number of Evelina London staff	Number of families with experience of the current services	Number of families with no experience of cancer services
Male	9	11	33	8
Female	93	30	79	33
Transgender	0	0	0	0
Non-binary	0	0	0	0
Prefer not to say	2	3	0	0

A5.5 Gender identity

Is your gender identity the same as the gender you were given at birth?	Number of staff (working full or part time in the current service at The Royal Marsden and St George's Hospital)	Number of Evelina London staff	Number of families with experience of the current services	Number of families with no experience of cancer services
Yes	99	42	109	41
No	2	2	1	0

A5.6 Age

Which of the following describes your age?	Number of staff (working full or part time in the current service at The Royal Marsden and St George’s Hospital)	Number of Evelina London staff	Number of children and parents/carers with experience of the current services	Number of children and parents/carers with no experience of cancer services
Under 13			22	4
13-15			4	0
16-18	0	0	7	0
19-25	7	0	10	4
26-40	38	10	36	23
41-65	45	15	39	11
66-74	0	0	1	0
75 or over	0	0	0	0
Prefer not to say	3	4	0	0

A5.7 Physical or mental health conditions, disabilities, or other non-cancer related illnesses

Do you have any physical or mental health conditions, disabilities, or illnesses?	Number of staff (working full or part time in the current service at The Royal Marsden and St George’s Hospital)	Number of Evelina London staff	Number of families with experience of the current services	Number of families with no experience of cancer services
Yes	13	8	28	6
No	88	36	90	37

A5.8 Ethnicity

How would you describe your ethnic group?	Number of staff (working full or part time in the current service at The Royal Marsden and St George’s Hospital)	Number of Evelina London staff	Number of families with experience of the current services	Number of families with no experience of cancer services
Asian/Asian British	10	4	14	7
Black/ Black British	5	3	4	10
Mixed/ multiple ethnic groups	5	2	11	4
White	77	31	83	19
Any other ethnic group	3	2	5	3
Prefer not to say	4	2	2	0

A5.9 First language

Do you speak English as your first language?	Number of staff (working full or part time in the current service at The Royal Marsden and St George’s Hospital)	Number of Evelina London staff	Number of families with experience of the current services	Number of families with no experience of cancer services
Yes	99	42	101	30
No	3	1	18	13

Appendix 6: Travel time and mode data – identified through survey data

Children, young people families and staff were asked about mode of transport and travel times to the site at which they were currently receiving treatment. This information is indicative and not necessarily representative of the way individual cohorts may travel. Anecdotal information shows that this information may change depending on a number of factors, with some estimating or averaging their travel times. Therefore, this data captures a snapshot in time.

A6.1 Mode of transport to The Royal Marsden, Sutton – current parents

Mode of transport	Numbers	Percentages
We travel by taxi	4	5%
We travel using our car	60	76%
By bike	1	1%
On foot	0	0%
We take public transport (bus, train etc.)	9	11%
We use hospital transport	5	6%
Total	79	100%

A6.2 Travel time to The Royal Marsden, Sutton – current parents

Average journey time	Numbers	Percentages
Under 15 minutes	4	5%
15 minutes to 30 minutes	10	13%
31 minutes to 45 minutes	25	32%
46 minutes to an hour	9	11%
Over an hour	31	39%
I don't know	0	0%
Total	79	100%

A6.3 Mode of transport to St George's Hospital – current parents

Mode of transport	Numbers	Percentages
We travel by taxi	0	0%
We travel using our car	7	78%
By bike	0	0%
On foot	1	11%
We take public transport (bus, train etc.)	1	11%
We use hospital transport	0	0%
Total	9	100%

A6.4 Travel time to St George’s Hospital – current parents

Average journey time	Numbers	Percentages
Under 15 minutes	3	33%
15 minutes to 30 minutes	4	44%
31 minutes to 45 minutes	1	11%
46 minutes to an hour	1	11%
Over an hour	0	0%
I don’t know	0	0%
Total	9	100%

A6.5 Overall mode of transport to either site – current parents

Mode of transport	Numbers	Percentages
We travel by taxi	4	5%
We travel using our car	67	76%
By bike	1	1%
On foot	1	1%
We take public transport (bus, train etc.)	10	11%
We use hospital transport	5	6%
Total	88	100%

A6.6 Overall travel time to either site – current parents

Average journey time	Numbers	Percentages
Under 15 minutes	7	8%
15 minutes to 30 minutes	14	16%
31 minutes to 45 minutes	26	30%
46 minutes to an hour	10	11%
Over an hour	31	35%
I don't know	0	0%
Total	88	100%

A6.7 Mode of transport to work – current staff

Mode of transport	Number of staff (working full or part time in the current service) travelling to The Royal Marsden, Sutton	Number of staff (working full or part time in the current service) travelling to St George's Hospital
We travel by taxi	0	0
We travel using our car	31 (65%)	15 (21%)
By bike	2 (4%)	17 (23%)
On foot	4 (8%)	10 (14%)
We take public transport (bus, train etc.)	11 (23%)	31 (42%)
Total	48	73

A6.8 Travel time to work – current staff

Mode of transport	Number of staff (working full or part time in the current service) travelling to The Royal Marsden, Sutton	Number of staff (working full or part time in the current service) travelling to St George’s Hospital
Under 15 minutes	6 (14%)	6 (10%)
15 minutes to 30 minutes	18 (43%)	28 (48%)
31 minutes to 45 minutes	10 (24%)	10 (17%)
46 minutes to an hour	5 (12%)	12 (20%)
Over an hour	3 (7%)	3 (5%)
Total	42	59

Appendix 7: List of face-to-face or online events held/ attended

Session	Numbers reached	Audience
April 2023		
Cancer Operational Delivery Network (17th)	20	Clinical staff from the current Principal Treatment Centre, paediatric oncology shared care units (described as children’s cancer shared care units in this document), South Thames Paediatric Network (covering Kent, Medway, south London, Surrey and Sussex) and Cancer Alliances
Royal Marsden Teenage and Young Adults Forum (27th)	5	Teenagers and young adults who have completed their care at the children’s cancer Principal Treatment Centre
May 2023		
NHS England Stakeholder Group meeting (11th)	9	Parents and carers of current and previous users of the children’s cancer Principal Treatment Centre and charities
Ward visit to The Royal Marsden: Oak Centre (23rd)	30	Completing surveys with parents, children and young people and some individual meetings with staff
Ward visit to The Royal Marsden: Oak Centre (26th)	27	Completing surveys with parents, children and young people
Meeting with Joint Overview and Scrutiny Committee and Overview and Scrutiny Committee colleagues to discuss consultation plan and document (22nd)	15	Chairs and officers
June 2023		
Meeting of Trust leads to discuss response to Clinical Senate recommendations	20	Clinical and programme leads from Guy’s and St Thomas’, St George’s and The Royal Marsden
South West London and Surrey Joint Overview and Scrutiny Committee (7th)	12 ⁹	Councillors
Royal Marsden staff event (13th)	70	Staff working within the current service
Testing draft of consultation document (21st)	18	Volunteers from the Stakeholder Group, independent experts, Trusts, NHS England clinical and assurance leads, Overview and Scrutiny Committees, Integrated Care Boards.
On-demand briefing (22nd)	6	Voluntary and community group organisations

⁹ Number of committee members – does not include audience members of the public

Session	Numbers reached	Audience
Ward visit to Evelina London (23rd)	25	Completing surveys with parents, children and young people
Evelina London staff event (27th)	40	Staff working at Evelina London and Guy’s and St Thomas’
St. George’s staff event (30th)	70	Staff working within the current service and the wider Trust
July 2023		
Meeting with the Institute of Cancer Research	4	Institute of Cancer Research
South West London and Surrey Joint Overview and Scrutiny Committee Chair and Vice Chair informal briefing (5th)	3	South West London and Surrey Chair and Vice Chair
NHS England Stakeholder Group meeting (5th)	6	Parents and carers of current and previous users of the children’s cancer Principal Treatment Centre and charities
South East London Joint Overview and Scrutiny Committee (6th)	9 ¹⁰	Councillors
Brighton and Hove Overview and Scrutiny Committee (12th)	14 ¹¹	Councillors
Meeting with The Royal Marsden on research (13th)	8	Research staff from The Royal Marsden
Testing further draft of full consultation document (17th)	10	Volunteers from the Stakeholder Group, Trusts, NHS England clinical leads
Radiotherapy meeting (19th)	5	Radiotherapy colleagues from University College London Hospital and The Royal Marsden
Cancer Operational Delivery Network (19th)	24	Clinical staff from the current Principal Treatment Centre, paediatric oncology shared care units, South Thames Paediatric Network and Cancer Alliances
Integrated Care Board Communications and Engagement leads workshop (20th)	6	Integrated Care Board Communications and Engagement leads from across Kent, Medway, south London, Surrey and Sussex
Meeting with the Institute of Cancer Research (20th)	2	Research staff from the Institute of Cancer Research
Neurosurgery and neuroblastoma pathways workshop (25th)	15	Clinicians from Guy’s and St Thomas’, King’s College Hospital, St George’s, The Royal Marsden and NHS England South East

¹⁰ Number of committee members – does not include audience members of the public

¹¹ Number of committee members – does not include audience members of the public

Session	Numbers reached	Audience
August 2023		
Ward visits to St. George’s Hospital (4th)	15	Completing surveys with parents, children and young people
Ward visits to St. George’s Hospital (7th)	10	Completing surveys with parents, children and young people
Palliative care and leukaemia pathways workshop (10th)	10	Clinicians from Guy’s and St Thomas, St George’s, The Royal Marsden and NHS England London
Healthwatch workshop (14th)	9	Healthwatch organisations from across south London, Kent, Medway, Surrey and Sussex
Testing draft of summary consultation document and draft animation (18th)	4	Young consultants from Participation People
Ward visit to The Royal Marsden: Oak Centre (18th)	15	Completing surveys with parents, children and young people
Royal Marsden drop-in session (18th)	7	Clinical and research staff currently working in the current service
Royal Marsden drop-in session (18th)	5	Clinical and research staff currently working in the current service
Royal Marsden drop-in session (18th)	11	Clinical and research staff currently working in the current service
Ward visit to The Royal Marsden: Oak Centre (21st)	12	Completing surveys with parents, children and young people
Royal Marsden drop-in session (21st)	7	Clinical and research staff currently working in the current service
Royal Marsden drop-in session (21st)	2	Clinical and research staff currently working in the current service
Royal Marsden drop-in session (21st)	4	Clinical and research staff currently working in the current service
Testing designed version of full consultation document (26th)	9	Trusts, NHS England clinical leads

In addition to the activities above, NHS England have had ongoing and regular meetings with the trusts who are stakeholders in the Programme, including The Royal Marsden, St George’s, Guy’s and St Thomas’, University College London Hospitals and Kings College Hospital.

Appendix 8: Organisations and teams we have heard directly from/ worked directly with

Include:

- Children’s Cancer and Leukaemia Group – parents’ group
- Children’s Cancer and Leukaemia Group (member of our Stakeholder Group and Programme Board)
- Children with Cancer UK (member of our Stakeholder Group)
- Christopher’s Smile (member of our Stakeholder Group)
- Momentum Children’s Charity
- Ronald McDonald House
- St George’s University Hospitals NHS Foundation Trust
- Teenage Cancer Trust
- The Royal Marsden NHS Foundation Trust
- Young Lives vs Cancer (member of our Stakeholder Group and Programme Board)
- Young Lives vs Cancer Youth Board
- Guy’s and St Thomas’ NHS Foundation Trust
- Guy’s Teenage and Young Adult Cancer Group
- Institute of Cancer Research
- Royal Marsden Teenage and Young Adults Forum
- Joint Health Overview and Scrutiny Committees and Overview and Scrutiny Committees in each area
- Healthwatch Bexley
- Healthwatch Brighton and Hove
- Healthwatch Croydon
- Healthwatch Kingston
- Healthwatch Lambeth
- Healthwatch Merton
- Healthwatch Richmond
- Healthwatch Surrey
- Healthwatch Sutton
- Healthwatch Wandsworth
- South West London Voluntary, Community and Social Enterprise Alliance
- King’s College Hospital NHS Foundation Trust
- University College London Hospitals NHS Foundation Trust
- Great Ormond Street Hospital NHS Foundation Trust.