



# Consultation report on future location of very specialist cancer treatment services

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

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

**Research report**    January 2024

# 1 Executive summary

## 1.1 About the consultation

NHS England (London and South East regions) have consulted on proposals for the future location of very specialist cancer treatment services for children aged 1 to 15 (inclusive)<sup>1</sup>. Under these proposals, the future Principal Treatment Centre would be located at either Evelina London Children’s Hospital, in Lambeth, south east London, or St George’s Hospital in Tooting, south west London. Under both options, conventional radiotherapy services would be provided at University College Hospital, central London. Under both options, children would continue to travel for some specialist cancer services because of the specific expertise hospitals have in these areas and interdependencies with other services that these hospitals provide. A range of services were therefore considered ‘fixed-points’ and were not part of the public consultation.<sup>2</sup>

The public consultation about these options opened on Tuesday 26th September and closed on Monday 18th December 2023. Those who responded to the consultation were invited to give their feedback on the options to move the Principal Treatment Centre to Evelina London and St George’s Hospital, including the proposal to move conventional radiotherapy services to University College Hospital. People were asked what they would value most in a future Principal Treatment Centre, to reflect on the strengths and challenges of the proposals and to suggest any improvements that could be made. They were also asked for feedback on travel and access, and information and support needs. Respondents were asked for feedback about both options, avoiding comparisons or preferences, however people and organisations often chose to include this in their responses.

The consultation was necessary because the current service, which is provided in partnership between The Royal Marsden NHS Foundation Trust and St George’s University Hospitals NHS Foundation Trust, does not and cannot comply with the 2021 NHS England service specification for Principal Treatment Centres. The service specification makes it a clinical requirement for very specialist cancer treatment services for children to be on the same site as a level 3 children’s intensive care unit, which can give life support, and other specialist children’s services.

For the current Principal Treatment Centre, the teams leading and coordinating specialist care for children with cancer, including chemotherapy, conventional radiotherapy and bone marrow

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<sup>1</sup> The information presented in this section draws on the information NHS England shared as part of the public consultation.

<sup>2</sup> These are identified in NHS England’s consultation document available on their [website](#).

transplants, are based at The Royal Marsden's site in Sutton. Life-saving intensive care, most children's cancer surgery, and many other specialist services needed by children with cancer are led and coordinated by the teams at St George's Hospital eight miles away in Tooting. It is not viable to build a children's intensive care unit at The Royal Marsden to provide level 3 care for children who need it; as such; the service currently based in Sutton needs to move to a location that can provide this care (along with all other services mandated by the national service specification). Both Evelina London and St George's Hospital would do this.

## 1.2 About this report

This report presents the findings from the consultation, which will be used by NHS England leaders for London and South East regions to help them make a decision on the future location of the Principal Treatment Centre. It will be considered alongside all other relevant information, such as feedback from Joint Health Overview and Scrutiny Committees, advice from the London Mayor's Tests, findings from the Integrated Impact Assessment, petitions, and other relevant information. Leaders for NHS England (London and South East regions) will choose the option for the proposed future Principal Treatment Centre that gives them the greatest confidence that it will deliver the best quality of care for children with cancer in the future. In doing this, they will have regard to their statutory functions, Triple Aim duties (to reduce health inequalities in health and wellbeing, to avoid or manage and mitigate impact on other NHS services, and to support a sustainable and efficient use of resources) and the need to contribute towards compliance with the UK net zero emissions target.

Consultation feedback involved a mix of quantitative and qualitative data. Quantitative data provides numerical insights, such as the proportion of respondents who are feeling a particular way about the proposals. This enables the identification of patterns and strength of feeling in the feedback. Qualitative data produces rich and detailed descriptions, which explore those feelings and opinions, through questioning and observations. This can help us to further understand quantitative insights, such as why respondents are feeling a particular way. For the purpose of this report, quantitative and qualitative data has been analysed in triangulation, where they inform and validate each other, to develop a comprehensive understanding of how and why respondents are feeling the way they do about the proposals. A detailed account of the approach taken can be found in the main report.

People could take part in the consultation using more than one of the engagement methods. For instance, people may have attended a public meeting and also submitted a response to the questionnaire. Therefore, it is important to note that feedback numbers show responses, not unique individuals. In terms of the questionnaire<sup>3</sup>, many of the questions asked were open questions with no

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<sup>3</sup> Copies of the main and easy read questionnaire can be found in Appendix C of the main report.

word limit<sup>4</sup>. This meant that many responses were varied, detailed, and long. Sometimes people did not directly answer the question; they took the opportunity to state what mattered most to them. When analysing this qualitative data thematically, Explain used different codes for different aspects of the same topic to capture the richness of feedback<sup>5</sup>. So where numbers are given, it is important to remember that these refer to the number of responses received (from the questionnaire only), and not unique individuals. As such, it is not possible to add up the number of responses (e.g. travel) to understand how many people raised an issue, because there may be overlap between those who gave those comments.

All other qualitative feedback was analysed thematically. Given the qualitative methods of engagement used (such as focus groups, interviews, and meetings), it is not possible to 'quantify' this qualitative data. This is because these engagement methods were not structured in the same way, they sometimes involved the dynamics of a group setting, and the presence of a facilitator meant they could probe further for meaning by asking follow-up questions. This meant that some of the outputs from qualitative engagements involved a lot of description about personal and professional experiences and familial circumstances. Some of the outputs also had further explanation about why someone thought or felt a particular way.

To give the reader an idea of the strength of feeling of a theme, words such as many, some, and few have been used. Many refers to a large number of responses, but not necessarily a majority. A few refers to a small number of responses. Some is in between. Findings in the main report have been presented in chapters dedicated to key stakeholder groups<sup>6</sup>. These chapters provide a comprehensive understanding of what each stakeholder group said during consultation. This will enable decision makers to consider the perceptions, experiences, needs, and wants of each group.

### 1.2.1 Explain Research's role

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<sup>4</sup> An example of an open question from the questionnaire is: 'Please tell us what you think the good things are about this option.'

<sup>5</sup> For example, feedback relating to travel covered many different aspects, including: travel by car, parking availability, distance of parking from the hospital, travel by public transport, accessibility of public transport, travel costs, congestion and Ultra Low Emission Zone charges, accessibility specifically for sick children, practicalities of attending hospital with a sick child and siblings, and practicalities of attending hospital as a single parent with no support person.

<sup>6</sup> These chapters are: children and young people who have been affected by cancer; family members and advocates of children and young people who have been affected by cancer; children, young people, and their families and advocates, with no direct cancer experience; affected clinical and non-clinical NHS staff (defined as staff who work at the current Principal Treatment Centre at The Royal Marsden and at St George's Hospital, and staff who work at Evelina London); other clinical and non-clinical staff; equality groups; members of the public; and organisations and public representatives.

Explain Research was commissioned by NHS England (London and South East regions) to conduct independent thematic analysis and report on all feedback received during the consultation period. Research materials and research outputs (such as raw questionnaire data, transcripts, and verbatim notes) were sent directly to Explain Research on a weekly basis (digitally via a secure site or by freepost return from respondents). NHS England (London and South East regions), as well as independent providers where relevant, provided respondent numbers and demographic data for qualitative engagement undertaken by them. Explain Research had weekly meetings with the NHS England Programme Team prior to and during the consultation. At these meetings, the team at NHS England (London and South East regions) provided updates on communication and engagement activities already completed as well as upcoming planned activity. Some feedback included complex clinical and technical statements. These meetings were also an opportunity to share anonymised details of statements with the NHS England Programme Team for clarification and verification with subject matter experts. Some feedback also included misinterpretation of the proposals or factual inaccuracies. These were noted and analysed alongside all other feedback.

## 1.3 Approach to the consultation

### 1.3.1 Pre-consultation stage

NHS England undertook a period of pre-consultation engagement between April and August 2023. The primary purpose of this engagement work was to share the case for change and to gather insights from different groups and stakeholders to help develop the consultation plan, which guided how NHS England engaged through the consultation, who with, and what types of content and formats of information it provided.

### 1.3.2 Communications and engagement methodology

The consultation methodology was developed by NHS England in collaboration with key stakeholders. These stakeholders included the Stakeholder Group of parents and local and national charities, affected Trusts, Integrated Care Board communications and engagement colleagues, Overview and Scrutiny Committees within the service catchment area, as well as children and young people themselves. The Consultation Institute also provided NHS England with advice on their plan. Consultation activities were delivered by a combination of independent expert engagement partners as well as the NHS England Programme Team. Given the very specialist nature of the service, and a desire to engage with specific audiences such as children, families and staff involved with cancer services, tailored engagement methods were used with different audiences. These ranged from in

depth face to face conversations with clinicians to shorter conversations at flexible timings for busy and occupied parents, to play specialist sessions to enable children and young people to have a voice. These activities were the result of feedback from the pre-consultation phase of engagement that one size should not fit all.

At the consultation mid-point, a review was undertaken independently by Explain Research on behalf of NHS England (London and South East regions). This mid-point review documented the consultation activity that had happened by the mid-point and the profile of respondents who had given feedback. This enabled the identification of any gaps in feedback and assessed the appropriateness of planned activity to address those gaps. The review then identified a number of next steps and suggested actions for the NHS England Programme Team to consider in order to address gaps in representation from stakeholder groups, maximise reach from communications activity, and further assist individuals in completing feedback. Following receipt of the mid-point review by NHS England, it was clear that many planned NHS England activities, for the latter half of the consultation, would support in addressing gaps in reach. However, the team also undertook a range of additional activities, not previously planned, to respond to the recommendations. This included funding sessions with specific equalities groups that were being heard less from – including those with a learning disability, adding 13 site visits to the engagement plan to hear directly from families and children and young people in waiting rooms at The Royal Marsden and children’s cancer shared care units across the catchment area, and commissioning an independent organisation to facilitate feedback sessions with staff in the current Principal Treatment Centre and with parents of children currently using the service

### 1.3.3 Key stakeholders to reach

The consultation was open to all; however, the approach to communications and engagement focused on reaching groups who were identified to be most likely impacted by the proposed relocation, to ensure they had the opportunity to share their views during the consultation. These groups were identified through the pre-consultation engagement activity and the interim Integrated Impact Assessment, which was carried out for the consultation, and reflected in the consultation plan. NHS England’s priority was to hear from those directly impacted from across the entire catchment area, staff who work as part of/closely with the service; other stakeholders such as professional bodies who have expertise in this area, and those with protected characteristics.

Groups directly impacted:

- Children and young people with cancer or who have experienced cancer (and their families)

- Affected clinical and non-clinical NHS staff (defined as staff at the hospitals where the Principal Treatment Centre is currently, or could be - The Royal Marsden, St George's Hospital and Evelina London Children's Hospital)

Other key stakeholder groups:

- Other clinical and non-clinical NHS staff with an interest in the service, including staff of children's cancer shared care units
- Professional bodies, specialist children's cancer charities and research organisations
- Children, young people, and their families with related experience
- Members of the public
- Local government, including Overview and Scrutiny Committees and MPs

Communities with specific protected characteristics:

- People from ethnic minorities
- Families with poor literacy skills and/or language barriers
- People with autism
- People with physical disabilities
- People with learning disabilities or learning impairments
- People with mental health issues
- Families with caring responsibilities
- Looked after children and young people.

While not a group protected by equality legislation, families experiencing financial difficulties or who live in the most deprived areas were identified by the interim Integrated Impact Assessment as potentially experiencing a greater impact, and so were also included as a priority group.

### 1.3.4 Communications and engagement activities

There were two distinct but closely connected areas of consultation communications and engagement activity – promotional activity to raise awareness of the consultation, and engagement activity to gather feedback on the consultation proposals. These two areas are described in more detail below:

**1.3.4.1 Promotional activity:**

The consultation was promoted through a variety of means, including:

<p><b>Website</b></p>  <p>Including child friendly section</p>	<p><b>Animation</b></p> 	<p><b>Posters and printed documents</b></p>  <p>at the Principal Treatment Centre and Paediatric Oncology Shared Care Units</p>
<p><b>Facebook campaign</b></p>  <p>Widespread and paid-for</p>	<p><b>Proactive media releases</b></p>  <p>and responses to media enquiries</p>	<p><b>Social media</b></p>  <p>messaging by: NHS England (London and SE) <i>and</i> partners and others</p>
<p><b>Phone calls and offers of meetings</b></p>  <p>to groups working with communities identified by the Integrated Impact Assessment</p>	<p><b>Letters</b></p>  <p>to current and recent patients of the Principal Treatment Centre</p>	<p><b>Email briefings</b></p>  <p>to all stakeholder groups</p>



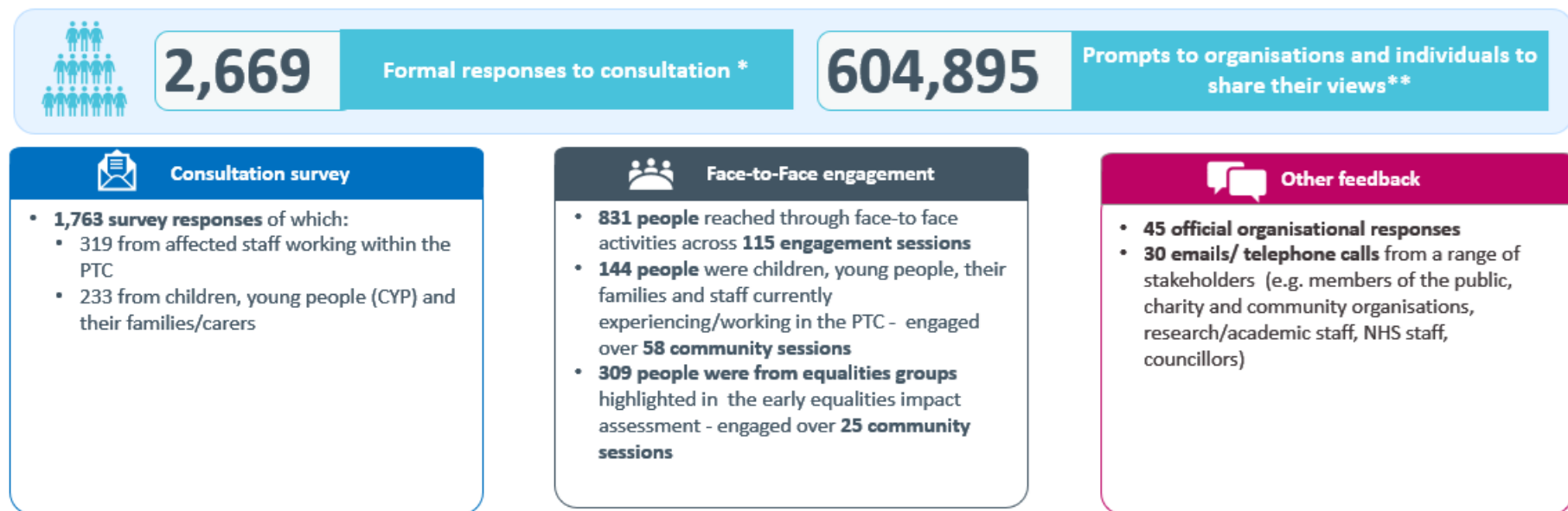
### 1.3.4.2 Engagement activity:

The table below summarises how people responded to the consultation, based on engagement activity type. The number of people engaged or responses received are also highlighted.

Activity	Number of sessions/events	No. of people engaged/ responses received
The consultation questionnaire, available to complete online and by paper copy, including easy read. Paper copies, along with freepost envelopes, left at key locations in the catchment area	N/A	1,763 responses
Play specialist sessions (with children with cancer in hospital settings and online - facilitated by an external expert organisation)	11 sessions	28
Parent focus groups (facilitated by an external organisation)	7 sessions	27
Site visits to the Principal Treatment Centre and some POSCUs to speak to children with cancer and their families	13 visits	91
Public listening events during the day and evening	3 events	31
Staff sessions: with the three Trusts directly involved in the consultation (facilitated by an external expert organisation and also NHS England)	5 sessions	63
Staff sessions: across the wider clinical community	11 meetings	156
Community meetings and equalities groups (facilitated by an external expert organisation as well as by NHS England)	25 meetings	271
One-to-one interviews (with staff/parents/ research staff for example)	22 interviews	22
Q&A sessions (facilitated by NHS England)	18 sessions	93
Emails, letters, and telephone calls	N/A	29 responses
Formal responses received from organisations	N/A	46 responses
Information giving (facilitated by NHS England via briefing or promotional opportunity to raise awareness of the consultation)	5 sessions	49

### 1.3.5 Consultation response rate and reach

An overview of the consultation response rate and reach is presented below.



An overview of the reach to different stakeholder types is presented below<sup>7</sup>.



**Petition** • #HeartheMarsdenKids campaign: 10,394 signatures / 304 written comments

<sup>7</sup> Organisational responses included feedback from the Surrey and South West London Joint Health and Overview Scrutiny Committee and other local authorities. The detail of these can be found in Section 13.8

### 1.3.5 Who responded to the consultation

The consultation has captured feedback from a diverse range of people across stakeholder types, ages, ethnicities, socio-economic groups, and geographical areas within the catchment area for the future Principal Treatment Centre. To help with decision making, it was necessary for NHS England (London and South East regions) to hear from different groups to understand their different perspectives. The following charts give an overview of the profile of consultation respondents to demonstrate reach and representativeness.

#### 1.3.5.1 Overview of the profile of consultation respondents

Overall, most respondents to the consultation were 'other clinical and non-clinical staff' (25%) as well as 'affected clinical and non-clinical staff' (23%). The smallest stakeholder group was children or young people (including parents/advocates responding on behalf of a child<sup>8</sup>) who have been affected by cancer (3%).

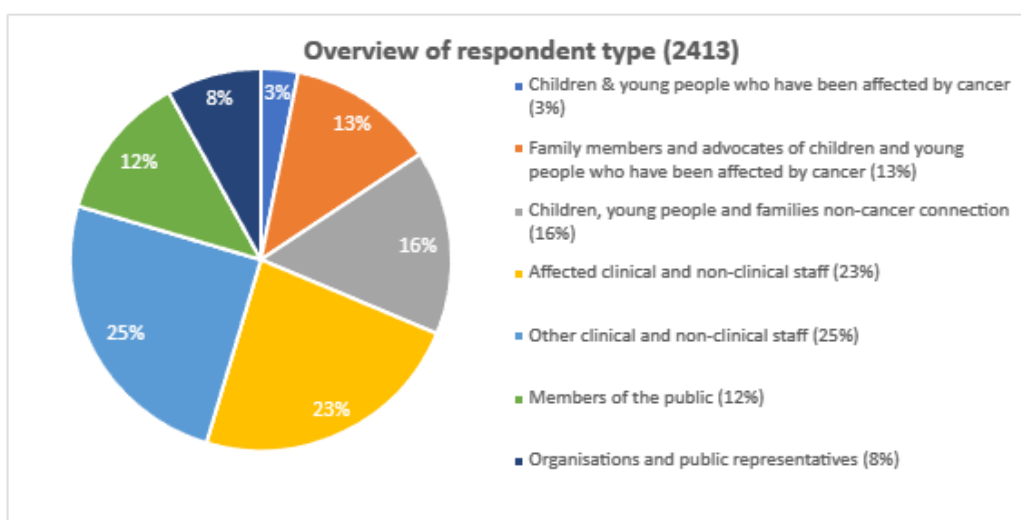


Figure 1: Overview of respondent type: across all engagement methods. (Base number of 2413 reflects number of respondents that disclosed their stakeholder type.)

#### 1.3.5.2 Geography

In terms of the patient cohort of the current Principal Treatment Centre, 21% live in South West London ICB, 20% live in Kent & Medway ICB, 18% live in Surrey Heartlands ICB, 17% live in South East London

<sup>8</sup> This includes questionnaire responses from parents or carers who selected 'child or young person' to identify their response as well as parents or carers who participated alongside their child during play specialist sessions.

ICB, 8% live in Sussex ICB, and 15% live outside of the Principal Treatment Centre catchment area<sup>9</sup>. Feedback was received from respondents living across the catchment area. Figure 2, below, outlines the location of respondent by Integrated Care Board (ICB) area. This shows an overrepresentation in responses from NHS South West London ICB (39%). There is good reach into Surrey and south east London, with fewer responses from other ICB areas.

It is important to note that there were no significant differences in feedback from respondents across different regions in the catchment area. In general, there was consensus with the overall themes outlined in the Executive Summary.

### Overview of location of respondents by Integrated Care Board (ICB) area (2209)

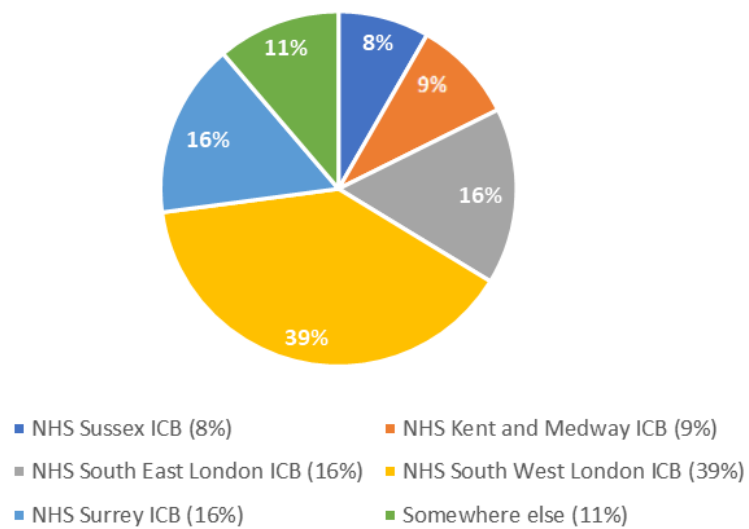


Figure 2: Overview of location of respondents by Integrated Care Board (ICB) area: across all engagement methods and respondent types. (Base number of 2209 reflects number of respondents who disclosed their location.) Please note, due to rounding, percentages in the chart do not total 100%

#### 1.3.5.3 Age

Overall, the majority of respondents across the consultation were aged 41-65 (52%) with the second highest age range being of those aged 26-40 (28%). The smallest number of respondents were aged 16-18 (2%) or 19-25 (3%). However, it is important to note that those aged 41-65 were likely to be overrepresented due to these age ranges more likely to comprise clinical staff or parents and advocates for children and young people, who responded in higher numbers to the consultation.

<sup>9</sup> Source: 2019/2020 data collection developed by NHS England with The Royal Marsden, St George’s and Guy’s and St Thomas’ to ensure a single set of data for planning the service change.

#### 1.3.5.4 Sex and gender

Overall, females were significantly overrepresented in the consultation making up around 70% of total responses across all engagement types.

#### 1.3.5.5 Disability

Looking at the breakdown of respondents who self-identified as having a disability reveals that the majority of people taking part in the consultation did not have a disability (82%) compared to 9% who are disabled under the Equality Act.

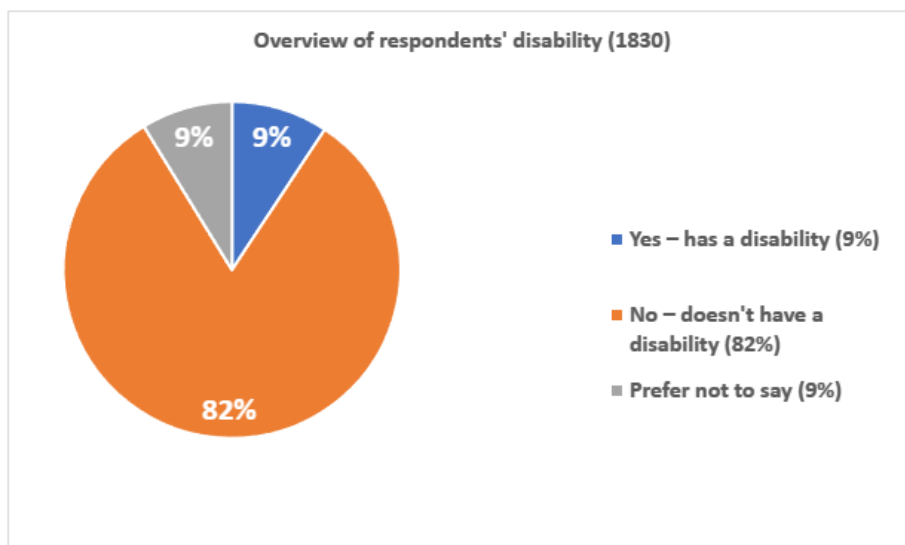


Figure 3: Overview of respondents' disability status: across all engagement methods and respondent types. (Base number of 1830 reflects number of respondents who answered this question.)

#### 1.3.5.6 Low income households

Questionnaire responses from children and young people affected by cancer analysed by socio-economic and income support reveals that deprivation levels are closely representative of the wider patient cohort.

The chart below shows the types of additional income support disclosed by all respondents who said that they were receiving some form of additional benefits.

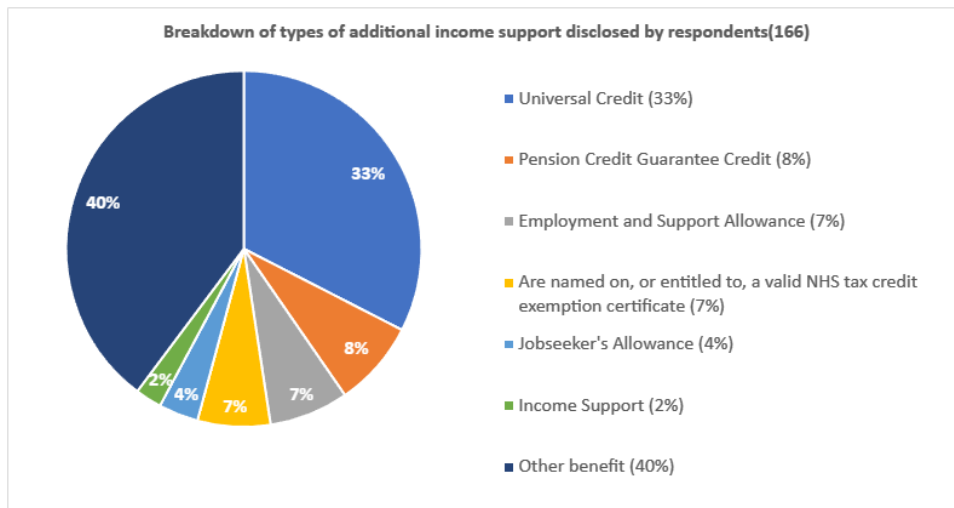
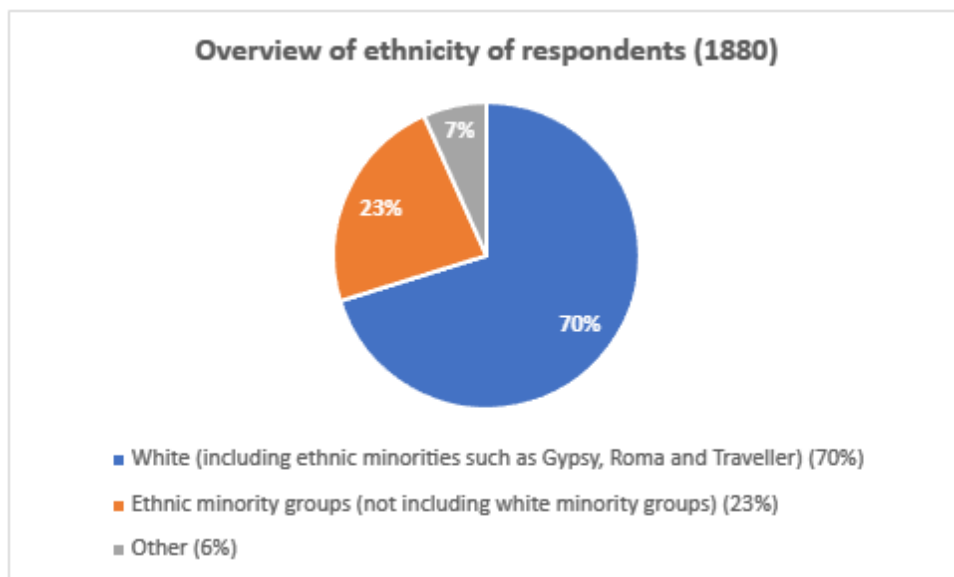


Figure 4: Overview of respondents who disclosed they were in receipt of additional income support: across all engagement methods and respondent types. (Base number of 166 reflects number of respondents that disclosed receipt of additional income support.)

### 1.3.5.7 Ethnicity

Ethnicity was shown to be largely representative of the wider population across the catchment area. Overall, 78% of the population across all ICB areas comprising NHS England (London and South East Regions) are white, while 22% are from ethnic minority groups and 3% from other ethnicities.<sup>10</sup>



<sup>10</sup>It is important to highlight the discrepancy in ethnic groupings between the patient cohort data and that collected during the consultation, since the patient data used only two demographic groupings (White, Other than white), while the consultation uses more accurate classifications of white ethnicities, ethnic minority groups (excluding white minorities), other ethnicities, and prefer not to say.

Figure 5: Overview of ethnicity of respondents: across all engagement methods and respondent types. (Base number of 1880 reflects number of respondents who disclosed their ethnicity.)

#### **1.3.5.8 Priority stakeholder group for engagement: Children and young people who have been affected by cancer and their families and advocates**

A priority group for engagement was children and young people who have been affected by cancer. There are around 1,400 children who use the current service. Children and young people affected by cancer have responded, as well as their family members or advocates who specifically stated they are responding to the consultation on their behalf, totalled 76<sup>11</sup>.

##### *Family members and advocates*

More broadly, a total of 303 responses were received from family members and advocates of a child or young person who has been affected by cancer. Although not direct recipients of care, family members and advocates have provided helpful insights into the experiences of younger children (who are not able to consent themselves or participate) and understanding of the impacts of cancer care on the wider family.

##### *Geography*

When grouped together, responses from children and young people affected by cancer, and their family members and advocates, came from across the catchment area. Many responses were from South West London (26%).

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<sup>11</sup> This would mean that around 6% of the current patient cohort responded to the survey; although it is noted that this figure could include recent patients and patients could have participated in more than one activity (e.g. questionnaire and play specialist session). Within an industry standard confidence level of 95% and a 5% margin of error, 6% response rate is not statistically significant and therefore cannot be considered representative.



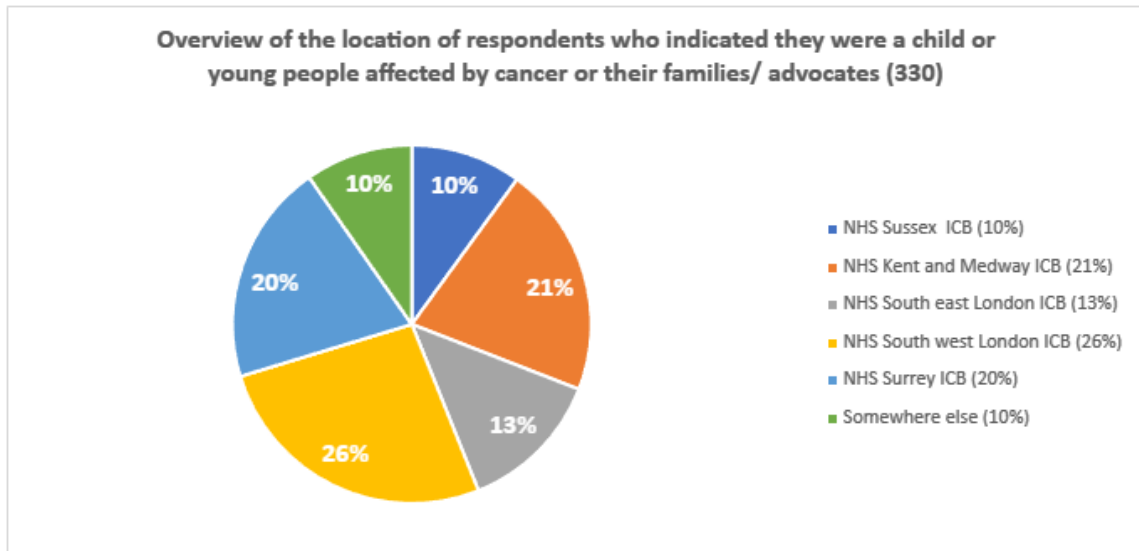


Figure 6: Breakdown of the location of respondents from children and young people who have been affected by cancer and their family members and advocates: across all engagement methods and respondent types. (Base number of 330 reflects number of respondents that disclosed their respondent type and location.)

*Ethnicity*

Around 69% of the patient population using the current Principal Treatment Centre are white, with 31% from ethnic groups other than white (excluding white minorities). In comparison, 79% of consultation respondents, who said they were a child or young person who have been affected by cancer and their family members/ advocates, identified as white; with 20% identifying as from ethnic groups other than white.

**1.3.5.9 Priority stakeholder group: Staff currently working full or part time as part of the current Principal Treatment Centre or closely with it**

The consultation received responses from 81% of staff at The Royal Marsden who work as part of the current Principal Treatment Centre (155 responses; 192 staff currently work full or part time at The Royal Marsden). The consultation received responses from 52% of staff at St George’s who work as part of the current Principal Treatment Centre or closely with it (216 responses; 416 staff currently work full or part time at St. George’s)<sup>12</sup>.

<sup>12</sup> The Royal Marsden and St George’s Hospital provided data on current staff numbers. For both The Royal Marsden and St George’s, this is a statistically significant number of responses and therefore can be considered representative. It should be noted, however, that some staff may have attended face to face or online sessions as well as completing the questionnaire, so the number is indicative.

## 1.4 Summary of findings

During the consultation, people were asked to give their feedback on what attributes mattered most to them when thinking about the future Principal Treatment Centre, the strengths and challenges of both options (Evelina London and St George's) as well as the proposal to move conventional radiotherapy to University College Hospital. People were also asked to make suggestions to address any challenges they had identified in relation to the proposals. They were also asked to reflect on travel and access; and information and support needs.

The consultation findings that are presented in this section are key findings that summarise feedback from all qualitative and quantitative engagement methods, from different stakeholder groups, across the catchment area. They are key findings because many people talked about them, there was a strength of feeling evident across engagement types, and they relate to the future service. It is noted that there were no key differences in findings when feedback was analysed by geography; it was consistent.

### 1.4.1 The future Principal Treatment Centre

**When thinking about the future Principal Treatment Centre, the attributes most valued by respondents were the provision of all or most specialisms and services needed for children's cancer care on a single site as well as having specialist knowledge and experience of children's cancer care.**

Many respondents highlighted that it would be desirable to have all or most specialisms and services needed for children's cancer care on a single site, such as surgery, neurosurgery, radiotherapy, children's intensive care unit, and heart and kidney care; have specialist knowledge and experience of children's cancer care; be conveniently located, particularly in terms of access by car; and have strong research facilities and track record.

Other key suggestions from all engagement activities included:

- Child-friendly hospital, with bright and colourful spaces and spacious facilities that cater to children's needs (such as age-appropriate play and education spaces, only for children with cancer)
- Preservation of the welcoming, family-friendly and homely environment of The Royal Marsden
- Personalised care for the child
- Ensuite accommodation, with space for at least one parent to stay overnight
- If there are wards, there is no mixing of different ages of children
- Spaces to accept visitors, especially siblings and other family members
- Good hospital food, catering for the child's needs, preferences, and tastes

- Family accommodation nearby
- Private facilities for parents, such as working showers and comfortable beds. Kitchen facilities, including space to store food and cook meals were also important
- Access to outdoor spaces that are dedicated to children with cancer
- Cancer charities have their own spaces and rooms in the ward to provide family support
- Lifts instead of stairs, with priority given to sick children
- Good signage
- Staff to help you to navigate hospital spaces, make introductions, make you feel welcome, explain what is happening and when; staff knowing your name; people who make an effort to listen
- Plenty of free parking spaces close to the hospital
- Good network of communication between Principal Treatment Centre, children's cancer shared care units, community nursing teams, and GPs.

## 1.4.2 Feedback on options: Principal Treatment Centre at Evelina London

Across all engagement activities, people were asked to give their feedback on the strengths and challenges of the proposal to move the Principal Treatment Centre to Evelina London.

**Strengths of Evelina London's proposal included the fact it is a dedicated children's hospital with many specialisms, such as heart and kidney care, and has a strong research proposition.**

Across feedback, there was agreement across stakeholder groups that the strengths of Evelina London's proposal included:

- It is a purpose-built children's hospital, which is child-focused, with good facilities
- It provides other important specialisms that children with cancer often need, including heart and kidney care
- It has a large children's intensive care unit with the perception that this would mean that would be capacity for intensive care for children with cancer, if needed
- The perception that it has excellent research infrastructure and expertise, with a strong track record of research. It has a good research proposition, in virtue of its membership of Guy's and St Thomas' NHS Foundation Trust and links to King's College London
- It has good public transport links given its location in central London for both families and staff
- It is well-located for access to local amenities, such as shops and recreational spaces
- It is located close to University College Hospital if a child or young person needed to travel for radiotherapy
- There is family accommodation nearby.

Affected and other clinical and non-clinical staff highlighted these additional strengths of Evelina London's proposal:

- Staff at Evelina London already work with some children with cancer and children's cancer services through their existing work
- It has existing links with many different healthcare providers in the catchment area, including King's College Hospital and hospitals which also provide children's cancer shared care units
- It has links to adult cancer services through Guy's and St Thomas' NHS Foundation Trust - Guy's Hospital has an adult cancer centre and Experimental Centre for Cancer Medicine
- It uses the same IT system for patient records as The Royal Marsden, which could help with a smooth transition of the Principal Treatment Centre
- It is considered by some staff to be a good place to work.

**Challenges of Evelina London proposal included that it lacks experience and expertise in children's cancer care and it would be challenging for families to access.**

Challenges of the proposal from Evelina London, identified across all stakeholder groups, included:

- It has a lack of experience and expertise in children's cancer care and treating children's cancer
- It does not provide neurosurgery
- While it conducts a wide range of other paediatric research, it does not conduct research in paediatric cancer, which leads to concerns about the continued provision of children's clinical cancer trials
- It is perceived that it may face significant recruitment issues as it would be heavily reliant on retaining experienced staff from The Royal Marsden
- There is the possibility that staff would not want to work in and travel to central London, given the lack of financial incentive and the potential detrimental impact on family life
- It would be difficult for families to access Evelina London by car, which is a preferred method of transport
- It would be costly and time consuming for families to travel to Evelina London, acknowledging schemes to reimburse congestion charges and Ultra Low Emission Zone
- Family accommodation at Evelina London considered not being close to the hospital. Eligibility for and the availability of accommodation may not be guaranteed and has not been confirmed at this stage.

Affected and other clinical and non-clinical staff highlighted these additional challenges of Evelina London's proposal:

- Recruitment to Evelina London could have a potential negative impact on the recruitment and retention of staff for other nearby NHS services, due to competing demand
- Due to the proposed layout of the service across different buildings, it would operate a distributed workflow, with staff working in different areas across the hospital, which could compromise communication between team members and care for some patients
- There is a perception that Evelina London lacks space to take on the service.

### 1.4.3 Feedback on options: Principal Treatment Centre at St George's

**Strengths of St George's Hospital focused on it already being part of a well-established Principal Treatment Centre, its 25 years of experience and expertise in aspects of children's cancer care, and its existing strong links with The Royal Marsden.**

Feedback from all stakeholder groups focused on St George's 25 years of experience and expertise in some children's cancer care. Other strengths included:

- It is part of a well-established Principal Treatment Centre, with services and pathways already in place
- It has existing links with The Royal Marsden, which were viewed as beneficial for transitioning the Principal Treatment Centre
- Some neurosurgery is offered on site and a well-established children's cancer surgery service
- It would offer a separate unit, which was considered important to make it more child-friendly and minimise infection risk when mixing with other patients and visitors
- Easy to access by car
- Lots of private rooms with ensuite facilities
- Family accommodation nearby
- It is already known and familiar to some families, meaning the continuity of care would be maintained for those families when the transition happens.

There were no additional strengths identified by clinical and non-clinical NHS staff; feedback was consistent across all stakeholder groups.

**Challenges of the St George's Hospital proposal focused largely the fact it is not a dedicated children's hospital.**

Feedback on the challenges of the St George's Hospital proposal included:

- Reflections on the current estate, which was described in some feedback as being outdated, with facilities considered to be poor, was a cause for concern when thinking about the ability of St George's to accommodate the future Principal Treatment Centre

- There is perceived to be a lack of privacy on the ward and in other parts of the hospital where adults are also being cared for
- It feels busy and chaotic, particularly given the delivery of adult healthcare services there; and there is a perception that this poses an infection risk
- Some key specialisms are missing, such as specialist heart and kidney care
- There is a perception that children would not be prioritised on surgery lists, because of treatment of trauma patients
- There is a perception that the research proposition is not strong, with lack of experience in running clinical trials for children with cancer
- It would be difficult for families to access, including by car
- It would be costly and time consuming for families to travel
- There is not enough family accommodation
- There is a perceived lack of recreational facilities and activities, both indoor and outdoor, suitable children and young people receiving treatment for cancer.

Affected and other clinical and non-clinical staff highlighted these additional challenges of St George's Hospital proposal:

- There are perceived financial constraints at St George's Hospital, which could make the transition to the Principal Treatment Centre a risk for its future
- Disentangling existing relationships to set up the new Principal Treatment Centre could be challenging, for example, if key people had different views on what should be done
- It does not use the same IT system for patient records as The Royal Marsden, which could have a negative effect on the transition of the Principal Treatment Centre.

#### 1.4.4 Feedback on the proposal to move conventional radiotherapy services to University College Hospital

**Feedback on the proposal to move radiotherapy services to University College Hospital was mixed. Some respondents talked about the strengths of this proposal, particularly in terms of benefits associated with consolidating radiotherapy expertise and services in one location, including existing knowledge and experience of staff there. Others expressed concerns that, under these proposals, radiotherapy could not be offered on the same site as the Principal Treatment Centre. They talked about the potential negative impact this would have on the patient experience, especially in relation to travel and access.**

In terms of positive feedback on this proposal, some respondents said it made sense to consolidate radiotherapy expertise at University College Hospital, benefiting from the existing knowledge and

experience of staff there. References were made to proton beam therapy and how this is available at University College Hospital.

Many respondents voiced concern about radiotherapy being delivered on a different site to the Principal Treatment Centre, this included family members and advocates as well as clinicians who raised concerns about:

- The transport of very sick children, into central London, to receive treatment
- Some families would face longer journey times to University College Hospital to receive radiotherapy treatment, particularly when compared to The Royal Marsden
- The capacity and resourcing of University College Hospital to take on the service on behalf of the Principal Treatment Centre
- The loss of resilience in having a single radiotherapy site across London and much of the south east
- The potential negative experience of disjointed care, with the need to travel to a different hospital to receive radiotherapy treatment.

### 1.4.5 Challenges affecting both proposals

**Challenges affecting both proposals related to the absence of a single-site solution for children's cancer care and the potential loss of the personalised care and expertise of The Royal Marsden.**

Some of the key findings were applicable to both proposals. These related to:

- Neither option could offer a 'single-site' solution, including where all neurosurgery, specialist heart and kidney services, and radiotherapy could be co-located at the Principal Treatment Centre
- Concern that the quality of personalised care and specialist skills and services of The Royal Marsden could be lost, including the dedicated spaces of the Oak Centre for Children and Young People. This related to both staff expertise and experience and the attributes of the healthcare spaces at The Royal Marsden (Oak Centre for Children and Young People, Maggie's Centre)
- Concern that the excellent research infrastructure and expertise of The Royal Marsden could be lost, including the loss of access to children's cancer clinical trials (which could be a temporary loss as the move happens, or longer term loss if the move has a detrimental impact on the ability of the Principal Treatment Centre to secure future research funding)
- Both options could be costly, at a time when financial resource is perceived to be stretched in NHS England
- Both would need more parking spaces and more parent accommodation

- Suggestion that children receiving cancer treatment should use public transport to travel to Evelina London and St George's was considered at odds with advice that parents and family advocates have received in the past
- Staff recruitment and retention, given the wider issue of staff recruitment in the NHS, as well as the London-based locations of both Evelina London and St George's Hospital
- Potential detrimental effect on the resilience of the current service at The Royal Marsden due the potential for staffing losses, such as early retirement
- Potential negative impact on The Royal Marsden's teenage and young adults (TYA) service.

There was also feedback from some parents, carers, and advocates who thought that the change should not happen at all; this is detailed in the case for change section that follows.

### 1.4.6 Other ideas

In a few cases, respondents requested that alternative proposals are considered by NHS England (London and South East regions) for the future location of the Principal Treatment Centre. This included:

- A risk-adapted model that retains the Principal Treatment Centre at The Royal Marsden and St George's. Any patients who, upon diagnosis, are deemed likely to require children's intensive care throughout the course of their treatment would receive their specialist care at St George's to minimise the need for transfers. This would mean all other patients would continue to receive care at The Royal Marsden
- A 3-stage solution, which involves (1) adoption of the risk-adapted model outlined above, then (2) adopt new technologies to support a hub and spoke model by which intensivists based at a 'hub' can support 'spoke' services; with a trial at The Royal Marsden and (3) the building of a new children's specialised services hospital at a South Thames location (current site of the Sutton Hospital or Kenley, south of Purley, Surrey).
- Utilisation of the new hospital to be built in Sutton, next to The Royal Marsden, by including a level 3 children's intensive care unit.

In the questionnaire, there was a final question asking for any other thoughts or ideas. This was a broad question with many different types of comments left. The top three themes were comments relating to:

- Selecting St George's as the Principal Treatment Centre (16% of questionnaire responses to this question). Most respondents who left comments of this nature were affected staff (31%), closely followed by other clinical and non-clinical staff (22%), with these respondents most likely to come from the South West London ICB area (56%)



- Keeping the Principal Treatment Centre at The Royal Marsden (15% of questionnaire responses to this question). Most comments making this point were left by affected children or affected family members or advocates for children, with many referencing how children are comfortable or familiar with the current hospital setting, as well as the expertise and high standard of care they have received or are receiving from The Royal Marsden
- The importance of listening to feedback from staff and patients (8% of questionnaire responses to this question). The meaning of this varied across comments, with some stating that NHS England (London and South East regions) must choose the proposal which best addresses the needs of those they considered most important, the patients and staff, while others considered that if they focused on the needs of patients and staff, they would not move the services at all.

### 1.4.7 Case for change

Although the focus of the consultation was to elicit feedback on the two proposals for the future location of the Principal Treatment Centre (St George’s Hospital and Evelina London), many respondents took the opportunity to voice their opinion about the case for change.

There is evidence of strong clinical support for the case for change. This was found in the formal responses submitted by organisations (including Children’s Cancer and Leukaemia Group, Children’s Hospital Alliance, Great Ormond Street Hospital, Guy’s and St Thomas’ NHS Foundation Trust, Royal College of Paediatrics and Child Health, and South Thames Paediatric Network,) as well as feedback left by clinicians in the questionnaire, during focus groups, and in emails. Some family members and advocates also support the case for change. Some of those with lived experiences of children’s intensive care unit transfers involving their child or close relative shared details of this, calling for the change to be made to improve patient safety and patient experience, in line with the national service specification.

There was feedback from some parents, carers, and advocates who thought that the change should not happen in the first place – with some calling on NHS England to rethink the move (such as keeping the Principal Treatment Centre at The Royal Marsden) and consider alternative proposals (often because the proposals from Evelina London and St George’s did not appear, for them, to guarantee the experience, expertise, quality of care, and research capability of The Royal Marsden). It is also noted here that the #HeartheMarsdenKidsCampaign, a petition calling on the NHS to reconsider the move, reflects wider opposition to the consultation.

### 1.4.8 Travel and access

**Support and information about public transport near the future Principal Treatment Centre, the availability of family accommodation nearby, and parking availability were very important.**

This feedback was gathered in response to specific questions included in the questionnaire about the importance of travel to the future Principal Treatment Centre and the requirement for support and information about the move. It was clear that support and information about public transport near the future Principal Treatment Centre, the availability of family accommodation nearby, and parking availability were very important. Similar sentiment, where gathered, was evidenced through qualitative engagement. Other feedback referenced the importance of help with parking and travel costs, including Ultra Low Emission Zone and congestion charges.

Across all engagement methods and answers to most of the questions asked in the questionnaire, many respondents left comments and reflections about travel and access. This was a big topic. While some felt positively about the location of Evelina London, St George's, and University College Hospital, there were many more who highlighted challenges associated with all three sites in relation to travel and access.

### 1.4.9 Support and information for patients and staff

**When thinking about what support and information would help to make the move to the new Principal Treatment Centre easier for patients and staff, understanding which staff would be involved in ongoing care was the most important factor.**

In responses to the questionnaire, the three most important factors to consider when supporting patients and staff when the move happens were:

- To understand which staff would be involved in ongoing care (mean score of 4.77 out of 5)
- Receiving reassurance about when and how the move will happen (mean score of 4.7 out of 5)
- Having access to additional support (such as a dedicated point of contact) for those who need it (mean score of 4.65 out of 5)<sup>13</sup>.

### 1.4.10 Support for equality groups

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<sup>13</sup> Mean scores given because this question involved a five-point sentiment scale (1 – not at all important, 2, 3 – neither important nor unimportant, 4, 5 – very important, don't know).

It is important to note both related and wider feedback on the disproportionate burden of impacts which affect individuals who are from equalities groups when they access and experience NHS healthcare services. These include:

Understanding and accessing NHS services can be difficult	Feeling dismissed or ignored due to language barriers	Travel and accessibility to healthcare services problematic; may not have private transport or adequate funds to pay for public transport upfront
Negotiating change can be daunting and worrying, particularly for people with mental health and learning difficulties	Feeling distrust towards healthcare practitioners; feeling misunderstood due to past experiences	Nomadic lifestyle can mean individuals are not registered with GPs; even those who are registered may not take up screening and immunisations

In relation to this, respondents reflected on what NHS England (London and South East) could do to minimise the disproportionate burden of impacts when the Principal Treatment Centre moves. This feedback is summarised below, by equality group:



### People from ethnic minority groups and people who speak English as an Additional Language

1. Translated healthcare information available
2. Translated information on travel options to the Principal Treatment Centre available
3. Free hospital transport available, with eligibility criteria for this reconsidered so more people can benefit from it
4. Hospital food to cater for dietary needs
5. Bedside family accommodation important so family can stay together



### People with mental health difficulties

1. Videos used to communicate the change, featuring parents, carers, and staff
2. Offer of visits to the future Principal Treatment Centre to meet staff
3. Allowance for time to have repeated conversations with individuals who may need repeated assurances about the change



### People with physical disabilities

1. Access ramps and working lifts
2. Flexibility in appointment times
3. Disabled parking, and ample parking available
4. Support with the cost of transport and provision of hospital transport where available
5. Communications and hospital signage suitable for those with sight impairments



### People with learning disabilities

1. Training for staff; provision of dedicated disability liaison nurses
2. Good communication, including slowing down and speaking in plain English
3. Support to navigate new or unfamiliar healthcare spaces, in particular when thinking about the transition to the new Principal Treatment Centre
4. Use of Hospital Passports
5. Having menus with photographs
6. Easy read that is not so dumbed down to cater for those with less severe learning disabilities



### People with autism

1. Trained staff
2. Having quiet rooms available



### Children with special needs

1. Involving children in decision-making about their care; talking and explaining to them about what is happening, so they feel involved and able to discuss their preferences
2. Letting parents or carers into treatment rooms
3. Allowing children to listen to music or watch video as a distraction
4. Having mirrors in scanners so children can see their parent or carer; it was noted that many children find the noises in the scanners difficult to deal with
5. Offering sedation for children who struggle with scanners; offer numbing cream for injection sites
6. Thinking about the transition to teenage and young adult services



### Looked after children

1. Ensuring smooth transition, with tailored information and support
2. Reassurance about which members of staff would be moving to the new Principal Treatment Centre



### Families on low incomes

1. Speedy reimbursement of travel costs
2. Affordable accommodation
3. Affordable amenities in the surrounding area, with families being away from home and needing to use cafes and takeaways
4. Help with childcare costs



### Rural families

1. Flexibility with appointment times
2. Offer of overnight accommodation if travelling a long way or experiencing a long journey time
3. Support with travel costs

### 1.4.11 Criticism of the consultation

Although not a key theme, it is appropriate to acknowledge that some respondents across the stakeholder groups and the catchment area expressed criticism of the consultation. This feedback focused on:

- The perception that the consultation was biased or the result already decided, because Evelina London had been identified as the preferred option
- A feeling from a few parents, carers, and advocates that their feedback has not been listened to (during pre-consultation)
- A feeling of doubt from some parents, carers, and members of staff that their feedback could actually affect the decision making process
- The perception that there was a lack of financial detail, and financial scrutiny, associated with the proposals.

### 1.4.12 Suggestions to address challenges

Across engagement activities, people were asked to provide any suggestions they had to address challenges they had outlined to the proposals. The purpose of these suggestions would be to minimise or reduce any negative effects that might happen when the Principal Treatment Centre moves from The Royal Marsden to either Evelina London or St George's. These will be important issues for decision makers to consider during the implementation of the proposals. These suggestions, as proposed by consultation respondents, are summarised below.



	<h3>Access to healthcare</h3> <ol style="list-style-type: none"> <li>1. Improvement of children's cancer care closer to home</li> <li>2. Working together with the team that manages POSCUs</li> </ol>
	<h3>Travel</h3> <ol style="list-style-type: none"> <li>1. Improvement to the provision of effective and free hospital transport; expanding eligibility criteria for this</li> <li>2. Dedicated parking spaces</li> <li>3. Reimbursing travel costs/charges for all visitors to child in hospital</li> <li>4. Supporting families with travel costs in advance of travel</li> <li>5. Support with flexible appointment times and overnight accommodation</li> </ol>
	<h3>Facilities</h3> <ol style="list-style-type: none"> <li>1. Outdoor spaces dedicated to children cancer patients</li> <li>2. Guaranteed parental accommodation on or very close to the Principal Treatment Centre</li> <li>3. Dedicated, separate entrance to the Principal Treatment Centre</li> </ol>
	<h3>Research</h3> <ol style="list-style-type: none"> <li>1. Using The Royal Marsden @ model to safeguard continuity of research and funding</li> </ol>
	<h3>Staffing</h3> <ol style="list-style-type: none"> <li>1. Using The Royal Marsden @ model to support staff retention and recruitment</li> <li>2. Implementing a staff retention package for staff who move to the new Principal Treatment Centre, specifically relating to costs</li> <li>3. Flexible working contracts</li> <li>4. Assurances to staff that their role is safeguarded</li> </ol>

## 1.5 Conclusions

This report draws together feedback on the NHS England (London and South East regions) proposals for the future location of very specialist cancer treatment services for children aged one to 15 years (inclusive). The consultation heard from a range of stakeholder and equality groups, with good coverage of representation across the geographical regions in the catchment area of the current Principal Treatment Centre. Findings highlighted in the Executive Summary are reflective of feedback from all stakeholder groups and equality groups, as well as geographical regions. Feedback from affected members and other clinical and non-clinical NHS staff highlighted some additional findings,



which have been presented in the Executive Summary. These findings reflect their personal and professional experience and knowledge as NHS staff either working directly with the service or as part of the wider community.

Overall, the feedback received on the proposals was mixed. There were strong views on the benefits and challenges of both options, including the proposal to move conventional radiotherapy to University College Hospital. Travel to and accessibility of the future Principal Treatment Centre was a very important topic for respondents across all stakeholder groups. While some respondents identified strengths of the proposals in relation to travel and accessibility (such as good public transport links for Evelina London and good access by car at St George's), overall, feedback was negative and concerns were raised about how people would be able to access the future Principal Treatment Centre, afford the increased travel costs, and manage longer journey times.

In terms of suggestions to address challenges, a lot of the feedback related to helping people with travel and access challenges, including broadening assistance with travel costs to help those who are in need and speeding up reimbursement of costs incurred. Others suggested utilising The Royal Marsden @ model to help retain staff and research capability. Alternative proposals were put forward by a small number of respondents, including the implementation of a risk-adapted model for patients deemed most at risk of needing level 3 intensive care across the split sites of The Royal Marsden and St George's, and the utilisation of the new hospital being built next to The Royal Marsden in Sutton.

Although it falls outside the scope of the consultation, strong views were also received about the case for change. These views were mixed. There was strong clinical support for the case for change, largely found in responses from clinical NHS staff and in the formal responses submitted by organisations. Some family members and advocates also gave their support the case for change; these were typically individuals who had lived experience of children's intensive care unit transfers involving their child or close relative. Many of those who opposed the case for change were children, young people, family members and advocates. It is also important to note the criticism that has been received about the consultation. Although these comments have been made by a relatively small number of respondents, compared to the total number of responses received, it is essential that the decision-making process provides assurances about the ways in which the consultation has listened to and taken into account feedback given.

The consultation report gives NHS England (London and South East regions) a clearer picture of the perceptions of key stakeholder groups, as well as their support and concerns in relation to both options. It provides details of factors that leaders of NHS England (London and South East regions) may need to consider in taking its decision on the future location of the Principal Treatment Centre.





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