



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)¹. 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.²

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

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

² 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 questionnaire³, many of the questions asked were open questions with no

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

word limit⁴. 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 feedback⁵. 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 groups⁶. 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

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

⁵ 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.

⁶ 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>Website</p>  <p>Including child friendly section</p>	<p>Animation</p> 	<p>Posters and printed documents</p>  <p>at the Principal Treatment Centre and Paediatric Oncology Shared Care Units</p>
<p>Facebook campaign</p>  <p>Widespread and paid-for</p>	<p>Proactive media releases</p>  <p>and responses to media enquiries</p>	<p>Social media</p>  <p>messaging by: NHS England (London and SE) <i>and</i> partners and others</p>
<p>Phone calls and offers of meetings</p>  <p>to groups working with communities identified by the Integrated Impact Assessment</p>	<p>Letters</p>  <p>to current and recent patients of the Principal Treatment Centre</p>	<p>Email briefings</p>  <p>to all stakeholder groups</p>

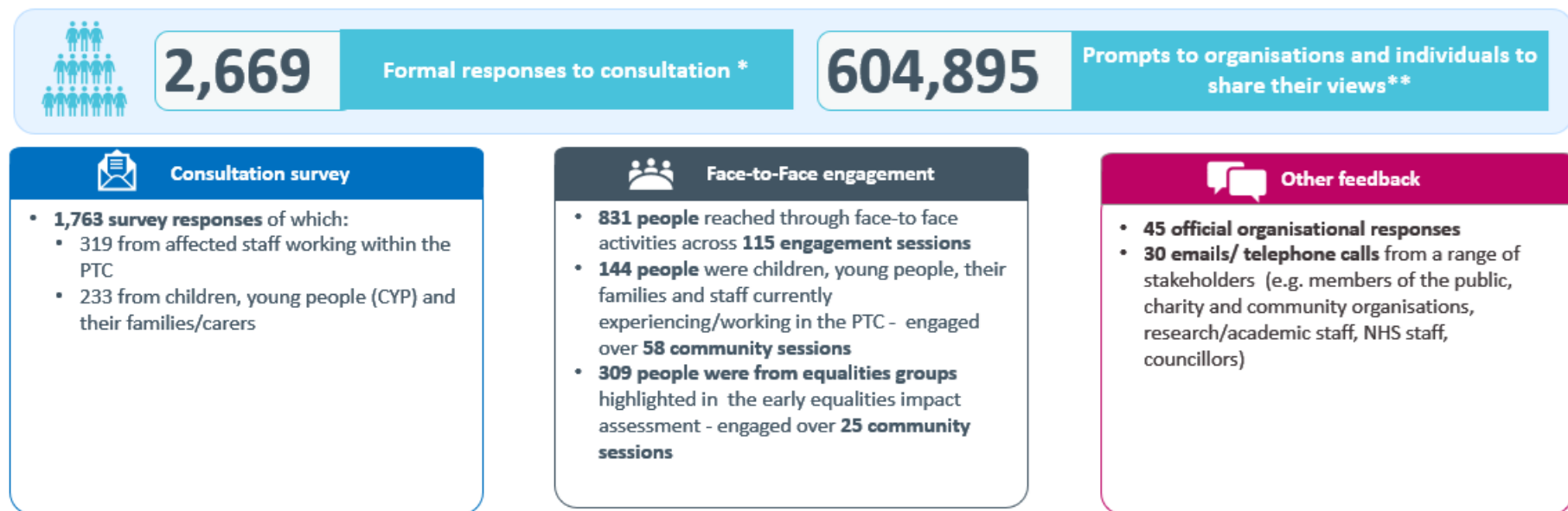
1.3.4.2 Engagement activity:

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 below⁷.



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

⁷ 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 child⁸) who have been affected by cancer (3%).

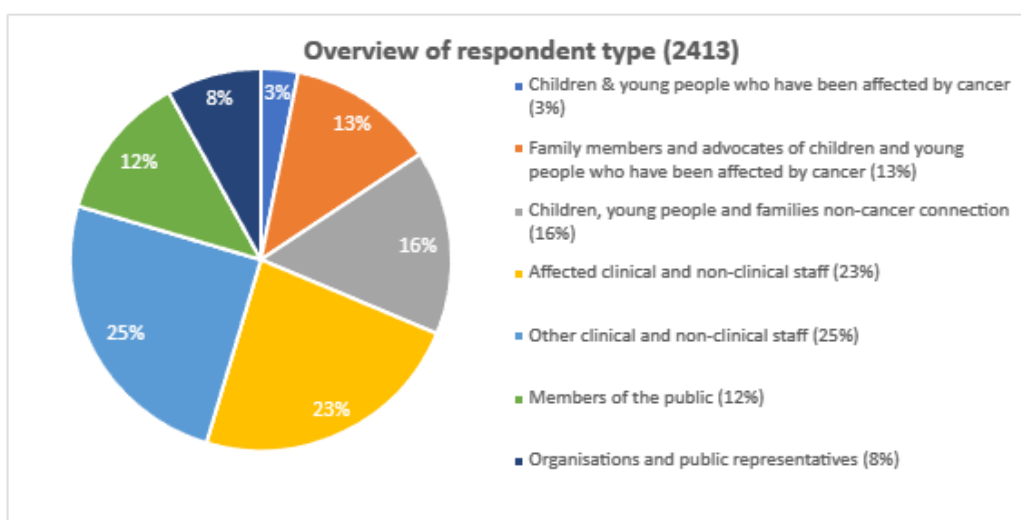


Figure 1: Overview of respondent type: across all engagement methods. (Base number of 2413 reflects number of respondents that disclosed their stakeholder type.)

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

⁸ 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 area⁹. 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)

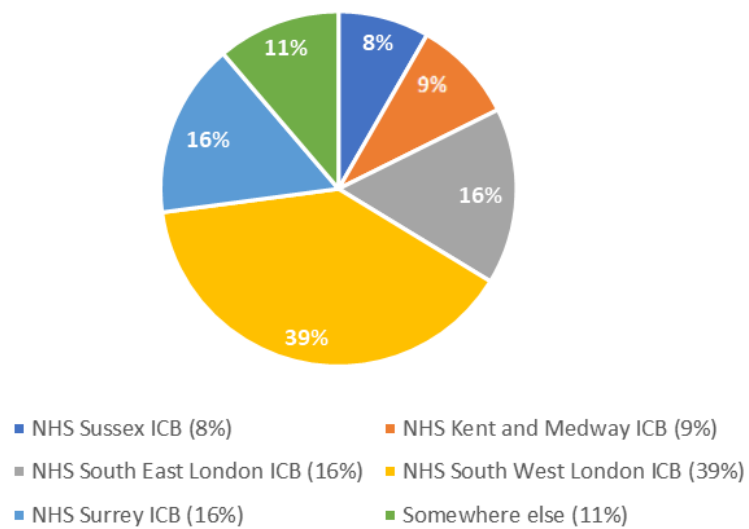


Figure 2: Overview of location of respondents by Integrated Care Board (ICB) area: across all engagement methods and respondent types. (Base number of 2209 reflects number of respondents who disclosed their location.) Please note, due to rounding, percentages in the chart do not total 100%

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.

⁹ 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.

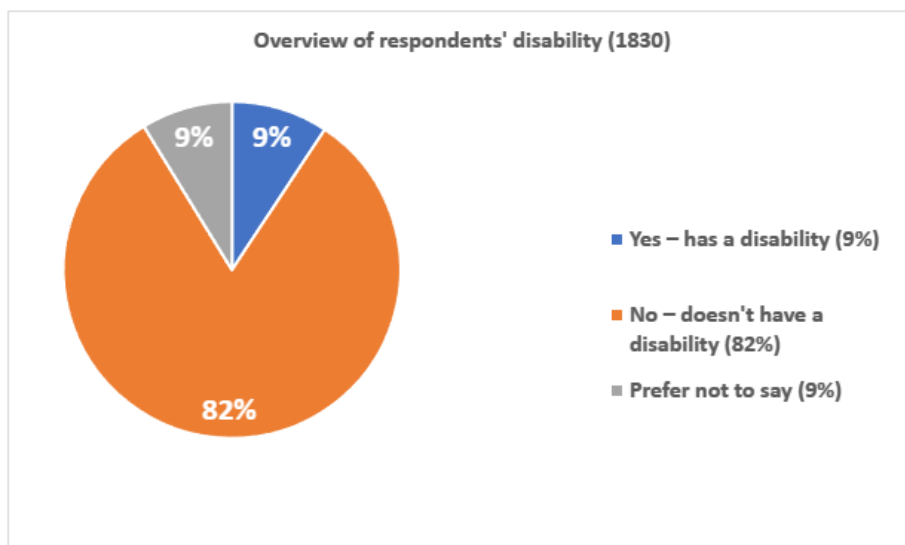


Figure 3: Overview of respondents' disability status: across all engagement methods and respondent types. (Base number of 1830 reflects number of respondents who answered this question.)

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.

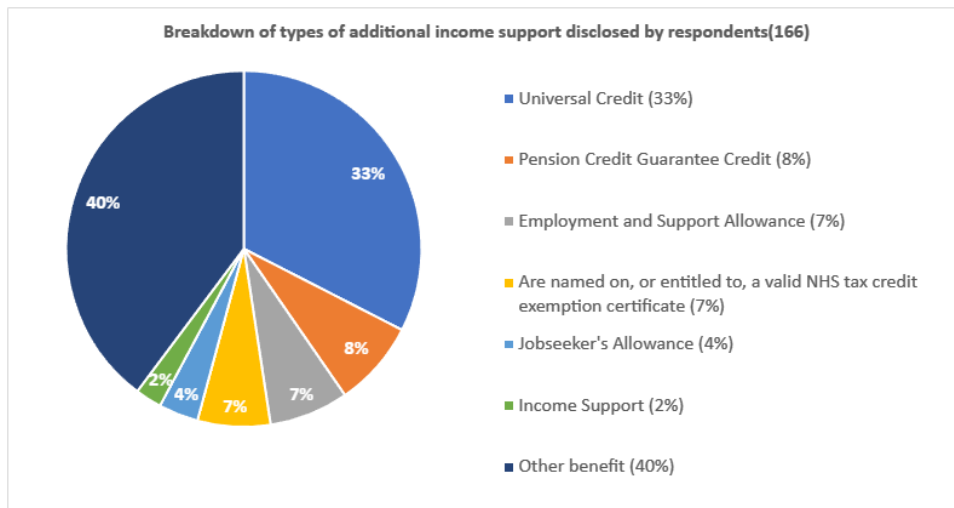
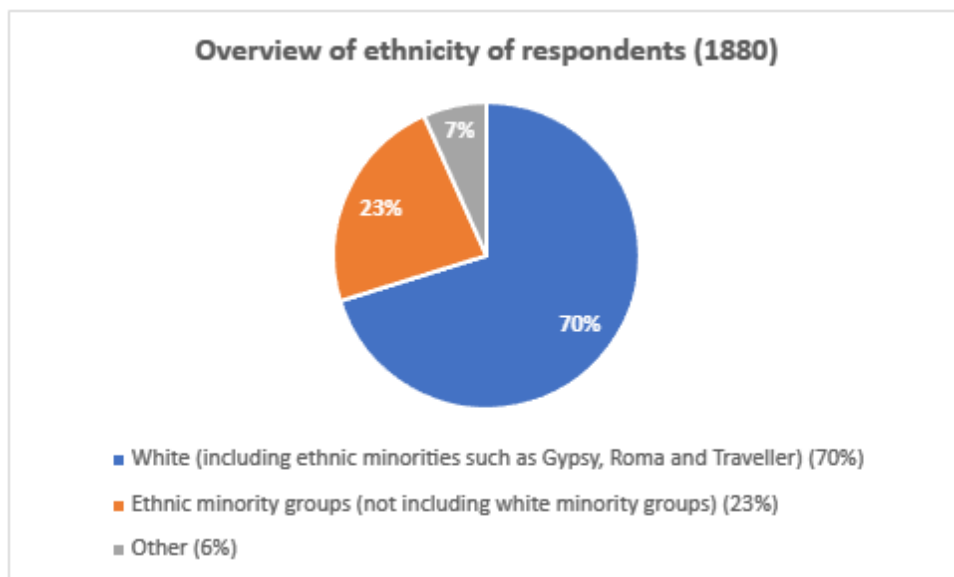


Figure 4: Overview of respondents who disclosed they were in receipt of additional income support: across all engagement methods and respondent types. (Base number of 166 reflects number of respondents that disclosed receipt of additional income support.)

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.¹⁰



¹⁰It 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 76¹¹.

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%).

¹¹ 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.

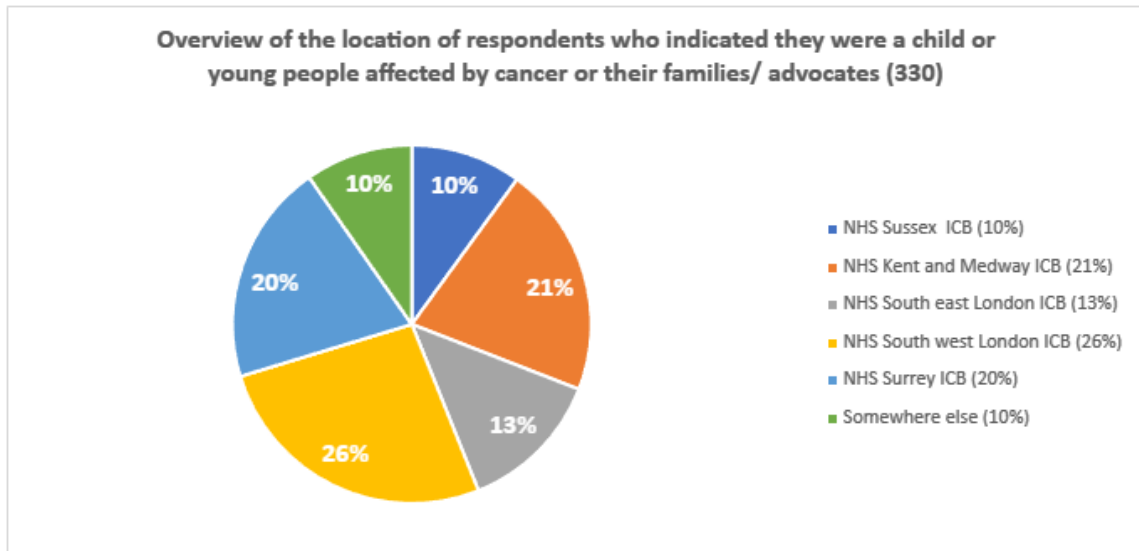


Figure 6: Breakdown of the location of respondents from children and young people who have been affected by cancer and their family members and advocates: across all engagement methods and respondent types. (Base number of 330 reflects number of respondents that disclosed their respondent type and location.)

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)¹².

¹² 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)¹³.

1.4.10 Support for equality groups

¹³ 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">1. Improvement of children's cancer care closer to home2. Working together with the team that manages POSCUs
	<h3>Travel</h3> <ol style="list-style-type: none">1. Improvement to the provision of effective and free hospital transport; expanding eligibility criteria for this2. Dedicated parking spaces3. Reimbursing travel costs/charges for all visitors to child in hospital4. Supporting families with travel costs in advance of travel5. Support with flexible appointment times and overnight accommodation
	<h3>Facilities</h3> <ol style="list-style-type: none">1. Outdoor spaces dedicated to children cancer patients2. Guaranteed parental accommodation on or very close to the Principal Treatment Centre3. Dedicated, separate entrance to the Principal Treatment Centre
	<h3>Research</h3> <ol style="list-style-type: none">1. Using The Royal Marsden @ model to safeguard continuity of research and funding
	<h3>Staffing</h3> <ol style="list-style-type: none">1. Using The Royal Marsden @ model to support staff retention and recruitment2. Implementing a staff retention package for staff who move to the new Principal Treatment Centre, specifically relating to costs3. Flexible working contracts4. Assurances to staff that their role is safeguarded

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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Introduction

An overview of the project background, objectives and methodology.

2 Introduction

2.1 Project background

NHS England (London and South East regions) have consulted on proposals for the future location of very specialist cancer treatment services for children aged one to 15 (inclusive). 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 consultation¹⁴.

The public consultation about these proposals opened on 26 September and closed on 18 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, 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 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 transplants, are based at The Royal Marsden’s site in Sutton. Life-saving intensive care, most children’s

¹⁴ These are identified in NHS England’s consultation document available on their website.



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 current service 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. About 1,400 children are under the care of the current Principal Treatment Centre at any given time. More than 60% of the Principal Treatment Centre's patients are from outside London. These changes to very specialist cancer treatment services for children will affect the catchment area of Brighton and Hove, East Sussex, Kent, Medway, South London, and Medway.

2.2 Purpose of this report

The purpose of this report is to present the findings from the consultation on proposals for the future location of very specialist cancer treatment services for children aged one to 15 (inclusive) who live in south London and much of south east England. This report will be used by leaders of NHS England (London and South East regions) to help them make a decision on the future location of the Principal Treatment Centre. There are two options: Evelina London Children's Hospital, in Lambeth, south east London, and St George's Hospital in Tooting, south west London. In taking the decision, they will look at all the evidence available to them, including feedback from the public consultation.

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 consider the need to provide care for children across the entire catchment area of south London and much of the south east. They will also have regard to their statutory functions and their 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.

The decision is currently expected to be taken during Spring 2024.

2.3 Outline of the report

The report is split into key sections:

- **About the consultation**
 - o This details the key stakeholder groups, and the communication and engagement methodology, which includes specific methods of engagement



- **Respondent profile**
 - A summary of demographics for those who responded to the consultation. This tells us who responded to the consultation in terms of their sex/gender, age, ethnicity, stakeholder group (for example, if they are a child or young person affected by cancer, a family member or advocate, a member of clinical or non-clinical staff, or a member of the public), and where they live
- **Findings summary**
 - This is a summary of findings across all stakeholder groups and integrated care board areas. These key findings are what many people, across all stakeholder groups, said in response to the consultation
- **Findings by stakeholder group**
 - This focuses on findings from specific target stakeholder groups. Each chapter follows a similar format. At the beginning, there is an engagement snapshot. The engagement snapshot summarises how stakeholders responded to the consultation to tell us what they think, and it is these responses that provide the evidence for the findings that follow. That means both questionnaire and qualitative engagement data are analysed together and presented together to provide a comprehensive understanding of what stakeholders think. Following the engagement snapshot, the proposal for Evelina London is considered first, with the strengths, challenges, and suggested improvements outlined. The proposal for St George’s Hospital is then considered, with the strengths, challenges, and suggested improvements presented. The proposal to move radiotherapy services to University College Hospital is considered next. Finally, the chapter reflects on what stakeholders consider important features of a future Principal Treatment Centre. This feedback will be considered when the transition to the future Principal Treatment Centre is being implemented.
 - In the chapter on organisations and public representatives, there is summary of each formal response submitted to the consultation.
- **Findings by geography**
 - This focuses on findings from respondents based on their geographical location. These findings are organised by integrated care board area.
- **Conclusions**
 - A summary of feedback on both proposals is presented. This is followed by a review of mitigating actions proposed by stakeholders across all groups. In the case of the consultation, mitigations are actions that could be taken 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 Hospital.

2.4 Explain Research's role

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 post where responses were submitted by people using freepost). 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.

2.5 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 test the approach set out in its draft consultation plan by gathering insights about how NHS England should be engaging, who it should be engaging with, and to understand the types of content and format of information that should be provided through consultation.

The views and feedback received helped to shape the information provided for the consultation. This in turn helped people to make informed responses to the consultation. It helped to shape and support the communications and engagement approach set out in the final consultation plan which was enhanced by suggestions such as: offering a range of ways to feedback including digital and non-digital means, and where possible, producing short documents with links to more information as well as short videos to make information accessible. Other suggestions included ensuring play was part of engagement with children and young people – which was taken forward through commissioning an expert play specialist organisation to deliver play sessions with child cancer patients at The Royal Marsden and St George's Hospital. Suggestions around additional stakeholders to add to mapping were adopted.

2.6 Mid-point review



This report follows the mid-point review, which Explain conducted independently on behalf of NHS England (London and South East regions). The mid-point review was part of the ongoing review process for the consultation, conducted by the NHS England Programme Team.

The review itself 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 also provided details of emerging themes from the thematic analysis being conducted on the consultation feedback. Drawing this together, the review then presented 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.

The review was examined externally by the Programme Stakeholder Group (including parents and local and national charities), Programme Board (including Trust, Integrated Care Board, and patient representatives), and Joint Health Overview and Scrutiny Committees, in partnership with the NHS England Programme Team. Explain Research was satisfied that the next steps and suggested actions had been considered thoroughly by the Team and implemented where agreed necessary.

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. Some examples include:

- 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
- Running a paid-for social media campaign to target geographical regions with lower response rates as well as parents with a connection to child cancer services
- 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
- Commissioning online play specialist sessions to increase uptake for those who are no longer in active treatment
- Auditing key organisations to check messages were being shared through their channels and following up with new communications materials to support promotion of the consultation



- Follow-up phone calls to voluntary and community organisations who support specific equalities groups, to follow up with new communications materials to support promotion of the consultation
- Adding videos to the online questionnaire to help people learn more about both options as they completed the questions, and using these videos in face-to-face sessions
- Asking the external expert play specialist organisation to review their approach to ensure they were capturing the most useful feedback from children and young people
- Working with University College Hospital to raise awareness of the consultation with current proton beam patients and seek their experiences of radiotherapy on the site.

2.7 Notes on analysis

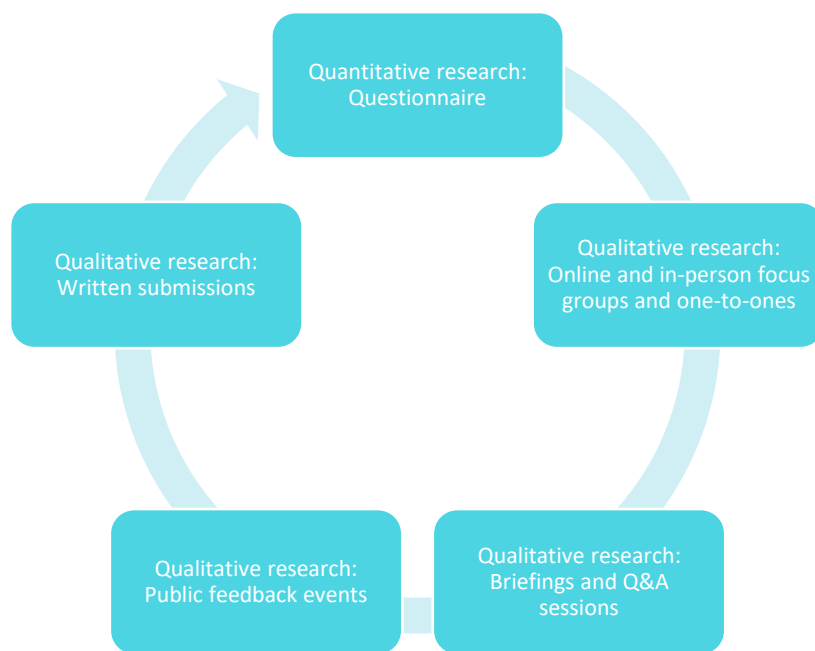
2.7.1 Thematic analysis

Explain Research conducted thematic analysis of all consultation feedback. This was to understand what respondents thought about the proposals for change, including any concerns and any mitigations they feel would support the change to happen. Ultimately, the report will help to answer the question, 'Where should the future location of very specialist cancer treatment services for children be?'

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. An example of this is the 5-point scale question in the questionnaire about 'how important travel would be' to the future Principal Treatment Centre. Quantitative data 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. An example of qualitative data is a discussion between respondents in a focus group setting. Qualitative data 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. The diagram below shows how this triangulation works:





Thematic analysis has been conducted on all qualitative data, including open questions in the consultation questionnaire. An open question invites the respondent to explain their thoughts and reasons; an open question cannot be answered with a simple yes or no answer¹⁵. In terms of the open question responses in the questionnaire specifically, a thematic analysis approach enabled the identification of recurring themes and the presentation of data in a more systematic way throughout the report. As such, the report presents the top themes identified within each open response question, with most of these presented in graphs. It is made clear where graphs are shown on an overall basis (that is, all questionnaire responses included, across all stakeholder groups and catchment areas) or where graphs are shown by an individual stakeholder group or integrated care board area.

2.7.2 Stakeholder voice chapters

Findings in the main report have been presented in chapters dedicated to key stakeholder groups. 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

¹⁵ An example of an open question from the questionnaire is: 'Please tell us what you think the good things are about this option.'



- Affected clinical and non-clinical NHS staff (staff at the hospitals where the Principal Treatment Centre is currently, or course be – The Royal Marsden, St George’s Hospital and Evelina London Children’s Hospital)
- Other clinical and non-clinical staff (who may also work with the Principal Treatment Centre or have a related interest)
- Equality groups
- Members of the public
- Local government, including Overview and Scrutiny Committees and MPs
- Organisations.

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.

2.7.3 Number of responses to the consultation

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.

2.7.4 Questionnaire responses

It is important to note that the questionnaire was made up of mostly open responses and this produced a wealth of data which was all read and analysed. Some respondents chose to write a few words and others wrote long answers to the questions (some individual responses to single questions were around 1,500 words long), detailing many different and varied points.

When analysing this qualitative data thematically, Explain used different codes or themes for different aspects of the same topic to capture the richness of feedback¹⁶. Graphs show the number and percentage of comments relating to that theme to represent the range and specificity of respondents’ feedback. As such, it is important to highlight that numbers and percentages given in graphs relate to the number and percentage of comments made about a particular theme in relation to that question.

¹⁶ 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.



It is typical that in response to an open question, there is no majority, given the wide-ranging comments and no limit on word count, which is the case here. Relatedly, it is not possible to add up the number of responses for an issue (e.g. travel) to understand how many people raised an issue, because there may be overlap between those who gave those comments.

2.7.5 Graphs and base sizes

When looking at a graph, readers will notice that there is a base size included. A base size is the number of responses received for a question, depending on the sample queried (for example, all responses, responses by stakeholder group, responses by integrated care board area). This is why the base size changes for most graphs, because a different number of respondents answered each question. On occasion, the number of responses received for a question (the base size) is too small to produce graphs. In these cases, feedback from open responses is included in the main text of the report. Figures displayed in graph or table format throughout the report may not add up to the total number of responses received or base sizes provided (100%), due to no question being mandatory as well as the rounding of individual figures.

Due to the lower number of responses to the easy read questionnaire, responses are displayed as an overall picture, rather than being broken down by stakeholder group or integrated care board area. However, individual responses from the easy read questionnaire have been included where possible. It is important to note that feedback from the easy read questionnaire reflected the findings of the questionnaire; there was no significant difference.

2.7.6 A note about graphs and changes to the questionnaire

During the early stages of the consultation, from 23 October 2023, questions seven and eight (on travel and support/information) were refined to ensure that the questionnaire could capture a more accurate picture of respondents' sentiment. This entailed changing questions from a three-point sentiment scale (not at all important, quite important, very important) to a more comprehensive five-point sentiment scale (1 – not at all important, 2, 3 - neither important nor unimportant, 4, 5 – very important, don't know). As such, throughout the report, data captured for these questions after 23 October 2023 are presented in graph format displaying the mean score for each question, while data captured before the change is presented in a stacked bar chart style. Data for stakeholder type and region captured for these questions before 23 October 2023 is not presented in chart format due to low base sizes.

2.7.7 Use of direct quotes and commentary



Following this, all qualitative data was analysed alongside all other feedback to understand strength of feeling as well as individuality. Comments have been included in the main body of the report, under the relevant sections. These include open responses in the questionnaire, but also qualitative feedback received from other engagement activities. There was some variability in terms of the detail some respondents shared in their responses to the questionnaire questions; qualitative feedback from other engagement activities has been used to triangulate and further understand these views, given the additional detail provided.

Most of these comments are representative of views expressed within the key themes. This has been made clear in the report. Other comments are illustrative of feedback received from some or a few respondents. This has also been made clear in the report where this is the case. In some cases, comments are included that were made by one or two respondents, often because they relate to something specific or technical and warrant acknowledgement in the report. This is also made clear where this is the case.

It is not always possible to quantify the number of respondents. This is because much of the analysis combines questionnaire and qualitative feedback. To quantify this as a number of respondents who said or thought something would be misleading. The open nature of most of the questions in the questionnaire means that quantification here is based on themes and the frequency of comments.

For feedback received from some engagement activities, it has not been possible to attribute comments to a particular stakeholder type, demographic group, or place of residence. This is because feedback has been recorded without attributing it to a particular person with their circumstances known. Feedback has been anonymised at the aggregate level. This feedback has been nonetheless analysed and accounted for; it just means that commentary about an engagement activity (and associated direct quotes) cannot be included in specific stakeholder or geographical chapters because it cannot be known who said what.

This report aims to give quotes from different geographies, types of stakeholders (where appropriate) and organisation, particularly for affected and potentially affected staff. However, it is clear that the majority of staff working at a particular hospital site were more likely to state the positives of the proposal for their hospital than the challenges or weaknesses. As such, although there has been an effort made by Explain Research to balance comments by affected staff, this was not always possible.

2.7.8 Feedback on strengths and challenges



Readers will notice that while some respondents think a particular feature or detail of a proposal is a strength, others think it is a challenge. This mix in sentiment is characteristic of feedback received during the consultation and is evident across other stakeholder groups.

2.7.9 Dealing with comments that are technical, factually inaccurate, or out of the scope of the consultation

Some feedback included complex clinical and technical statements. Where necessary, anonymised details of statements were shared 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. In a few cases, feedback has been presented in this report alongside a footnote, which appears at the bottom of the page, to provide additional context to help readers understand what the respondent is saying in light of the proposals.

Within the two open questions which asked respondents to suggest improvements to the challenges of each proposal, it is clear that some respondents took this opportunity to urge NHS England to pick a particular option. Due to these comments falling outside of the parameters of the question (given they are not improvements), they have not been presented in the graphs within the stakeholder groups and region chapters, but have been noted, nonetheless.

Some respondents used the consultation as an opportunity to express their feelings about the case for change (the reasons why the current Principal Treatment Centre must be moved, in line with the national service specification). Feedback on the case for change fell outside of the scope for the consultation; indeed, no question facilitated feedback on the case for change. However, given the strength of feeling communicated in a lot of the feedback about the case for change across key stakeholder groups, this feedback has been included in a dedicated section in the Findings Summary chapter.





About the consultation

A review of the consultation activity, including communications and engagement, and key methods



3 About the consultation

3.1 Key stakeholders

The consultation was open to all. However, there were a number of specific stakeholder groups that the consultation targeted. These stakeholder groups were targeted because they were identified as being likely to be impacted by the proposed move of services in an early Integrated Impact Assessment for the programme. As such, it was important that these groups were represented in the consultation feedback. The level of engagement of these groups was tracked and communications and engagement activities adjusted as the consultation progressed to maximise opportunity for their engagement. These specific stakeholder groups were:

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 and public representatives
- 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.

3.2 Communications and engagement methodology

The consultation methodology was developed 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 advice. Consultation activities were delivered by a combination of independent expert engagement partners as well as the NHS England Programme Team.

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 are listed above. Other key stakeholders, including Overview and Scrutiny Committees and MPs, and those with a more general interest, were also included in the approach. Overall, the approach was aligned with best practice guidance on undertaking appropriate 'proportionate' engagement activities.

The NHS England Programme Team provided the same information and opportunities to engage to all stakeholders no matter where they lived in the catchment area, through digital events. Specific engagement activities that were commissioned in the community engaged with people who were representative of different characteristics, for example those who lived in more rural locations rather than towns, and in inner rather than outer London, as well as other demographic characteristics. Many children and young people who are currently using the service are unlikely to be affected by the change in location as it will not happen before 2026, when they will no longer be receiving treatment, however their experiences were sought through play specialist sessions and parent focus groups. In line with advice from Healthwatch, the approach to communications and engagement also included engagement with other parents and carers in the catchment area who have children with long-term conditions who might have experienced similar long-term hospital treatment.

It was also important to make engagement accessible for those with little time to be able to participate – NHS England enabled email replies, one-to-one interviews scheduled at a time convenient to the participant, as well as posters in key hospital locations with QR codes to the consultation website, so information could be accessed on the go.



3.3 Key methods of communication

The consultation was promoted widely by the NHS England Programme Team and key partners. This included:

- Letters, social media messaging and publicity about online events to young people with cancer and the families of children with cancer (current service users and teenagers and young adults with experience of cancer) shared via several routes including the Facebook group for The Royal Marsden parents, and by The Royal Marsden, St George's Hospital and children's cancer shared care units
- Emailed briefings, phone calls and offers of meetings to groups working with communities identified by the Integrated Impact Assessment (listed above) and other charities, reaching more than 550 organisations
- Emailed briefings and publicity about meetings to staff directly impacted by the consultation, Joint Overview and Scrutiny Committees and Health Overview and Scrutiny Committees, Institute of Cancer Research and other research organisations, specialist children's cancer charities, Healthwatch organisations, MPs and other political stakeholders (e.g. London Mayor's Office, local councillors), Local Authorities including Directors of Public Health, children's cancer shared care units, Royal College of Paediatrics and Child Health, the children's cancer clinical network
- Bulletins to other staff not directly involved in the programme (e.g. Integrated Care Boards (ICBs), pharmacy, primary care)
- Proactive media releases and online information, and responses to media enquiries

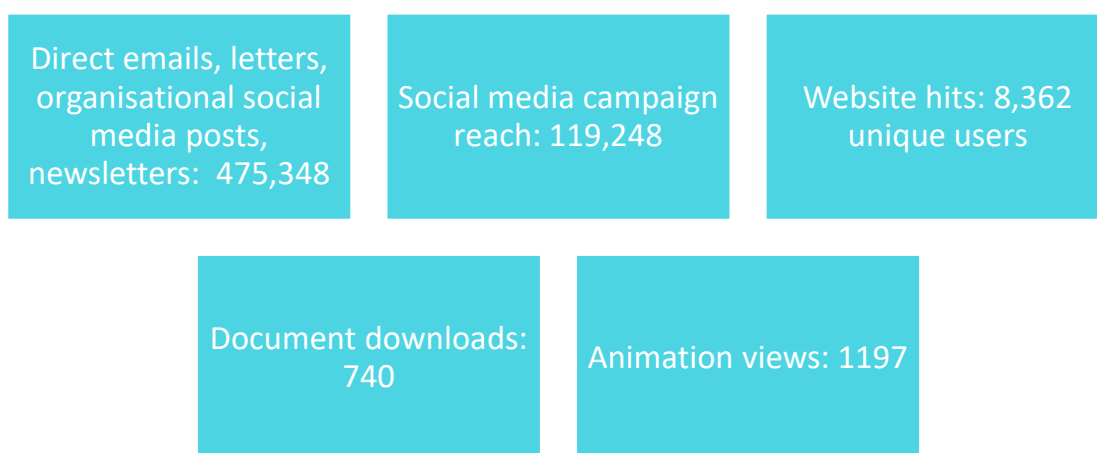
In addition, a wide range of information about the consultation was published and shared to cover different levels of interest and desire for detail. These included:

- An easy-to-understand animation which was tested with young patients and was subtitled in the languages spoken by the greatest numbers of non-English speakers in the catchment area
- Posters and flyers, an easy read consultation document and questionnaire with simple text and lots of pictures; a summary consultation document available online as an accessible html and for download – all of which was available in hard copy at sites across the catchment area providing care for children with cancer and at Evelina London along with envelopes for people to return the questionnaires by freepost (the summary document was tested with young people and their comments had a significant impact on the final version)



- A full version of the consultation document which was available online as an accessible html and for download and in hard copy at the three hospitals most closely involved (The Royal Marsden, St George's Hospital and Evelina London)
- An online consultation questionnaire which could also be downloaded and returned via freepost
- Very detailed online information about aspects of the consultation for those who wanted to know more about the process
- The pre-consultation business case, integrated impact assessment and other detailed, technical documents
- Information for staff to help them answer patients' and families' questions
- A communications toolkit with key messages, website copy, and social media posts and assets, which was shared with Trusts, specialist children's cancer charities, Integrated Care Boards, voluntary and community organisations and Healthwatch organisations. This toolkit was used by many to raise awareness of the consultation
- A social media campaign that reached parents in the catchment area, particularly in areas with lower levels of responses, and encouraged them to give their views on the proposals.

Below is a summary of communications reach totalling 604,895 prompts to organisations and individuals to share their views:



3.4 Key methods of engagement

The public consultation adopted a multi-method approach, involving all Integrated Care Board areas, with a mix of quantitative and qualitative research activities.

3.4.1 Questionnaire



The questionnaire was designed by the NHS England Programme Team, Programme Board, Trust senior management leads, Stakeholder Group (of parents and local and national charities), with input from The Consultation Institute. Explain Research also provided comments on the questionnaire design. The questionnaire itself focused on key questions that would help inform decision-making in relation to both proposals (good points, challenges, and improvements), travel and accessibility, feedback on the proposal for University College Hospital to take on the radiotherapy service, and feedback on key features of the future Principal Treatment Centre. A copy of the questionnaire and the easy read questionnaire can be found in Appendix C. The questionnaire was open for the full consultation period, opening on 26 September, and closing on 18 December 2023 at midnight. A total of 1,763 questionnaire responses were received.

Total questionnaire responses: main questionnaire and easy read

	Online	Paper	Received after the consultation closed ¹⁷	Total
Questionnaire	1709	2	4 paper questionnaires	1715
Easy read questionnaire	40	5	3 paper questionnaires	48
Total	1749	7	7	1763

Table 1 A summary of total questionnaire responses

The questionnaire was available to complete online and by paper copy¹⁸. Links to the online questionnaire were shared widely, including via the dedicated consultation website¹⁹, health bodies, staff and patient networks, voluntary and community organisations, and relevant social media channels. An easy read version of the questionnaire was also available online and in paper format. Printed copies of the easy read questionnaire, along with freepost envelopes, were left at key locations in the catchment areas, including the affected hospitals.

3.4.2 Play specialist sessions with children and young people in the current Principal Treatment Centre

¹⁷ Questionnaire responses that were received after the consultation close were not included in the questionnaire tables and graphs. However, these questionnaire responses were read and analysed separately by Explain Research.

¹⁸ All paper copies received were subsequently entered into the applicable online version of the questionnaire.

¹⁹ <https://www.transformationpartners.nhs.uk/childrencancercentre/>



A total of 11 play specialist sessions were conducted (either one-to-one or in small groups) in-person at The Royal Marsden and St George's Hospital or online, with children and young people currently receiving treatment for cancer. Activities were tailored to the age and interests of the child. For younger children, a toy hospital and ambulance were used. For older children and young people, activities such as ideas boards, cartoon strips, and written letters were used. These activities focused on likes and dislikes of their current hospital experience, as well as what they would like the future Principal Treatment Centre to be like. In later sessions, children were asked questions about their experiences of attending hospital, including travel.

Examples of materials used for elicitation during play specialist sessions are shown below:



3.4.3 Parent focus groups

A total of seven parent focus groups were conducted by an independent provider. To begin each session, parents and carers of children and young people affected by cancer were shown an overview of both proposals. Then the opportunity was given to each respondent to share their experiences and give feedback on the proposals.

3.4.4 Staff focus groups

A total of five staff focus groups took place. NHS England Programme Team delivered one focus group for Evelina London staff. The other focus groups at St George's Hospital and The Royal Marsden were run by an independent provider. To begin each session, staff were shown an overview of both proposals. Then opportunity was given to each respondent to share their experiences and give feedback on the proposals.

3.4.5 One to one interviews



The NHS England Programme Team facilitated 22 interviews with parents and members of staff, including research staff. These were offered on-demand for those who had limited time to attend sessions or complete the online questionnaire, or for those who preferred to give their feedback in this way. During the interviews, respondents were given information about the consultation and both proposals before being invited to provide feedback on the consultation questions.

3.4.6 Wider staff sessions

A total of 11 sessions with staff from across the wider clinical community were carried out by the NHS England Programme Team. These included colleagues from South Thames Operational Delivery Network, Paediatric Clinical Networks, Great Ormond Street Hospital (GOSH), and children's cancer shared care units. During these sessions, staff were asked to provide feedback on the two proposals.

3.4.7 Community focus groups

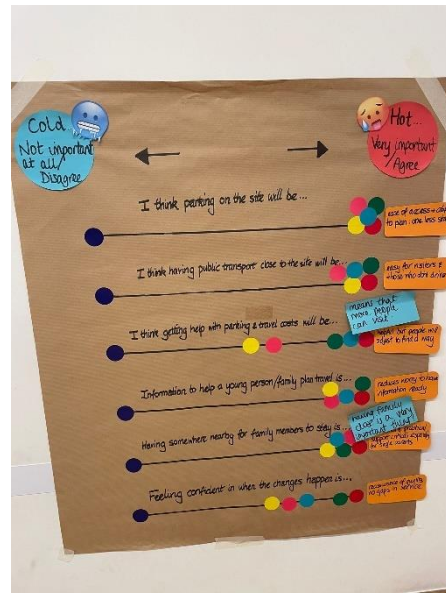
An independent provider ran 13 community focus groups, involving children, young people, and families from across the catchment area. These children, young people, and families reflected characteristics highlighted in the equality impact assessment, but they did not necessarily have experience of cancer services. A mix of online and face-to-face focus groups took place. Further detail about these sessions, who was involved, and the achieved geographical coverage can be found in Appendix B, the engagement log.

Before the session, participants were given an easy-read document and shown an animation to give context to NHS England's (London and South East regions) public consultation. At the beginning of the session, key features of the two proposals were visually shown and described to respondents using physical boards if the meeting was happening in person or digital boards if online (Miro²⁰). Then respondents were asked to take part in a number of interactive activities to elicit their feedback. Each option was taken in turn and discussed and then respondents were asked to consider the importance of a range of factors when considering the move of the Principal Treatment Centre. As a thank you for their time, respondents were given a digital gift voucher.

Examples of the physical boards used are provided below:

²⁰ Miro is a digital collaboration tool; see more here <https://miro.com/>





Examples of the digital boards used:

St George's

A large teaching hospital that provides specialist services for adults and children.

The NHS would convert a wing in the hospital with its own entrance for young cancer patients.

This is what it will feature...

- 22 single ensuite rooms
- 6 ensuite for families
- Some extra accommodation for parents/careers of children on the same hospital site
- Dedicated garden space which could be closed off to other patients and visitors
- In 2019/20, treated almost 60,000 young patients living in South West London, Surrey and Essex
- Has 25 children's researchers and a good track record in national and international research
- A drop-off zone and dedicated parking outside the centre helps families with travel arrangements for appointments and the journey home by taxi or patient transport
- Playrooms
- TV
- Childminders and gaming rooms for children of different ages

Heart (Emotional)

- Loved the TV and Games Room
- The games and the ensuite!
- 22 single ensuite rooms

How does this idea make you feel?
Who else would care about this?
What do you love about this option?

Head (Logical)

- The ensuite for families is an important thing
- Gardens are cool, and provide a different space (p)
- Parking is very useful (p)
- This feels calmer and it feels bigger.

Does this make sense to you?
Is this best for children & young people?
What sounds out about this option?

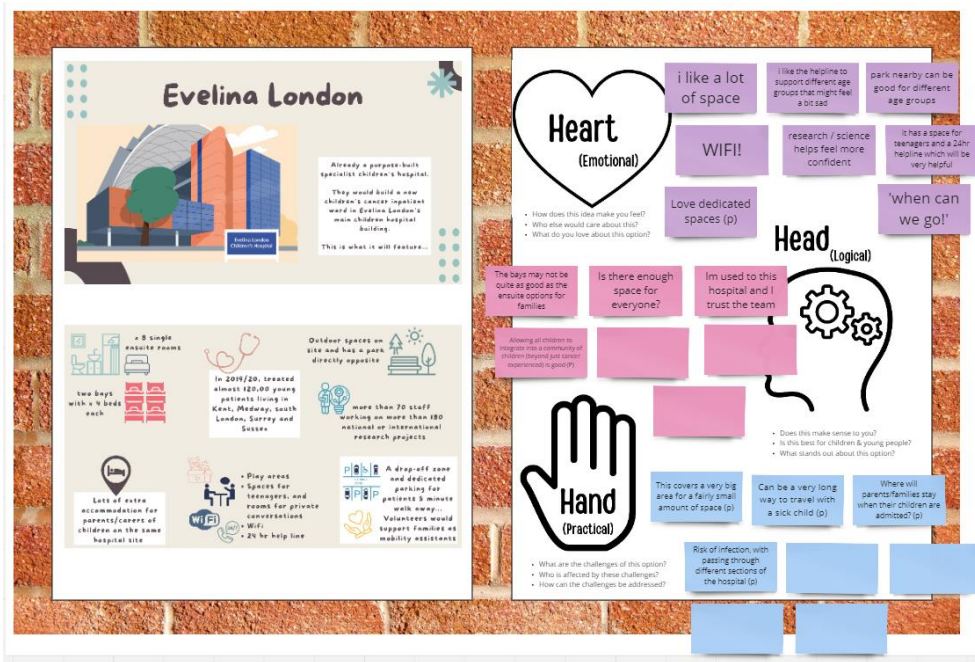
Hand (Practical)

- Funding could be a challenge (p)
- Are there multiple TVs or just one in one room?
- There may not be enough toys for young people
- Build a timetable for use of the games space so people know what ages will be in the space and when (p)
- Do a survey in advance of patients coming in, asking age and things they like, so that when they get there there is enough stuff they like

Very good opportunity for YP struggling with cancer

options like the games room can help people feel happy





3.4.8 Equalities groups

The NHS England Programme Team attended 12 meetings organised by support groups and others, reaching the following communities: people with a learning disability, parents/carers, refugees and migrants, people from Gypsy, Traveller and Roma communities, black people and people from other ethnic minorities, and people with mental health issues.

3.4.9 Site visits to clinical areas

A total of 13 site visits were undertaken by the NHS England Programme Team to The Royal Marsden and some children's cancer shared care units to speak to children with cancer and their families. These visits took place mainly in outpatient clinics when it was clinically safe and appropriate to do so. Information was shared with patients and their families about the consultation and the proposals and they were invited to give their feedback on the consultation questions.

3.4.10 Public listening events

A total of three online public meetings were held by The NHS England Programme Team. These events were open to all. They involved the team presenting the key details of the two proposals, taking questions on the proposals and gathering feedback from attendees. Public listening events were promoted by NHS England using their website, targeted communications including social media, and



other channels. These were held at different times with specific arrangements made to support accessibility needs (on request).

3.4.11 Emails, letters and phone calls

A freephone number, freepost postal address, and a dedicated email address were provided for individuals to submit questions or formal responses to the NHS England Programme Team. A total of 28 email responses were received and one voicemail. These were from a mix of stakeholders, including: members of the public; charities and community organisations; NHS staff (including from The Royal Marsden); research or academic staff; and local councillors.

3.4.12 Formal responses

Organisations were also invited to submit a formal response to the consultation. A total of 46 formal responses were received. Formal responses from organisations have been recorded separately in the report, in the stakeholder chapter for organisations. Formal responses are organised by organisation type. These are:

- Government bodies and representatives (four responses)
- Health bodies and associated groups (17 responses)
- Local Authorities (seven responses)
- Parent bodies and representatives (three responses)
- Research organisations (five responses)
- Charities and not-for-profit organisations (eight responses)
- Other responses (one response).

3.4.13 Q&A sessions

A total of 18 Q&A sessions were run by the NHS England Programme Team, where information about the consultation was shared and questions taken from the audience. These were not sessions for gathering consultation feedback, however questions asked gave an indication of the key issues for those who participated. Participants were also encouraged to give their feedback via the questionnaire or in other ways.

3.5 Accessibility and the consultation



It was important that the consultation was accessible to maximise responses from individuals across key stakeholder groups and geographical areas, including deprived areas and rural areas. A range of digital and in-person activities were carried out to ensure accessibility. The following measures were put in place with accessibility at the forefront:

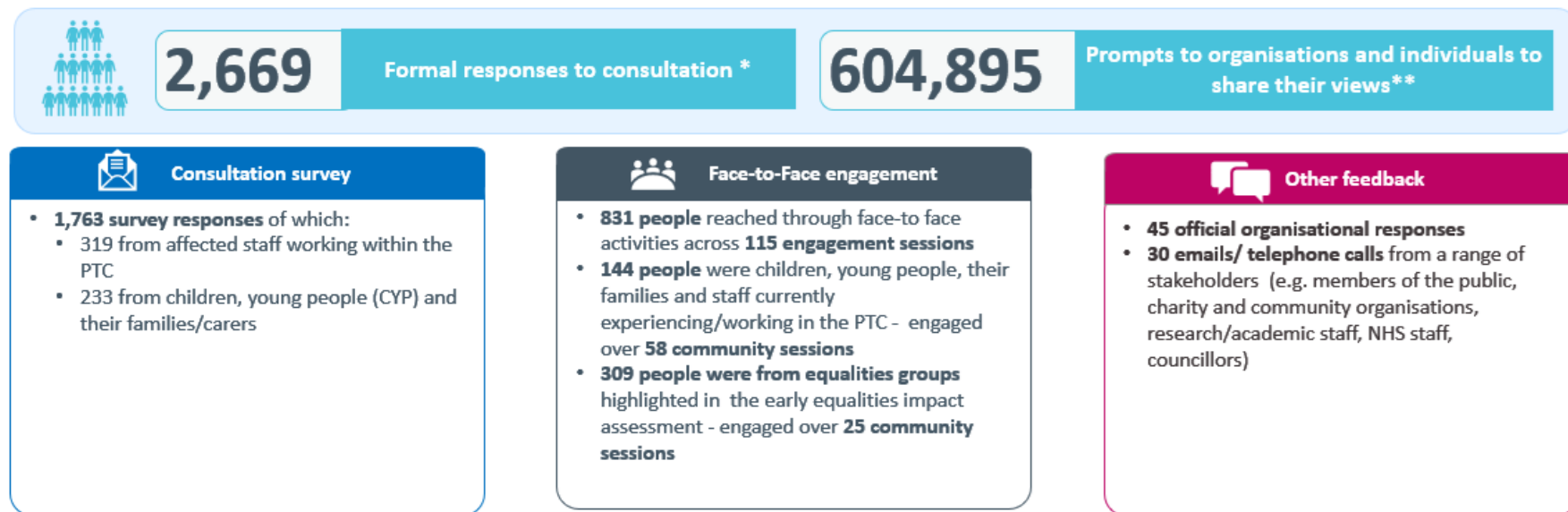
- Key documents were available as html pages on the consultation website
- A short animation providing an overview of the reasons for the consultation. The script was tested with children and young people and subtitled in the main languages spoken by people who do not speak English in the catchment area
- An online questionnaire which was also available to complete on paper – the questionnaire was formatted so that it could be printed on demand, to support those who are digitally excluded
- An easy read version of the questionnaire, developed in partnership with easy read experts, which was accessible online and on paper
- An easy read version of the consultation summary document
- Multiple language versions of the questionnaire, available on request
- Paper copies of the easy read questionnaire left where they could be picked up at key hospital locations
- Printed and posted paper versions of questionnaires to anyone who requested one
- Freepost address so respondents could return paper questionnaires at no cost
- Freephone number provided so people could call free of charge and receive a callback
- Parent focus groups organised at convenient times (e.g. evening) in consultation with parents themselves
- Staff focus groups organised at convenient times, around work commitments²¹
- Community focus groups carried out online and face-to-face to meet individual needs and preferences
- Play specialist sessions which took place at the Principal Treatment Centre and online
- Site visits to children's cancer shared care units to speak to children and families, to ensure that feedback was encouraged from across the catchment area.

²¹ The Royal Marsden supported their staff to attend sessions and complete the questionnaire by back-filling time on shift so they could complete/attend during work hours and offered incentives such as refreshment vouchers.



3.5.1 Overall rate and reach of the consultation

Below is a summary of overall response rate and reach:





Respondent profile

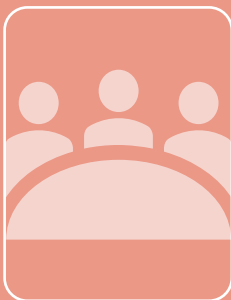
An overview of the profile of respondents who participated in the consultation.



4 Respondent profile

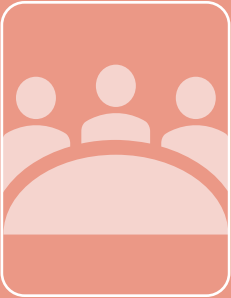
This section gives an overview of the demographic details of individuals who responded via all methods to the consultation, both the main and easy read versions of the questionnaire, and other means, such as meetings, interviews and focus groups. People had a choice about how much information they wanted to share with no demographic questions being mandatory in either the main or easy read questionnaire. Fewer details were captured by qualitative means, and via emails and telephone calls no demographic information was captured. The consultation has captured feedback from a diverse range of people across stakeholder types, ages, ethnicities, socio-economic groups and areas within NHS England's London and South East regions, with 2,669 responses via one of the questionnaires and qualitative events ²². It is also important to note that demographic quotas were not set for this consultation.

Key demographic strengths of the consultation



- **Ethnicity:** broadly reflective of the population across Intergrated Care Board regions with 70% being from white ethnicities and 23% from ethnic minority communities (excluding white minorities).
- **Patient cohort:** Children and young people in the consultation are broadly representative of the wider patient cohort in terms of Integrated Care Board region and socio-economic group/deprivation levels.
- **Staff:** The consultation heard from 81% of The Royal Marsden Staff and 52% of St George's staff currently working as part of/with the Principal Treatment Centre.

Key demographic gaps of the consultation



- **Age:** most respondents were aged 41-65 (51%), compared to 32% of members of the public across the catchment area. Younger ages were significantly underrepresented with around 10% of consultation responses from young people and children under 18 years of age compared to around 22% of the catchment population.
- **SEG:** Around 91% of total respondents were from socio-economic groups ABC1 compared to around 66% from across Integrated Care Board regions. As well as this, only 9% of respondents were from SEG C2DE compared to around 37% of the wider population across the catchment area.
- **Gender:** 67% of overall responses were from Females compared to only 52% of the population across Intergrated Care Board regions.

Children and young people who took part in the consultation are broadly representative of the wider patient cohort when compared to joint patient cohort figures from 2019/20, in factors such as Integrated Care Board region, socio-economic group and deprivation levels. Despite this, other

²² Main questionnaire, with a total of 1715 responses. Easy read questionnaire, with a total of 48 responses. Qualitative events, 831 people reached, 45 official organisational responses via email, and 30 emails/telephone calls from a range of stakeholders.



demographics were less reflective of the patient cohort. Females were overrepresented, with this group comprising around 70% of responses from affected children and young people, compared to around 55% of the current patient cohort. Furthermore, affected children in the consultation are also more likely to not have an unrelated physical/mental health condition or disability compared to the current patient cohort.

The consultation received a representative number of responses from staff who work as part of the current Principal Treatment Centre at The Royal Marsden with 81% engaging in the consultation across all engagement types (155 responses; 192 staff currently work full or part time at The Royal Marsden). From data provided by St George's Hospital, 416 staff currently work for or with the Principal Treatment Centre as part of their employment at St. George's Hospital, meaning the questionnaire heard from a representative figure of just over 52% of staff (216 responses; 416 staff currently work full or part time at St. George's).

Within this, the majority of respondents involved in the consultation were aged 41-65 (51%), while those under the age of 18 made less than 10% of total responses. From this, it is clear that the consultation has been unreflective of the wider population in this area, with around 32% of individuals across the catchment area aged between 41-65 while around 22% are under the age of 18. However, it is to be expected that those aged 41-65 will be over reflected in the consultation responses as they encompass parents and carers for children and young people as well as staff across affected sites.

Females made up around 67% of total respondents compared to only 52% of individuals across all Integrated Care Board regions. In terms of socio-economic groupings, respondents from SEG ABC1²³ are significantly over-represented across all engagement types, making up around 90% of total responses, compared to 66% of individuals across all Integrated Care Board regions. As such, this means that gender and socio-economic classification are the most unreflective demographic areas of the consultation compared to the region as a whole. Despite this, it is important to note that socio-economic groups would be unreflective due to a larger number of senior NHS clinical staff taking part in the consultation compared to the wider population.

²³ SEG refers to approximate social grade and includes six socio-economic categories produced by the ONS. The classification assigns every household to a grade, usually based upon the occupation and employment status of the Chief Income Earner. Commonly social grade classifications are grouped into two categories ABC1 and C2DE. Individual classifications are as follows These include A (Higher managerial, administrative, professional occupations) B (Intermediate managerial, administrative and professional) C1 (Supervisory, clerical & junior managerial, administrative, professional occupations), C2 (Skilled manual occupations) and D (Semi-skilled and unskilled manual workers) E (State pensioners, casual and lowest grade workers, unemployed with state benefits only)



Ethnicity was shown to be largely representative of the wider population across the catchment area (NHS England (London and South East region)). Grouping ethnicity by the total number of respondents of white ethnicities (net white), ethnic minorities which do not include white minority groups (net ethnic minority groups) and other reveals that the consultation as a whole has been reflective here, with 23% of respondents classified as net ethnic minority, compared to 70% net White and 7% Other.

4.1.1 Questionnaire responses

The information below gives an overview of the demographic details of respondents who shared their views via the main questionnaire. While 1715 respondents took part in the main questionnaire and 48 took part in the easy read questionnaire, it is important to note that base sizes differ for each demographic criteria as no questions within the questionnaire were mandatory.

In Appendix E, tables are available which provide a comprehensive breakdown of respondents by all stakeholder categories, as well as grouped stakeholder categories. In Appendix D, tables are available which provide comprehensive breakdowns of easy read respondent profiling.

To summarise the respondent profile, members of the public make up the largest proportion of responses along with those from members of staff who work for another part of the NHS. As well as this, the largest proportion of affected staff were from St George's Hospital, representing almost 12% of total questionnaire responses, compared to 9% from Evelina London²⁴ and 7% from staff at The Royal Marsden.

For grouped stakeholders, affected clinical and non-clinical staff made up the largest proportion of respondents (27.17%) closely followed by other clinical and non-clinical staff (20.19%) and members of the public (16.46%). Affected children and young people was the smallest stakeholder group in questionnaire responses, making up a little over 1% of responses, however the overall percentage of responses increases when considering targeted face to face engagement with this group.

Across demographics for gender, females (66.78%) made up the largest proportion of respondents. For sexuality, heterosexual/straight were the most common respondents at 84.29%. The majority of respondents reported to not have a disability (84.76%), as well as just over half of respondents were aged 41-65 years old, 53.17%.

Respondents from South West London were disproportionately high making up almost half of questionnaire responses (45.84%). This was followed by South East London (15.47%). Affected and non-affected clinical and non clinical staff, as well as members of the public were the largest

²⁴ Potentially affected staff at Evelina London



stakeholder categories within South West London. Almost a quarter of responses came from outside of London including Surrey (15.13%), Sussex (4.01%) and Kent and Medway (6.4%).

The majority of respondents (65.62%) identified as NET White and/or in socio-economic group ABC1 (77.25%).

4.1.2 Demographics from qualitative engagements

Overall, 831 people were engaged either face to face or online during the consultation, however not all demographic information was captured for every respondent who participated in these events. As such there will be differing base sizes provided in the tables below compared to the overall number of respondents. Given this, counts have been provided instead of percentages due to almost two thirds of people taking part in qualitative events having no demographic information attributed to them. As well as this, base sizes for each demographic category will vary due to demographic data captured not being comprehensive or consistent across all engagement types.

In Appendix F, tables are provided that detail a comprehensive demographic breakdown for respondents who took part in all qualitative engagements.

Overall, children and young people under the age of 15 were the largest age range captured with 148 being involved in qualitative events. This included 51 children and young people who have experience of cancer services and 97 who have no experience of cancer services. It was key that this group was directly targeted in these events due their low response rate in both the main and easy read questionnaire. Again, in an attempt to increase the voice of affected stakeholders in the consultation, 101 family members and advocates for children and young people who have been affected by cancer were reached in qualitative engagement work.

Leading on from this, other clinical and non-clinical staff were the largest stakeholder group captured in qualitative engagements, with 239 taking part in total. This was closely followed by organisations and public representatives, with 147 being reached.

As well as this, the qualitative engagement work did well to capture a wide variety of voices from equality groups, this included 111 individuals from ethnic minority groups and 192 from white ethnicities, 45 responses from those with a disability and 35 reached who receive additional income support. Here, the qualitative engagement work also captured a more representative gendered split of responses with 143 females and 103 males.

Yet, a similar issue was also encountered in qualitative engagement work as was seen in the demographic breakdown of questionnaire respondents, with those coming from lower socio-economic



groups being significantly underrepresented. Here, 56 respondents were from socio-economic groups ABC1 and only 9 from socio-economic groups C2DE.

4.1.3 Demographic profile for questionnaire responses by ICB area

The demographic breakdown of responses across each Integrated Care Board region closely reflects the demographic makeup of respondents on an overall level, with the majority of respondents across each area being female, aged 40-65, of a higher socio-economic grade and from a white ethnicity.

Reflecting the overall picture of respondents, the majority within each Integrated Care Board were female, with the highest proportion females within the Surrey Heartlands (73.08%) and Sussex (72.46%) ICB areas.

Looking at the breakdown of questionnaire respondents by each Integrated Care Board region by age, the majority of respondents across almost all regions were aged 41-65, with 55.35% from South West London, 56.15% from the Surrey Heartlands, 55.07% from Sussex and 59.09% from Kent and Medway. The only Integrated Care Board region in which 41-65 year olds did not make up the majority of respondents was in South East London (47.34%), which included a higher proportion of 26-40 year olds (36.47%).

The majority of respondents across each Integrated Care Board area were from socio-economic groups ABC1. South East London had the largest proportion of responses from ABC1 socio-economic groups (81.2%), an unreflective figure compared to the wider population of South East London (62%). While those from Sussex (68.12%) and Kent (69.09%) had the lowest proportion of respondents from this socio-economic category, they are still unreflective of the wider demographic makeup in each Integrated Care Board region, with 59% of members of the public being from socio-economic groups ABC1 and 58% from Kent and Medway respectively. Mirroring this, while the majority of respondents across all ICB regions were not on additional income support, Kent and Medway Integrated Care Board had the highest proportion of respondents receiving some form of additional income support (13.18%).

As outlined in the executive summary, affected clinical and non-clinical staff was the largest stakeholder category making up over 27% of main questionnaire responses. This was also the case for three Integrated Care Board regions, South West London (26.78%), South East London (30.83) and Surrey (29.62). In contrast, affected family members of children with cancer made up the highest proportion of respondents within Integrated Care Board areas Sussex (31.88) and Kent and Medway



(32.73%), while this stakeholder category only comprised a little over 11% of total questionnaire responses.

A comprehensive table of demographics across each ICB area has been provided in Appendix I.





Findings summary

A summary of key findings across key stakeholder groups.



5 Findings summary

This chapter presents a summary of the key findings from the consultation, across all qualitative and quantitative engagement methods, from different stakeholder groups and across the catchment area. They are key findings because they are what many people said when considering feedback from across the stakeholder groups. It is important to note that some findings may appear contradictory. What some respondents thought was a strength of a proposal, others thought was a challenge. Further detail on the reasons for these strengths and challenges are provided in the dedicated stakeholder chapters.

These key findings relate to:

- Most valued attributes of the future Principal Treatment Centre (Section 5.1.1)
- Feedback on the proposals from Evelina London and St George's Hospital (Sections 5.1.2-3)
- Feedback on the proposal to move conventional radiotherapy to University College Hospital (Section 5.1.4)
- Challenges affecting both proposals (Section 5.1.5)
- Other ideas (Section 5.2)
- Feedback on the case for change (Section 5.3)
- Feedback on other targeted questions (Section 5.4.1-2)
 - o Travel and access
 - o Support and information needs
- Petition (Section 5.5)
- Criticism of the consultation (Section 5.6.1-3)
- Suggestions to address challenges (Section 5.7)



5.1 Key findings from all stakeholder groups, across all catchment areas

This section focuses on feedback relating to the future Principal Treatment Centre. Where percentages are shown, this refers to the proportion of comments received in response to the question ‘What matters to you most about a Principal Treatment Centre?’ For ease of reading, written analysis has only been provided in the sections below; associated graphs can be found in Appendix G.

5.1.1 The future Principal Treatment Centre

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

In responses to the questionnaire, the most valued attributes of the future Principal Treatment Centre were:

- The provision of 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 health and kidney care (20% of questionnaire comments to the relevant question)
- Specialist knowledge of and experience in children’s cancer care (20% of questionnaire comments to the relevant question)
- A convenient location (18% of comments), particularly in terms of access by car (16% of questionnaire comments to the relevant question)
- Strong research facilities and track record (16% of questionnaire comments to the relevant question)²⁵.

For respondents answering the easy read questionnaire, the most important issue about a future Principal Treatment Centre was the ability to travel to the site easily (41%) whether this be the site having good public transport links nearby or having good parking availability on site for patients, families and staff. Related to this, some left more general comments about accessibility (18%). Another key theme included the new site having a good level of knowledge and experience in treating children with cancer (20%).

²⁵ Data here given for the main questionnaire, after 23 October 2023 when the change was made to the question scales. Data for before 23 October 2023 can be found in Appendix G.



Feedback from qualitative engagement activities validated these attributes as important ones.

Other key suggestions 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 communication between Principal Treatment Centre, children's cancer shared care units, community nursing teams, and GPs
- Good communication of key information when a child first becomes a patient of the Principal Treatment Centre; easily digestible information and guidance
- Good communication with the Principal Treatment Centre; so they answer your call first time you ring.



5.1.2 Feedback on options: Principal Treatment Centre at Evelina London

This section, and the sections that follow detailing the feedback received on the proposals, presents a summary of key findings across all stakeholder groups, from all regions of the catchment area. Importantly, these are findings from all forms of feedback when considered together, including the questionnaire and qualitative engagement activities. This gives us a robust understanding of what people think about the proposals, which has been validated across different engagements, with different groups.

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 there 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.

5.1.3 Feedback on options: Principal Treatment Centre at St George's Hospital

As a reminder, this section, and the sections that follow detailing the feedback received on the proposals, presents a summary of key findings across all stakeholder groups, from all regions of the catchment area. It is important to note that these are findings from all forms of feedback when considered together, including the questionnaire and qualitative engagement activities.

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 Hospital 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 at St George's Hospital 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.

5.1.4 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. 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, 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. Others 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.

5.1.5 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 (such as specialist integrated haematology malignancy diagnostic service (SIHMDS)) 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 the NHS
 - 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 Hospital 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 to the potential for staffing losses, such as early retirement
 - Potential negative impact on The Royal Marsden's teenage and young adults (TYA) service.

5.2 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. These views were captured in formal responses and questionnaire responses made by parents and carers. They included:

- A risk-adapted model that retains the Principal Treatment Centre at The Royal Marsden and St George's Hospital. 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 Hospital 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
- 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

At the end of the main and easy read questionnaire, respondents were asked if there were any other ideas or thoughts that they wanted to share. This was a broad question with many different types of comments left. When questionnaire respondents were asked to provide other ideas at the end of the questionnaire, the most common theme was respondents stating that St George's Hospital should be



selected as the future Principal Treatment Centre (16%). 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%). Here, comments typically centred on the level of experience St George's Hospital has in paediatric cancer care, and the perception that this would be the most cost-effective and/or the least disruptive option.

- *'I strongly feel that St. George's is the best option for the care and treatment of children with cancer. They provide an excellent service with a wealth of expertise and knowledge, spanning across a variety of specialties' (Questionnaire response from respondent from South West London ICB region, Member of NHS staff - who currently works for Evelina London)*
- *'Cancer care is significantly expensive, the NHS needs to deliver the best for patients using funding in the most effective way. Further enhancing the existing centre at St George's Hospital makes the most sense. The service at St George's Hospital delivers' (Questionnaire response from NHS South West London ICB, Member of NHS staff - who currently works for the Principal Treatment Centre at St. George's Hospital)*
- *'Taking this service away from St George's Hospital would be the worst thing going. It will have a knock on impact on families and their support networks. It's a good centralised location with a fantastic team of staff. I can't praise St George's Hospital enough. And losing this service from St George's Hospital would be awful' (Questionnaire response from NHS South West London ICB, Parent, carer or advocate for a child or young person - who has never had cancer).*

This was closely followed by the theme of respondents stating that services should remain at The Royal Marsden (15%). While this would not deliver the service specification and therefore is not an option that can be considered, since this was an open question, responses to it are accurately reflected here. 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 RMH is a very special hospital. It provided personalised care to my daughter going through AML treatment including a bone marrow transplant. We spent 10 weeks in hospital during her BMT and this was only bearable because of the pleasant surroundings provided by the RMH. The play team were brilliant and the facilities for carers were great' (Questionnaire response from NHS South West London ICB, Family member or advocate for child or young person affected by cancer)*
- *'It still seems like it will be a fragmented service wherever it is located - a lot of disruption and change for not much gain, not to mention the financial implications when there is an*



amazing purpose build unit which is relatively new at RMH' (Questionnaire response from NHS Surrey Heartland, Affected clinical or non-clinical staff)

5.3 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, with conventional radiotherapy moving to University College Hospital), many respondents took the opportunity to voice their thoughts about the case for change. The consultation heard from some respondents who thought that the change should not happen – with some calling on NHS England to rethink the move and consider alternative proposals. It is also noted here that the #HeartheMarsdenKidsCampaign, a petition calling on the NHS to reconsider the move, reflects wider opposition to the consultation²⁶. However, there is also evidence of strong clinical support for the case for change, largely found in responses from clinical NHS staff and in the formal responses submitted by organisations. Many organisations gave their support for the case for change, 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.²⁷ 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. In the section that follows, feedback on the case for change is provided according to stakeholder group.

Case for change: children and young people who have been affected by cancer

Some children and young people across all feedback types expressed their support for the case for change. One young person had been transferred nine times from The Royal Marsden to St George's Hospital children's intensive care unit and was in favour of the case for change (Site visit to The Royal Marsden, December 2023). Another young person recognised how beneficial it would be to have everything you needed (children's cancer ward, day care, inpatients. MRI, children's intensive care unit, radiotherapy) co-located in one building (Child or young person, site visit to The Royal Marsden, December 2023). Although it is noted that with the proposed move, radiotherapy would be located on a different site (at University College Hospital).

²⁶ It is important to note that the petition was not analysed as part of the consultation feedback. It was analysed separately and there is a dedicated section to the petition and comments left by signatories later in this chapter.

²⁷ Full details can be found in the formal responses section.



Across all feedback types, a few children and young people expressed their wishes that the change did not happen at all and that the Principal Treatment Centre remained at The Royal Marsden. Those who expressed this wish, expressed it strongly. One young person, during the play specialist session, stated that they did not want the Principal Treatment Centre to move from The Royal Marsden. However, if the Principal Treatment Centre had to be moved, the young person said:

- *'If [a Principal Treatment Centre] could be built next to The Royal Marsden, that would be a dream of mine' (Young person, 13 years old, play specialist session at St George's Hospital, November 2023)*

Case for change: family members and advocates of children and young people who have been affected by cancer

Through qualitative feedback, some parents expressed their support for the case of change, because they thought they would feel safer if their child was being treated at a Principal Treatment Centre with a level 3 children's intensive care unit on site. One parent reflected on their personal experience; they felt safer when their child was being treated at King's College Hospital than they did at The Royal Marsden, because the services provided at King's (who provide level 2 and 3 paediatric care) could avoid the need for a children's intensive care unit transfer²⁸. Another parent said having their child transferred from The Royal Marsden to St George's Hospital was a scary experience. Another parent talked about their child being transferred from The Royal Marsden to St George's Hospital for an operation. They were concerned that the new clinical team would not have time to read their child's notes properly; there was a disconnect between teams which meant there was a lack of continuity when difficult conversations were had or decisions were made. This parent commented:

- *'Having to move to a different hospital was necessary because the operation needed to happen but it posed such a risk to her health, which was unnecessary' (Parent interview, child was treated at Royal Marsden and St George's Hospital, December 2023)*

Another parent said they wished that intensive care and chemotherapy services were co-located. Their son was transferred by ambulance nine times as he contracted an infection each time he started a cycle of chemotherapy. This was a difficult time for the family. The parent also noted the staffing requirement for ambulance transfer (one or two nurses go with you), and the associated cost of this, could be avoided if the services were co-located (Parent, site visit to The Royal Marsden, December

²⁸ NHS England (London and South East regions) used 2019/20 data for an in-depth look at the service (a check in 2021/22 showed numbers were still very similar). Between 1 April 2019 and 31 March 2020, 35 children were taken by ambulance from The Royal Marsden to St George's Hospital because they needed or might need intensive care, some of them more than once. Of these, 15 children were treated in the intensive care unit.



2023). Another parent (who is also a nurse) expressed a strong view that, for patient safety and patient experience, it is important that the service change happens. This parent had personal experience of this as their child was transferred from The Royal Marsden to St George's Hospital; they reflected on the feeling of disconnect between clinical teams at the two hospitals (Parent interview, December 2023).

Across feedback methods, many family members and advocates expressed their objections to the case of change. Some parents said they felt disappointed that the consultation was going ahead – and felt strongly that the very specialist cancer services for children should not be moving from The Royal Marsden. For some respondents, the premise of the case for change was flawed, despite the national service specification requirement for the co-location of the Principal Treatment Centre and a children's intensive care unit. For example, some parents said that the number of patients affected by children's intensive care unit transfers from The Royal Marsden is low²⁹. A number of parents reflected on their experience of their child's transfer to the children's intensive care unit at St George's Hospital, which they said was well managed. These respondents do not think the proposals for change (Evelina London or St George's Hospital) will provide an adequate solution. They do not think the transfer of children from The Royal Marsden to St George's Hospital for intensive care is a problem that needs to be fixed.

- *'Rarely does it become a need for a blue light service, and as is, as I think X mentioned, it's been 3...'* (Parent/carer Engagement session, November 2023)
- *'The prediction of increased need for intensive care is disputed as treatments improve all the time'* (Parent/carer Engagement session November 2023)

Some family members and advocates talked about the displacement of disruption from one issue to another; specifically, that more patients and their families will have to travel to receive conventional radiotherapy at University College Hospital, and patients will likely move for neurosurgery (even if St George's Hospital proposal is chosen, because it only provides treatment for some patients).

For other family members and advocates, they recognised the experience and expertise of The Royal Marsden. They trust The Royal Marsden. They acknowledge its history and track record of excellence in care and research. Some respondents have said that there is no guarantee that the relocation of the Principal Treatment Centre will result in positive change.

²⁹ NHS England (London and South East regions) used 2019/20 data for an in-depth look at the service (a check in 2021/22 showed numbers were still very similar). Between 1 April 2019 and 31 March 2020, 35 children were taken by ambulance from The Royal Marsden to St George's Hospital because they needed or might need intensive care, some of them more than once. Of these, 15 children were treated in the intensive care unit.



- *'I can't see any reason why they need to move because it is a purpose-built cancer hospital for the children and they have also got the Institute of Cancer Research right next door' (Parent/carer Engagement session, November 2023)*
- *'Huge risk that services will be negatively impacted if this goes ahead' (Parent, public listening event, November 2023)*
- *'Relocating services could disrupt established support networks and connections families may have built with local hospitals and healthcare providers' (Parent/carer Engagement session, December 2023)*

For some respondents, it was clear that they had concerns about what would be lost if the Principal Treatment Centre was moved from The Royal Marsden. This ranged from losing the care and additional services provided by Maggie's Centre³⁰ in a separate, dedicated space (such as counselling for patients, recreational spaces for parents), to the personalised care delivered by such a tight-knit and experienced team at The Royal Marsden.

³⁰ Maggie's Centre at The Royal Marsden provides dedicated spaces and services for cancer patients and their friends and families.



Case for change: children, young people, and their families and advocates, with no direct cancer experience

Some comments from children, young people and families with no cancer connection referred to keeping the Principal Treatment Centre at The Royal Marsden. This was mostly in reference to the positive perception they have of The Royal Marsden, rather than criticism of the rationale underpinning the change as included in the national service specification.

- *'They should just build a children's ICU at The Royal Marsden instead of a whole new centre at St Georges or Guy's and St Thomas' NHS Foundation Trust as there is a children's cancer centre at The Royal Marsden' (Child, young person, or family member with no direct experience of cancer, questionnaire response)*
- *'Leave the excellent Treatment Centre at The Royal Marsden in Belmont and build a new PICU at the new Sutton Hospital' (Child, young person, or family member with no direct experience of cancer, questionnaire response)*
- *'[The NHS should] discourage this change and block the move' (Child, young person, or family member with no direct experience of cancer, questionnaire response)*
- *'Just leave things as they are and you won't need to deal with any challenges' (Child, young person, or family member with no direct experience of cancer, questionnaire response)*

Case for change: affected clinical and non-clinical NHS staff

In giving feedback, some clinicians made a point of stating their support for the case for change, recognising that it is necessary and in the best interests of patients to move the Principal Treatment Centre (clinical safety as well as patient experience) so that it is co-located with a children's intensive care unit. Other staff said that this would be beneficial for staff skills, training, and retention.

- *'As a clinician in the acute service, my team regularly encounters situations where deteriorating patients need to move rapidly from The Royal Marsden but it takes time to access a bed in, or close to, a PICU, or there is a wait for the South Thames retrieval service, meaning that patients often wait some hours or even overnight from the decision to transfer to the actual move. Delay in the ability to move a patient is among the most stressful situations of all for the responsible consultant and the clinical team, as well as for parents/patients who have been informed of the decision to transfer but then have to wait. Through the excellent teamwork of staff at The Royal Marsden significant patient harm around the time of transfer has been avoided to date, but the situation is nevertheless very unsatisfactory and undeniably high risk. It is for these reasons ... that I strongly endorse the*



recommendation for colocation of children's cancer services with PICU' (Paediatric oncologist currently working at The Royal Marsden)

- *'The current system is not great. Centralising children's cancer services with intensive care is a good idea. I think everyone agrees with that. I think for children's safety, everyone would like to see everything co-located. There could be real gains for the care of children who are becoming very unwell. If they were round the corner, the surgical team or I would be able to assess them. You can't really get the feel for how a child is over the phone. If you have seen them, you can say, 'let's keep the child on the ward for now'. You can't do that if you can't see them' (Children's intensive care unit consultant at St George's Hospital)*
- *'To have an ITU on site would be very much a positive. No one talks about the move in a positive way, but it would be much nicer to wheel the patient down the ward to ITU than to transfer them to another hospital. It could be amazing, it could be a very positive move' (Meeting with members of staff at The Royal Marsden, December 2023)*

No direct objections to the case for change were recorded by affected and non-clinical NHS staff (for example, in relation to the statement that a level 3 intensive care unit should be co-located with the Principal Treatment Centre). However, some staff expressed concerns about the proposals, including concerns about moving the Principal Treatment Centre from The Royal Marsden given its experience and expertise, and concerns about the fragmentation of the service given that conventional radiotherapy would be moved to University College Hospital³¹.

Case for change: members of the public

In both questionnaire responses and emails received directly from members of the public, they criticised proposals to move the Principal Treatment Centre. Objections to the case for change included:

- Very sick children travelling by public transport into central London when families are specifically told to isolate that child to minimise the risk of infection³²

³¹ More detail can be found in the affected clinical and non-clinical NHS staff chapter.

³² NHS England's public consultation document notes that The Royal Marsden, in collaboration with Great Ormond Street Hospital and University College Hospital (which also provide specialist cancer services) has guidance which advises children and families that it is safe to travel on public transport for children with cancer, even with a weakened immune system. The guidance says that for some patients it might not always be appropriate to be in crowded areas, depending on the treatment they are receiving. It says that clinicians should assess patients on a case-by-case basis. For instance, staff at Great Ormond Street give specific advice to bone marrow transplant patients and advise, if possible not to travel at peak times.



- No guarantee that staff from The Royal Marsden will move to the new Principal Treatment Centre
 - o No guarantee that adequate staff numbers will be recruited to a new Principal Treatment Centre in a central London location given the wider NHS recruitment crisis
 - o Loss of the reputation and excellent care of The Royal Marsden
- Doubt that other options have been thoroughly considered by NHS England (London and South East regions).

Comments included:

- *‘Given the serious effect it would have on the people within the catchment area there doesn’t seem to have been any serious consideration given to retaining/upgrading the excellent facility, which is already there, actually on the same site as the Institute of Cancer Research’ (Email correspondence, October 2023)*
- *‘I mean using some of the £45m suggested spend to extend facilities at The Royal Marsden, or even at Queen Mary’s Hospital for Children at St Helier’s Hospital. It just appears to me that very little challenge has been made to the original report and that NHS England has been too quick to agree with the report to centralise within London, ignoring the many public transport issues involved in attending either of the two options being put forward’ (Email correspondence, October 2023)*

5.4 Feedback on other targeted questions

This section focuses on feedback on key questions relating to travel and accessibility of the future Principal Treatment Centre from the questionnaire results as well as support and information that would be beneficial during the transition phase. The data discussed below focuses on feedback received³³ from the main and easy read questionnaire³³. For these questions respondents were asked to score each statement on a 1-5 scale of importance rather than ranking all options together in overall importance. As such, all statements could be found very important or not at all important if that reflected their views meaning that ranking genuinely reflects respondents’ views, rather than a choice which was forced upon them. For ease of reading, written analysis only has been provided in the sections below; graphs can be found in Appendix H.

5.4.1 Travel and access

³³ Feedback shown here is after 23 October 2023 when the change was made to the question scales. Data for before 23 October 2023 can be found in Appendix H.



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

In responses to the questionnaire, 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. In fact, most respondents consider having 'Public transport availability in close proximity to the hospital site' to be the most important factor of travel with a mean score of 4.5 out of 5. As well as this, 'parking availability on the hospital site' and 'family accommodation nearby' were also of equal importance from respondents. While still important, the ability to get help with 'public transport costs' were of less importance to respondents compared to other travel concerns, with this receiving the lowest overall mean score of 4.08 out of 5. Within this, 'public transport availability in close proximity to the hospital site' received the highest mean scores from members of the public (4.72), organisations and public representatives (4.68) as well as other clinical and non-clinical staff (4.65). Its lowest mean score was from affected family members and advocates for children (3.94)³⁴.

Responses from those answering the easy read questionnaire closely reflect the main questionnaire with 'having somewhere to stay nearby for my family' as the most important factor for travel with a mean score of 4.76 out of 5, while other key factors included 'parking on the hospital site' (4.74), and support with 'parking and travel charges' (4.7). Aligning with responses from the main questionnaire, while still of importance, respondents found the 'cost of travel by public transport' as the least important factor for travel, with a mean score of 4.15 out of 5.

When asked to share more about their thoughts on travel, the top theme of comments left by respondents was 'risk management' (19%), particularly regarding the possible risks or dangers of exposing children to diseases and infections through the use of public transport.

- *'I think stating using public transport when a child is going through chemotherapy is a big NO. Their immunity levels are very low & most children are extremely sick. My son who had six days' chemotherapy, stopped eating after the 1st phase as he was so ill. Travelling in our own car was the only way he felt comfortable and minimised any risk of infections/viruses' (Parent or carer of a child with cancer, questionnaire response)*

³⁴ Sentiment of respondents captured before the 23 October closely reflects data captured after changes to the questionnaire were made, with 67% of respondents describing 'accommodation nearby' as being a very important factor in travel. Again, 'public transport cost' was seen as the least important factor with 45% of respondents before the 23 October 2023 describing this as very important.



Others talked about the need for parking on site (17%), travel time (15%), and the convenient location of services (8%). All themes presented in this section were considered important in qualitative engagements; this is discussed in more detail in the dedicated stakeholder group chapters that follow.

5.4.2 Support and information to make the move easier for staff and families

Understanding which staff would be involved in ongoing care at the future Principal Treatment Centre, being told when and how the move will happen, and the provision of additional support for those who need it were considered very important for stakeholders when thinking about the move.

Respondents were then asked on a scale of 1 to 5, where 1 is not at all important and 5 is very important, how important the following types of support and information would be to make the move easier. Most respondents³⁵ felt that understanding which staff would be involved in ongoing care would be the most important factor in making the move easier, with a mean score of 4.78 out of 5. Other factors included families and patients feeling reassured about when and how the move will happen (4.73), and the availability of additional support and information for those who need it (4.67). While still of overall importance, the least important factor to make the move easier for respondents was being involved in how the new location looks and feels, with this receiving the lowest mean score of 4.31 out of 5.³⁶

Respondents were then asked if there were any other types of support or information which would make the change easier. Thematic analysis was undertaken on responses to establish key themes. The top theme for comments left in response to this question related to the provision of accurate information on the proposals for change (12%), while others wanted to ensure that feedback from staff and patients is listened to (8%), as well as also providing reassurance that the provision and quality of care won't be affected by the change (8%).

- *'Knowing exactly where the new location is and being assured that the facilities will be as good as they are currently at RMH' (Parent, carer, or advocate of a child with cancer, questionnaire response)*

³⁵ Data after the 23 October 2023.

³⁶ In line with data captured after the 23 October 2023, respondents before the questionnaire change considered 'understanding which staff will still be involved in on-going care' to be the most important factor in making the move easier, with 76% stating it is very important. As well as this, 'being involved in how the location looks and feels' was also seen as the least important factor here from respondents before the 23 October with 53% finding it very important.



- *‘Supporting/reassuring staff who are on permanent or short-term contract that their job is secure’ (Member of NHS staff - who currently works for the Principal Treatment Centre at The Royal Marsden Hospital, questionnaire response)*
- *‘Full access to information given in a timely, accessible way’ (Other member of NHS staff, questionnaire response)*

While not answering the question directly regarding the types of support or information they might need, another key theme included respondents not wanting the current service to move from The Royal Marsden (12%).

- *‘It’s simple: please don’t close the Marsden. They are exceptional, and its closure will be a shame and will just shatter the confidence of the oncology families in the NHS and the care they receive’*

Easy read responses closely matched the main questionnaire,³⁷ with respondents regarding getting support and information about the changes if they need it (4.85) and being made to feel safe and ok about when the change will happen (4.8) as being important factors in making the move easier. As well as this, both respondents answering the easy read and main questionnaire considered being part of how the new site looks and feels to be one of the least important factors in making the move easier with a mean score of 4.3 out of 5.

5.5 Hear the Marsden Kids campaign and petition

Running alongside the public consultation was a petition against the proposed changes led by a parents group called ‘#HeartheMarsdenKidsCampaign’. Launching on the 10 October 2023, this petition to date has received 10,394 signatures³⁸ as well as 304 written responses, describing their reasons for signing.³⁹ Petitions and locally organised questionnaires are an important source of consultation feedback, indicating public views and concerns about important aspects of the proposals.

The #HeartheMarsdenKids petition and associated media campaigning is led by parents with personal experience of their children being treated at The Royal Marsden for cancer. Some are also part of the Stakeholder Group for NHS England’s (London and south east) reconfiguration programme.

³⁷ Data after 23 October 2023.

³⁸ The number of signatures was recorded immediately after the consultation closed on 19 December 2023.

³⁹ #HearTheMarsdenKids Campaign - [Petition · #HearTheMarsdenKids campaign · Change.org](#)



The parents who set up the petition do not agree with the need for the move of very specialist cancer treatment services from The Royal Marsden. Instead, they proposed a solution which would maintain services on two sites, with children at highest risk of needing intensive care as part of their treatment identified at diagnosis so they could receive all their care at St George's Hospital.

Within these written responses, the predominant theme raised by signatories centres around the high standard of care and level of expertise available at The Royal Marsden (113 comments of this nature). Here, signatories discuss how The Royal Marsden is a centre for excellence in children's cancer care and do not believe that either of the proposed new options (Evelina London or St George's Hospital) will meet or exceed the level of care currently available, therefore depriving children and young people of the 'best cancer care available in the country'. Other comments within this theme address the immediate access to clinical trials which are available at The Royal Marsden, with some expressing their concern how this could be lost if moving to another site. As well as this, some are also concerned that expert staff could be lost, since there is a perception that not all staff at The Royal Marsden will transfer to the new site of the Principal Treatment Centre.

- *'It is a fact that The Royal Marsden, as the leading hospital of its kind in the country and with The Institute of Cancer Research on the same site puts the hospital in the unique position of giving children immediate access to clinical trials that may not be afforded to them if the hospital were too close. As such, the hospital should be given unique status and allowed to continue the fantastic work it does for all cancer patients but especially children'*
- *'Why deprive children of the best cancer care in the UK? The expertise they have access to will be diminished if this goes ahead'*
- *'This centre of excellence is providing top class successful treatment. Don't undo something that already works. This would be at great cost to the patients. Undoubtedly the world class team would not all transfer to a new location and this centre of excellence saving young lives would be lost. The local infrastructure supports the patients and their families'*

Another key theme within the comments left on the petition surrounded travelling to either of the new proposed locations (56 comments of this nature). Here, signatories expressed the added stress that patients and families would have to go through by travelling even further to receive care. As well as this, others mentioned the added difficulties and costs of having to drive into central London such as possible congestion charges, as well as the dangers of exposing a sick child to infections/diseases if using public transport instead.

- *'We won't be directly affected as my son has finished treatment now. But having to go to St George's Hospital would have made life so much harder especially in those early days and weeks when we were just in shock and struggling to meet all the demands. Over time we got*



Disability Living Allowance for children and a blue badge so we could now drive in and park for free, but you don't get these things straight away, even if you had the headspace for the admin you're not entitled immediately'

- *'We are in the South East and it was still a gruelling two hour journey with a neutropenic child. The thought of having to do that journey even further fills me with horror'*
- *'The added stress and risks of trying to get a neutropenic child to central London without anywhere to park, regardless of the additional costs of this which are significant and cannot be ignored. There is a lot to consider, but I feel the logistics or regular costs are a major consideration'*
- *'Last winter we drove there at 7 every morning in icy, dark conditions for six weeks, for his radiotherapy. The car would be warmed up, then he was carried, asleep / grumpy, and starved ahead of his daily general anaesthetic, to and from the car. The notion of using public transport for a sick, and in our case, paraplegic four-year-old at sub-zero temperatures is dangerous and unthinkable. Adding in the medicine, feeding pumps and equipment we needed to have with us, it becomes absurd'*



5.6 Criticism of the consultation

Some respondents across the stakeholder groups expressed criticism of the consultation, mostly in terms of how it has been organised and how feedback has been considered during the pre-consultation stage. In this section, feedback from respondents is summarised, but it is noted feedback from this group of respondents makes up a small proportion of the total responses received.

5.6.1 Feedback from family members and advocates of children and young people who have been affected by cancer

Some parents and carers took the opportunity to voice their concerns about the consultation and how it has been conducted.

A few family members and advocates were critical of NHS England's decision to reveal their preferred location. Comments related to the perceptions that this decision could have biased the consultation by shaping how people reviewed the proposals, as well as making them think that their voice would not count as the final decision had already been made.

- *'And I also feel when we're talking about Evelina, NHS England has already stated a preference for Evelina and I don't think that that's fair' (Parent/carer Engagement session, November 2023)*

Of those comments relating to the consultation itself, some family members and advocates said they felt that their feedback had not been listened to and accounted for during pre-consultation. This largely related to the consultation for change going ahead at all, as well as perceptions that alternative options are not being properly considered (particularly alternative options that involved retaining The Royal Marsden as part of the Principal Treatment Centre).

'They should possibly look at having the funds to build the ICU facilities within Marsden and just leave it as it is' (Parent/carer Engagement session, November 2023)

'Let's look at having maybe a smaller ICU facility, but within the Marsden so that that could solve the issue' (Parent/carer Engagement session November 2023)

'It has been brought to my attention that perhaps we should be asking for a judicial review needed to reconsider maybe an option 3, which is to partner with the new St. Heliers Hospital' (Parent/carer Engagement session November 2023)

A few family members and advocates who were participants of the Stakeholder Group, which was involved in the pre-consultation evaluation, took the opportunity to express their frustrations that their



feedback was only considered to be valid for parts of the evaluation, and not all. For example, comments related to the travel time analysis and assumptions underpinning it.

- *'As part of the parent stakeholder group supposedly responsible for scoring transport, yet this was then taken away from us - huge issues with how this was worked out and still continues to be a huge issue. Hundreds of parents have come forward, now we are at public consultation phase to share their concerns and worries about this' (Parent, public listening event, November 2023)*
- *'If you look at Google Maps or something, it will always say that St. Georges is 1/2 an hour drive for us and we've never managed to actually get there, park and everything in less than an hour. So, I feel like there's an inaccuracy there as well in the travel times' (Parent/carer Engagement session, November 2023)*

The perception that the financial costs of the proposals were not provided in sufficient detail was voiced by some parents.

- *'We know the NHS is on their knees and they believe, well, we believe this is going to cost at least 40 million to transfer or to get one of these sites up and running. However, especially Evelina are keeping their cards very close to their chests and won't disclose the actual amount and they're keeping this very hidden to what that might be' (Parent/carer Engagement session, November 2023)*
- *'Under the heading of finance, the detail and the absence of planning permission is a worry and therefore the delay in delivery would be anxious making' (Parent/carer Engagement session, November 2023)*
- *'Where is the money going to come from to fund these additional hotels that are going to care for the children staying at St George's Hospital and Evelina? There's no mention of that in the proposal' (Parent/carer Engagement session November 2023)*

5.6.2 Feedback from affected clinical and non-clinical staff

Echoing comments from parents and carers outlined above, a few members of staff objected to Evelina London being named as the preferred location for the Principal Treatment Centre, questioning the scoring and evaluation process of the pre-consultation stage. It is noted that these members of staff were from St George's Hospital.

- *'We're unhappy about Evelina chosen as the preferred option – St George's Hospital is an outstanding hospital and has the experience working in paediatric oncology. - It's difficult for*



us to understand why the decision has been made. There's a complex scoring mechanism. We believe it was put together in a way that would always disadvantage George's. The weighting of the whole thing was odd: we made all these points at the time. They were put to one side. We are not anti-Evelina, we are pro-George's' (Member of staff at St George's Hospital, December 2023)

- *'To me, the evaluation process seems bias towards Evelina. Presenting two options for consultation, but then saying that Evelina is the 'preferred' option is clearly biased. Why not just leave it open and let people give their views?' (Member of NHS staff - who currently works for the Principal Treatment Centre at St George's Hospital)*

However, a few members of staff called into question the way that St George's Hospital had communicated with families and the wider community about the consultation, including suggesting that specialist cancer care would be lost for families affected by the move..

- *'The campaign being led by St George's Hospital has been unhealthy and prompted anxiety – the way organisations have conducted themselves during the consultation should be considered when making the final decision' (Evelina London staff event, November 2023)*
- *'It has been very interesting to watch how the public consultation is unfolding, with very strong feelings expressed by many parties... Claims from St George's Hospital to have been running paediatric oncology services for 25 years, and some of the behaviour of their clinical staff speaking in public fora, is also proving challenging for Royal Marsden clinical staff to swallow. Those who apparently feel they know what is best for the service speak loudly without reference to those who actually provide the service' (Member of staff, The Royal Marsden, email correspondence, December 2023)*
- *'There are also misleading statements in the campaign such as 'St George's Hospital research centre has been studying cancer in children for many years' - but your documents show that there are 0 staff in SGH working on children's cancer research' (Member of staff at Evelina London, questionnaire response)*

There were a few comments related to perceptions that information presented in the consultation materials were incorrect or misleading.

- *'It is incorrect to say that most cancer surgery is provided at St George's Hospital when in fact it is not. Most cancer surgery is neurosurgical and the majority is performed at King's and has been for many years. Unfortunately this video and some of the texts provided are at risk of misleading those filling in the questionnaire and therefore skewing the decision in a manner that is not a reflection of the reality on the ground and the needs of the patients and*



families' (Member of NHS staff - who works for a Paediatric Oncology Shared Care Unit in London or the south east, questionnaire)

5.6.3 Feedback from organisations and public representatives

A few organisational representatives expressed concern about the consultation process itself. For example, at a meeting with Healthwatch South West London, reference was made to the perception that NHS England (London and South East) had already made a choice by announcing that Evelina London was the preferred option. They said people wanted to feel their voice is being heard and being valued. They wanted assurances that the consultation process could affect the final outcome. The Scrutiny Committee also heard that family members did not understand why feedback based on their lived experience was not taken into consideration for part of the pre-consultation process on travel.

A letter received from Healthwatch Richmond and Healthwatch Merton states that their view is the consultation is insufficient, based on:

- Insufficient information provided for people to give 'intelligent consideration' to the consultation
- Proposals are not at a formative stage, therefore the extent to which feedback can meaningfully influence the decision is questioned
- Conscientious consideration cannot be given to consultation responses because information that would allow this is not being collected, such as enabling respondents to express a preference or asking respondents to describe the relative strengths and weaknesses of the two options.

5.7 Suggestions to address challenges

Suggestions to address challenges were also identified through the consultation. These are reflected within individual stakeholder chapters and summarised later on in the Report in Section 20.





Stakeholder findings

A presentation of findings by each stakeholder group.



6 Children and young people who have been affected by cancer

This chapter draws together feedback from children and young people who are currently being treated for cancer or have previously had cancer. This stakeholder group includes:

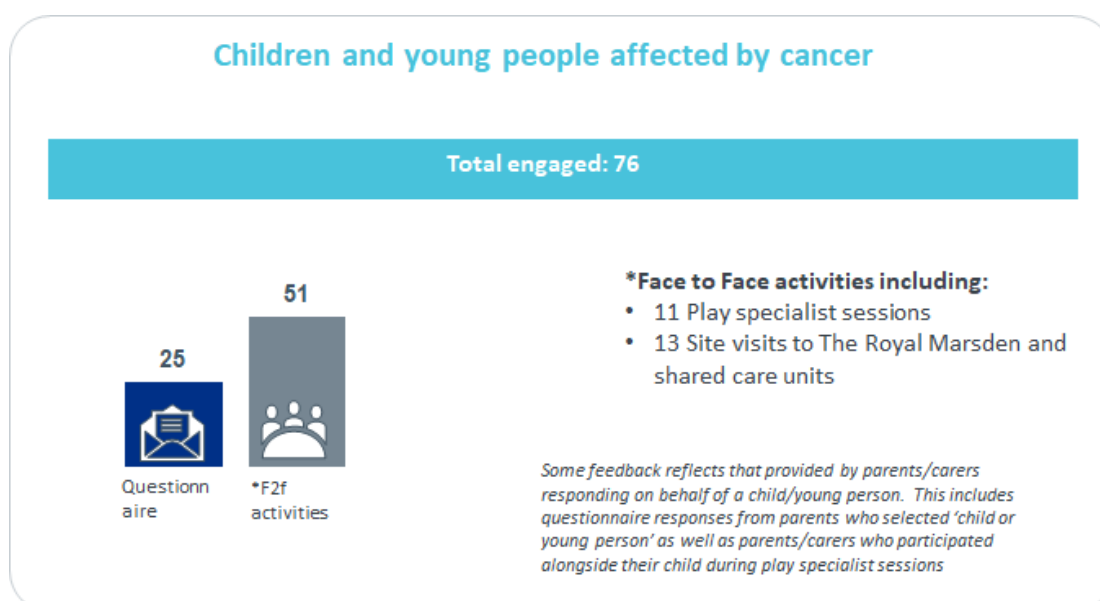
- Children and young people (aged one to 18, inclusive)
- Young adults (from 19 to 25) who have recent experience of being treated for cancer as a child or young person
- Parents or carers responding on behalf of a child or young person who has been affected by cancer. This includes questionnaire responses 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.

This chapter details what this stakeholder group thinks about the proposals from Evelina London and St George's Hospital, the proposal to move conventional radiotherapy to University College Hospital, and what would be valued the most in a future Principal Treatment Centre. This chapter includes analysis of data from both the questionnaire and qualitative engagement; they have been analysed together to provide a comprehensive understanding of what children and young people think. Where percentages are given, this refers to the proportion of comments made by individuals who answered the questionnaire only. The number of comments made refers to the specific question being addressed in that section only. Some direct quotes are given; where this is the case, it is said which engagement method the child or young person used to give their feedback.

Readers will notice that while some respondents think a particular feature or detail of a proposal is a strength, others think it is a challenge. This mix in sentiment is characteristic of feedback received during the consultation and is evident across other stakeholder groups. In the case of this chapter, it is also important to note that some children and young people have personal experience of receiving care or services at St George's Hospital; they reflect on this when asked questions about the future Principal Treatment Centre. They do not necessarily have the same personal experience of receiving care or services at Evelina London. This needs to be considered when reading the feedback given. Feedback from other stakeholder groups is addressed in the chapters that follow.



6.1 Engagement snapshot



6.2 The proposal for Evelina London Children's Hospital

6.2.1 Good points

Evelina London is a dedicated children's hospital, and is the specialist heart and kidney centre for the catchment area

There were 14 responses in the questionnaire detailing the positive aspects of the proposal for Evelina London. Here, some stated that they consider Evelina London to have good facilities in a general sense (14%) and be a provider of holistic care (14%), due to the fact it is already a specialist children's hospital (14%). A few comments made by children and young people who gave feedback during site visits to The Royal Marsden echoed these points. One young person referred specifically to Evelina London's specialisms in heart and kidney care.

- *'Already a children's hospital so already know how to deal with children. Will have facilities for children. That is really important' (Parent or carer, responding on behalf of a child or young person affected by cancer, questionnaire response)*
- *'It's not too big. Quite child-focused. It's all about children. There aren't adults [adult patients]. All the other staff there are already quite used to children' (Young person, site visit to The Royal Marsden, December 2023)*



- *‘It’s a good thing they have the specialist heart and kidney centre – there are heart failures and kidney failures [in children with cancer]’ (Young person, site visit to The Royal Marsden, December 2023)*

A couple of children reflected on their personal, positive experience at Evelina London, when they had attended for diagnostics services or treatment.

Good facilities are available at Evelina London

A couple of comments from children and young people highlighted Evelina as providing a suitable environment for children and young people. For example:

- *‘Great atmosphere and environment for children and their families, with open spaces, colour and art work’ (Young adult affected by cancer, questionnaire response)*

The perception is that Evelina London is located in close proximity to University College Hospital

One young person, during a site visit to The Royal Marsden, reflected on the benefit of Evelina London’s location being in close proximity to University College Hospital for access to radiotherapy services.

6.2.2 Potential challenges

Travel to and accessibility of Evelina London could be challenging

In terms of the questionnaire, there were 11 responses to this question on the potential challenges of locating the future Principal Treatment Centre to Evelina London. Most left concerns relating to travel, with some stating their concerns with the increased distance or time to travel to Evelina London (27%), while others raised issues relating to traveling into London more specifically, for example traffic congestion or public transport concerns (27%).

- *‘It’s extremely hard with traffic and parking to get to Evelina from outskirts of London’ (Parent or carer, responding on behalf of a child or young person affected by cancer, questionnaire response)*
- *‘It will be much more difficult for families in the South East to travel to’ (Parent or carer, responding on behalf of a child or young person affected by cancer, questionnaire response)*

In questionnaire responses, others expressed the concern about the negative impact the move could have on children receiving treatment and their families, particularly caused by stress and disruption by



moving them from one location to another as part of the transition (18% of questionnaire responses to this question).

- *‘To move the treatment centre away for such vulnerable young people would be cruel, and I personally think it would be too stressful for them and their families’ (Parent or carer, responding on behalf of a child or young person affected by cancer, questionnaire response)*

One young person with personal experience of Evelina London noted that the distance to walk from the car park to the hospital is long, which can be difficult if you are not feeling well (Young person, site visit to The Royal Marsden, December 2023).

No expertise in or experience of children’s cancer care at Evelina London

Across all engagement activity, there were a few references made by children and young people to the lack of expertise in and experience of children’s cancer care at Evelina London.

6.2.3 Improvements

Children and young people were asked if they had any suggestions for improvements to the proposal from Evelina London. Very few suggestions were proposed. In terms of responses to the question about improvements to the proposal from Evelina London in the questionnaire, some children and young people stated that they did not want any change to occur, preferring for the Principal Treatment Centre to remain at The Royal Marsden (30%). Others expressed that if the move to Evelina London were to take place, then sufficient communications would need to be made to make people aware of the relocation of the services (20%).

- *‘Dedicated teams of people available to answer questions and support people all throughout the move - before, during and after’ (Young adult affected by cancer, questionnaire response)*
- *‘Availability of videos aimed at children and young people featuring staff they are already familiar with to explain the move and ease them into the process’ (Young adult affected by cancer, questionnaire response)*

6.3 The proposal for St George’s Hospital

6.3.1 Good points

St George’s Hospital already provides a good level of children’s cancer care



In terms of the questionnaire, 16 respondents left comments about the positive aspects of the proposal for St George's Hospital. Most stated that they see St George's Hospital as already providing a high level of service since some cancer care is already being provided here (25%).

- *'Outstanding care' (Parent or carer, responding on behalf of a child or young person affected by cancer, questionnaire response)*
- *'Qualified and trained staff' (Parent or carer, responding on behalf of a child or young person affected by cancer, questionnaire response)*

A few children and young people reflected on their recent positive experience of being treated at St George's Hospital, including time spent in the children's intensive care unit there (Site visit to The Royal Marsden, December 2023). One child said staff were really caring and supportive.

Good facilities at St George's Hospital

In responses to the questionnaire, other comments related to St George's Hospital providing accommodation for families, holistic services, and accessibility of nearby green spaces (13% for each theme).

Provision of private rooms that would be available at St George's Hospital

In terms of accommodation, one child felt positive about the number of private and ensuite rooms that would be available at St George's Hospital. This child did not like being on a ward in hospital (Child, 8 years old, online play specialist session). Some children said they did not want to hear hospital noises, including those from other children; this was described as being very distressing for them.

6.3.2 Potential challenges

Travel to and accessibility of St George's Hospital could be challenging

In terms of questionnaire responses, 9 respondents commented the potential challenges of locating the future Principal Treatment Centre at St George's Hospital. Key themes here centred around the accessibility of the site, both in terms of issues with parking (22% of questionnaire responses to this question) and with travel to the site more generally (22%). Challenges relating to travel and accessibility were also reflected on by children and young people via other feedback methods.

- *'Travel links are not good enough' (Young adult affected by cancer, questionnaire response)*
- *'Additional travel – and limited parking' (Young person, 13 years old, play specialist session at St George's Hospital, November 2023)*



- *'Travel to Tooting from outskirts is challenging but not as bad as Evelina' (Parent or carer, responding on behalf of a child or young person affected by cancer, questionnaire response)*
- *'Parking is horrible – very muddy. You have to go all the way round the hospital and there are no markings to show which way you should go so you could easily have an accident' (Young person now over 16 years, with experience of paediatric cancer services, meeting at The Royal Marsden, December 2023)*

St George's Hospital is not a dedicated children's hospital, with an environment which is not suitable for children

Across feedback types, a few children and young people thought that the fact St George's Hospital was not a dedicated children's hospital was a limitation to the proposal. Comments included:

- *'No separate children's hospital to main adult general hospital' (Young adult affected by cancer, questionnaire response)*
- *'Not specifically for children' (Young person affected by cancer, questionnaire response)*
- *'St George's Hospital is too big, too busy and not the right place for children going through cancer treatment. Infection would be a much bigger risk, and the mental impact could be devastating' (Parent or carer, responding on behalf of a child or young person affected by cancer, questionnaire response)*
- *'I don't think St George's Hospital is particularly child-friendly, staff-wise, or the way it's set out or anything about it' (Young person now over 16 years, with experience of paediatric cancer services, meeting at The Royal Marsden, December 2023)*

One young person talked about their experience at St George's Hospital. They said it was noisy when all you want to do is sleep. The walls were blank. It was not a pleasant environment. In contrast, they described The Royal Marsden as a peaceful place, where they feel calm. They said:

- *'You want to get out of here [St George's]' (Young person, 13 years old, play specialist session at St George's Hospital, November 2023)*

The estate and facilities at St George's Hospital are old and outdated

Some respondents across the feedback types commented on the old and outdated facilities at St George's Hospital, reflecting on their experience or knowledge of what the hospital spaces are currently like.

- *'Older and dated environment - will need a lot of resource to upgrade' (Young person affected by cancer, questionnaire response)*



- *'We've been there a few times – the room was very dated, the toilet didn't flush, and the bathroom was falling apart. We spent ages without anyone coming to see us. Here (The Royal Marsden) is much better'* (Young person now over 16 years, with experience of paediatric cancer services, meeting at The Royal Marsden, December 2023)
- *'The ward was horrible'* (Young person now over 16 years, with experience of paediatric cancer services, meeting at The Royal Marsden, December 2023)

Lack of recreational facilities and activities suitable for older children and young people

A few respondents across feedback types commented on the lack of age-appropriate play and recreational spaces for children and young people currently at St George's Hospital. For example, one young person said the playroom at St George's Hospital was not suitable for teenagers; it is filled with toys for younger children (Play specialist session at The Royal Marsden, December 2023). They also referenced a booking system, which is restrictive, meaning you might not get to access it on a daily basis. The playroom was an important relaxation space for this young person.

6.3.3 Improvements

In terms of questionnaire responses, only five children or young people responded to this question, leaving comments against any changes to the current Principal Treatment Centre. Three out of five children or young people said they would prefer the Principal Treatment Centre to remain at The Royal Marsden. In other feedback, thinking about St George's Hospital, a few children and young people said that creating a self-contained children's cancer centre would improve the proposal. Improved signage to help you navigate the hospital was also suggested.

6.4 Views on the delivery of radiotherapy services at University College Hospital

In terms of questionnaire responses, comments were mixed, with some leaving positive comments about the move of conventional radiotherapy to University College Hospital, stating that it is conveniently located and accessible (10%).

- *'I had proton beam at University College Hospital. We stayed in hospital accommodation. It made me forget I had cancer. I could go to the shops at the weekend. I felt a bit more normal, like I was on a trip'* (Young person, site visit at The Royal Marsden, December 2023)
- *'If patients are there every day, there's a hotel that's just for the hospital. Patients who don't need to be in hospital go to the hotel. It's a good experience, but lunch and dinner, they*



provided you with food to microwave. You can't cook. There are a few food courts: Subway, McDonalds, Lidl, M&S' (Young person, site visit at The Royal Marsden, December 2023)

Others were more hesitant about this change, stating opinions around the dangers of children travelling while unwell and risking infection (10%), as well as losing play specialists by moving to University College Hospital (10%). Across all feedback types, children and young people focused on how sick and poorly you feel after radiotherapy treatment, and how the idea of travelling to a different hospital was difficult to comprehend.

- *'I can't imagine the stress of travelling by public transport with a child who has just had treatment, they need to get home easily not struggle on a train' (Parent or carer, responding on behalf of a child or young person affected by cancer, questionnaire response)*
- *'It would be better to keep it in the Marsden because the children have access to both chemo and radiotherapy there and an already great children centre. It would be much harder to travel to the other hospital so would be better option to bring proton beam to the Marsden' (Parent or carer, responding on behalf of a child or young person affected by cancer, questionnaire response)*
- *'Radiotherapy makes you really ill, especially when you are having a bone marrow transplant. It is worse than chemotherapy. I don't think radiotherapy should be on a different site from the cancer services. I don't think it would be fair on the child to be moved from place to place' (Young person now over 16 years, with experience of paediatric cancer services, meeting at The Royal Marsden, December 2023)*

6.5 Future Principal Treatment Centre

Children and young people were also asked what attributes they would value the most in a future Principal Treatment Centre. Across all feedback types, there was emphasis placed on having dedicated spaces for parents and carers, especially for parents or carers to stay overnight – particularly next to the child. The feedback was that a child always has at least one parent or carer with them, so space should be designed for at least two. One child said:

- *'Having mummy and daddy staying at night. It was hard having to say goodbye every night to mummy' (Play specialist session with a child aged 6, at The Royal Marsden, December 2023)*

There was also emphasis placed on privacy and having private rooms with ensuite bathrooms by some children and young people. One young person talked about their experience of sharing a bathroom in



hospital and how that concerned her, because of the potential spread of germs (Play specialist session, The Royal Marsden, December 2023).

Children and young people also talked about:

- A trusted hospital, with a track record in oncology care and research
- Bright and colourful space, with spacious facilities, bedrooms with access to technology (such as television, tablet, with good Wi-Fi)
- Spaces that feel like home, not a hospital (Maggie's Centre⁴⁰ was referenced by a few respondents as the archetype)
- Spaces specifically designed to minimise noise disturbance from other patients, machines, and other hospital noises
- Children's intensive care unit on site
- Family accommodation located next to the hospital
- Children grouped by age if there is a ward
- Playroom, library with books for different ages, video games, range of toys to meet age needs and interests. Separate areas for children and teenagers
- Space and facilities dedicated for parents, so they can have time to themselves if needed
- Kitchen facilities for families, that can also be used by older children to maintain a sense of independence
- Snack trolley, providing food options between meals
- Spaces to accept visitors, especially siblings and other family members
- Experienced doctors and nurses
- Play therapists
- Psychological support for patients as well as parents/carers and siblings
- Access to a wide range of therapies
- Good communication between the Principal Treatment Centre and local hospital/children's cancer shared care units
- Lifts instead of stairs, with priority given to sick children
- Hydrotherapy pool
- Plants and flowers in the hospital
- Toys and things to do, including provision of snacks, if travelling by ambulance
- Having chemotherapy treatment ready to go when you arrive to reduce wait times

⁴⁰ Maggie's Centre at The Royal Marsden provides dedicated spaces and services for cancer patients and their friends and families.



- Laundry room
- Clean and tidy
- Space and facilities for staff to rest and relax
- Allocated space to store belongings
- Outdoor space
- Good signage
- Medicines and treatments in a safe space away from children
- School room
- 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
- Good travel connections
- Plenty of free parking spaces.

Some of this feedback aligns with findings from the Under 16 Cancer Patient Experience Questionnaire. This is a national questionnaire from NHS England, sent to children under the age of 16 and their parents or carers who have recently had care at Principal Treatment Centres in England. Key findings from the Under 16 Cancer Patient Experience Questionnaire included the importance of food (quality, choice, availability), streamlining care to minimise delays, meeting the need for good sleep, and the provision of age-appropriate activities and entertainment.⁴¹

⁴¹ See Under 16 Cancer Patient Experience Questionnaire 2021 National Qualitative Report, November 2022, <https://www.under16cancerexperiencesurvey.co.uk/past-results/2021>



7 Family members and advocates of children and young people who have been affected by cancer

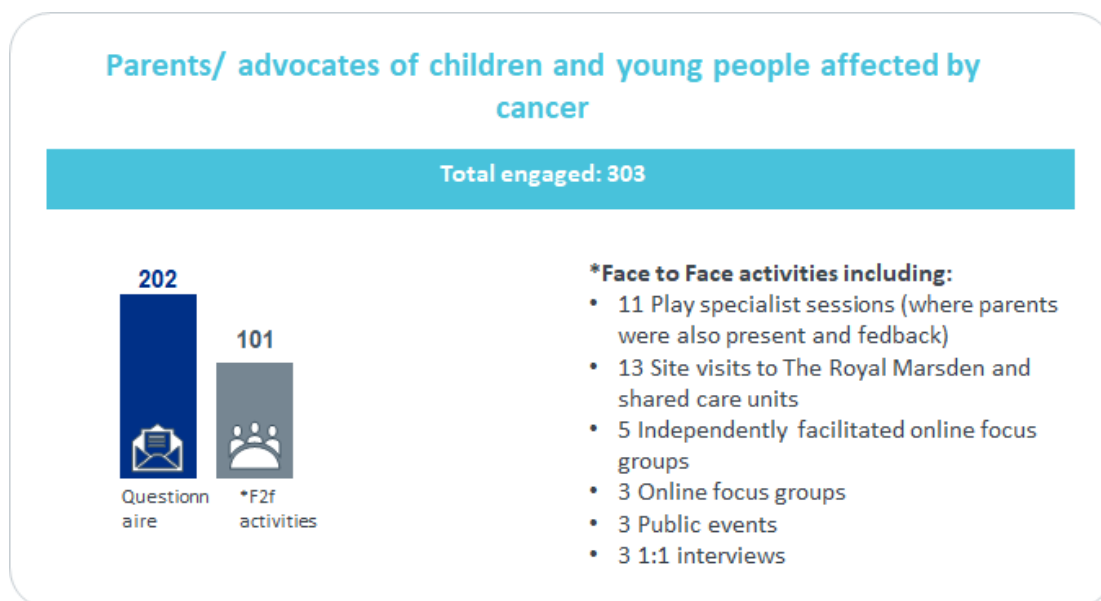
This chapter reflects on feedback from family members, including parents and carers, siblings, and other relatives, as well as advocates, of children and young people who have been affected by cancer. It includes analysis of data from both the questionnaire and qualitative engagement; data has been analysed together to provide a comprehensive understanding of what family members and advocates of children and young people who have been affected by cancer think. Feedback was about their experiences as parents, carers, or advocates, as well as their child's experiences.

Where percentages or numbers are given, this refers to the proportion or number of comments made by individuals from this stakeholder group who answered the questionnaire only. The percentages and number of comments made refers to the specific question being addressed in that section only. Some direct quotes are given; where this is the case, it is said which engagement method the family member or advocate used to give their feedback. It may appear that there are more good points or challenges for one option than the other; this reflects the feedback received.

It is also important to note that some family members and advocates have experience (direct or indirect) of a child receiving care or healthcare services at St George's Hospital; they reflect on this when asked questions about the future Principal Treatment Centre. They do not necessarily have the same experiences of Evelina London. This needs to be considered when reading the feedback given.



7.1 Engagement snapshot



7.2 The proposal for Evelina London Children's Hospital

7.2.1 Good points

Evelina London is a dedicated children's hospital with many specialisms

Across all feedback types, recognition was given to Evelina London as a dedicated children's hospital. Respondents talked about the environment being appealing as it is tailored to children and young people with murals, displays, and toys, with green space nearby.

- *'Evelina would be my preferred option due to it feeling like a much less daunting environment for parents and children alike' (Family member or advocate of child or young person who has been affected by cancer, questionnaire response)*
- *'Evelina building itself is modern, fresh and welcoming for children/young people. The PICU and ward rooms are light and welcoming with new family room/kitchen area overlooking the atrium. The atrium itself with the balcony outside provides a much-needed space for families, patients and staff to be able to catch their breath and balance. This aspect of well-being and mental health shouldn't be overlooked and Evelina has it tackled beautifully' (Family member or advocate of child or young person who has been affected by cancer, questionnaire response)*



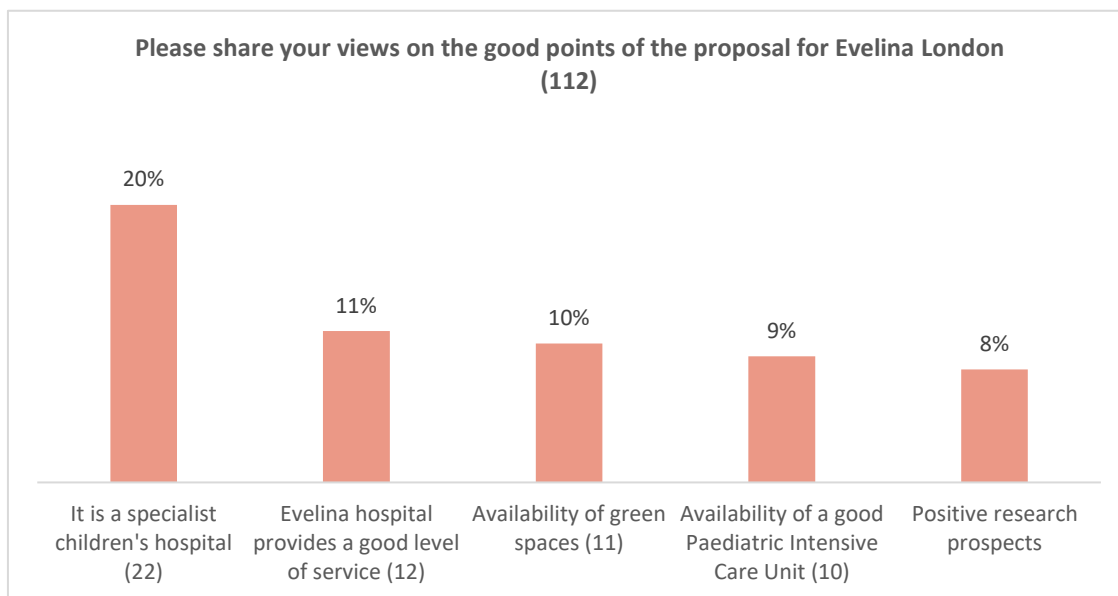


Figure 1 Family Members and Advocates, Evelina London, Good Points

In terms of the questionnaire, 112 family members or advocates left comments on the good points about the proposal for Evelina London. Here, a key strength of the proposal is the fact that Evelina London is already a specialist children's hospital (20%) and as such, respondents stated that Evelina London is able to provide a good level of service (11%).

There was also recognition from some respondents that Evelina London has many specialisms which would benefit patients and their families, including children with rare and very rare conditions.

- *'Lucky to have seen the best person within Evelina London – it's about the expertise rather than the site. Evelina London has wider expertise with kidney and heart services, which are needed by children with cancer' (Parent interview, child was treated at The Royal Marsden and St George's Hospital, later at Evelina London, December 2023)*
- *'It was striking to me that Evelina is already providing services to the PTC that St Georges would not be able to provide (kidney etc). To me, it feels much more sensible to put all specialities under one roof as the PTC' (Family member or advocate of child or young person who has been affected by cancer, questionnaire response)*

A few comments acknowledged that if the new Principal Treatment Centre was located at Evelina London, it would benefit from being part of the Guy's and St Thomas's NHS Foundation Trust, with their track record of securing research funding. There was also reference to the charity support available that could fund additional specialist provision such as play specialists (Parent or carer, public listening event, December 2023).



A larger children's intensive care unit at Evelina London than St George's Hospital

Across feedback types, some parents felt it was a positive that Evelina has more children's intensive care unit beds overall when compared to St George's Hospital. Although only two beds would be designated for cancer patients, it was considered a possibility that Evelina could accept more if needed and if capacity allowed.

Good transport links

Whilst there is much criticism of the accessibility of Evelina London, some respondents did reflect on the favourable location of Evelina London for access by public transport.

- *'Location of things is important – want to be able to see your child and see your other children and still perform at your job. Evelina London being located near Waterloo makes it very accessible. Transport facilities are great. Mainline train, bus, taxi etc. Easier for more people to get to. Closer to King's for neurosurgery'* (Parent interview, child was treated at The Royal Marsden and St George's Hospital, later at Evelina, December 2023)

Evelina London is well-located for access to services and recreational spaces

Some family members and advocates said the location of Evelina London was an advantage for accessing shops (with a reference to the on-site shops) and outdoor spaces.

- *'Easy access to facilities such as shops without having to leave the building - such as those provided at the Evelina London through access to Guys & St Thomas'* (Family member or advocate of child or young person who has been affected by cancer, questionnaire response)
- *'Green space with playground across at Archbishop's Park and walks along Thameslink path'* (Family member or advocate of child or young person who has been affected by cancer, questionnaire response)
- *'The Evelina has a nice environment for children and is easily reachable by public transportation. Coming in from the back, avoiding circulating through the whole hospital with an immune-compromised child is possible. There are plenty of options for buying food in the area, which is helpful to get some supplies in long stays'* (Family member or advocate of child or young person who has been affected by cancer, questionnaire response)
- *'Places to visit with siblings if visiting. Treats outside after visits if well enough (but expensive +++)'* (Family member or advocate of child or young person who has been affected by cancer, questionnaire response)

7.2.2 Potential challenges



Travel to and accessibility of Evelina London could be challenging

Although some family members and advocates thought that the location of Evelina London was a strength, more respondents were concerned about travel to and accessibility of Evelina London. In fact, the top five themes regarding the challenges of the Evelina London proposal all related to accessibility, with most making reference to the difficulty of parking nearby or onsite as there are too few parking spaces available (27%), as well as the difficulty of travelling into and within central London (26%). Others stated that the distance to travel to Evelina London would be too far, resulting in extended travel times (20%), while some mentioned how travel costs would increase due to fuel, congestion charges, and Ultra Low Emission Zone (15%).

It must be noted here that whilst many parents talked about perceived and experienced difficulty in travelling to both Evelina London and St George’s Hospital, there was more opposition to Evelina London as it would require travel into central London.

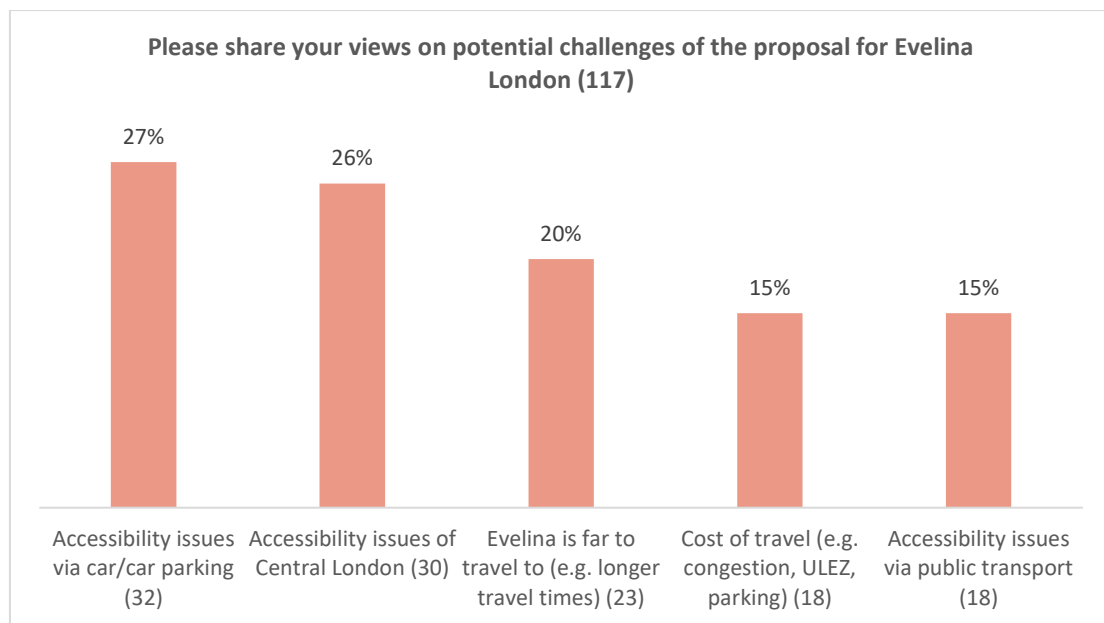


Figure 2 Family Members and Advocates, Evelina London, Potential Challenges

It is clear that travelling by car is the preferred mode of transport for family members and advocates; travel by car is seen as a necessity (where it is available to the family) in order to minimise discomfort and distress for a very sick child (the child might be too weak), as well as to minimise infection risk on public transport involving an immunocompromised child. These respondents raised issues about traffic congestion and travel times, the availability of car parking, and the accessibility of car parking at Evelina London (for example, the time it takes to walk from the car park to the hospital).



- *'You're asking people to pay the congestion charge and things like that. For a person having what would constitute a normal life, you would remember to do that. If you have a child that's having chemotherapy, he's very poorly. I can tell you that that would not be on the top of your list, so there's lots of things that are adding to things that where it's already a really, really stressful time'* (Parent/carer Engagement session, November 2023)
- *'If the treatment centre was at Evelina, we wouldn't be able to drive. There is no parking. We know this. We've been going there for a while. It's impossible. We get public transport to go there. I cannot imagine leaving that hospital with a child who's vomiting excessively into a paper pot and navigating her. She's also visually impaired, navigating her through Waterloo Station and getting on the train. I just cannot. Even getting in the car was hard enough, but I can't imagine taking her on public transport'* (Parent/carer engagement session, November 2023)
- *'Travel through central London in the back of ambulances stuck in traffic just seems so unnecessary when it could all be avoided'* (Parent/carer Engagement session, November 2023)
- *'Getting there traffic wise is awful. It's 32 miles and it can take us 3 hours'* (Parent, site visit to The Royal Marsden, December 2023)

There was also criticism of the lack of support proposed for parents and carers in terms of transport and accessibility. The idea of a drop-off zone was not considered feasible by some respondents, especially for those who have no other adult with them. The scheme for reimbursing one parent or carer was viewed as insufficient by some, highlighting that often a wider network of support is engaged in the direct care of a child with cancer. Hospital transport was also not seen as a viable mitigation, given past experiences of its unreliability.

- *'It would be one family member who will be reimbursed and as anyone who has been part of a family who has been through this experience, it's a tag team'* (Parent/carer Engagement session, November 2023)
- *'Hospital transport is very unreliable. We have missed multiple appointments before COVID-19 due to this and while the Marsden was very understanding and would still see children around this, Evelina is much more rigid around this. Will this change'* (Parent, public listening event, December 2023)

Lack of experience in children's cancer care at Evelina London

Some respondents, across all feedback types, talked about the lack of current experience and expertise in children's cancer care at Evelina London. The perception of this lack of experience also extended to



Guy's and St Thomas' NHS Foundation Trust (although it should be noted that Guy's and St Thomas' NHS Foundation Trust provides oncology to adults and to teenagers and young adults). The prospect of starting from scratch to build a Principal Treatment Centre at Evelina London was considered to be 'possibly the worst option' for one parent/carer (Parent/carer Engagement session, November 2023).

- *'With Evelina, they have no experience of delivering a paediatric cancer service and the Trust has no experience of running a paediatric cancer service'* (Parent/carer Engagement session November 2023)
- *'Lack of experience with rare cancers and lack of relationship with Marsden in a partnership capacity'* (Family member or advocate of child or young person who has been affected by cancer, questionnaire response)

No research experience in paediatric cancer at Evelina London, with concern about the continued provision of children's clinical cancer trials

Some respondents, across all feedback types, also commented on the lack of research experience in paediatric cancer at Evelina London. In particular, feedback focused on the potential impact on patient access to clinical trials.

- *'The research at Evelina is not in paediatric cancer, so the capacity and the breadth of knowledge that you have at the Marsden is going to be lost and patients are not going to be able to benefit from that. Having the Institute of Cancer Research on site is such an advantage for the children that are being treated there'* (Parent/carer Engagement session, November 2023)
- *'Cannot underestimate the life-changing opportunity being involved in a trial provides'* (Parent/carer Engagement session, November 2023)
- *'No experience of drug development for children with cancer at Evelina and with the Marsden, we know there's a network of 25 years'* (Parent/carer Engagement session, November 2023)

Family accommodation at Evelina London is not close to the hospital; eligibility for and availability of accommodation is not guaranteed

Some respondents talked about the 10-minute walk to Ronald McDonald House, which they felt was not ideal, especially when you have a very sick child with cancer. Some respondents questioned whether Ronald McDonald House would have capacity to cope with the increased number of families requiring accommodation if Evelina London was chosen as the location of the future Principal Treatment Centre.



- ‘At Ronald McDonald House in Evelina London it was a 10-minute walk from the accommodation to the hospital. I had to run over in the night across a park when it was dark if something happened to my child. Not ideal’ (Parent, public listening event, December 2023)
- ‘When my child was being treated for cancer, I had a 10-month-old child and was pregnant. As I lived in London, I was told I was not eligible for family accommodation even though the journey was more than 45 minutes to get there. They also didn’t have availability, so I had to leave my child and sleep in Reception. I had to pay for Gassiot House. We did eventually get into Ronald McDonald House for our final night there because they felt sorry for us’ (Parent, public listening event, December 2023)

7.2.3 Improvements

In terms of the questionnaire, in response to being asked what improvements could be made to Evelina London’s proposal, the largest proportion of comments stated that that they did not want the current service to move from The Royal Marsden (15%), and that there should be adequate provision of public transport support (8%), whether this be a dedicated service or financial support to families to cover public transport costs. Some stated that greater availability of parking on site as well as free parking would also be an improvement to the current proposal (7%). In other feedback, a few respondents focused on the lack of recreational spaces and activities for older children and young people.

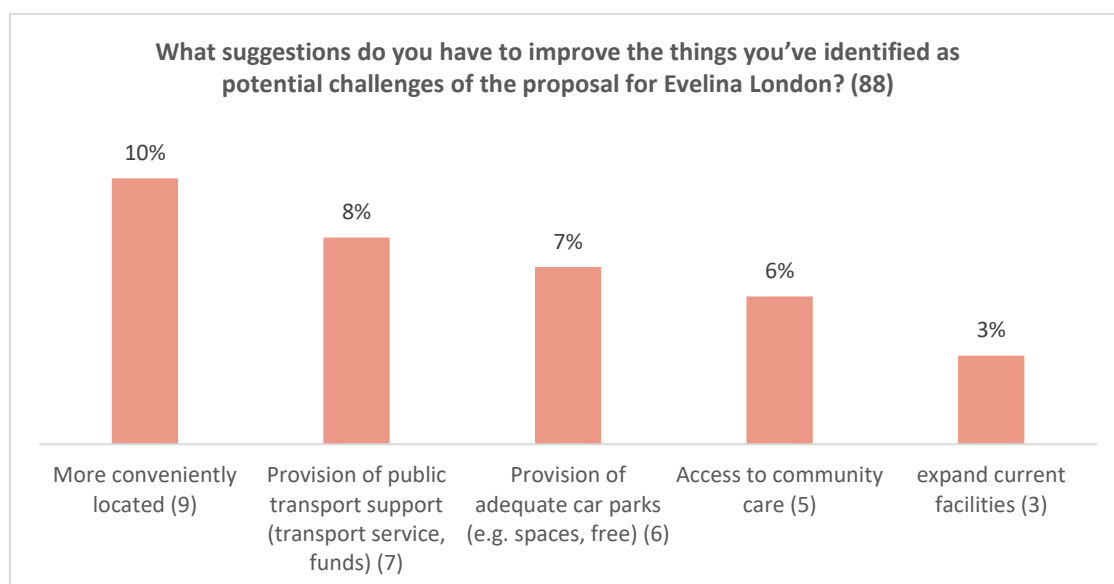


Figure 3 Family Members and Advocates, Evelina London, Improve Potential Challenges



7.3 The proposal for St George's Hospital

7.3.1 Good points

St George's Hospital is easier to access by car than Evelina London

Given the strength of feeling about travel and access to the proposed hospitals, some parents in response to the questionnaire said it would be easier for them to access St George's Hospital by car (20%) than Evelina London, and that St George's Hospital had a more convenient location than Evelina London (15%).

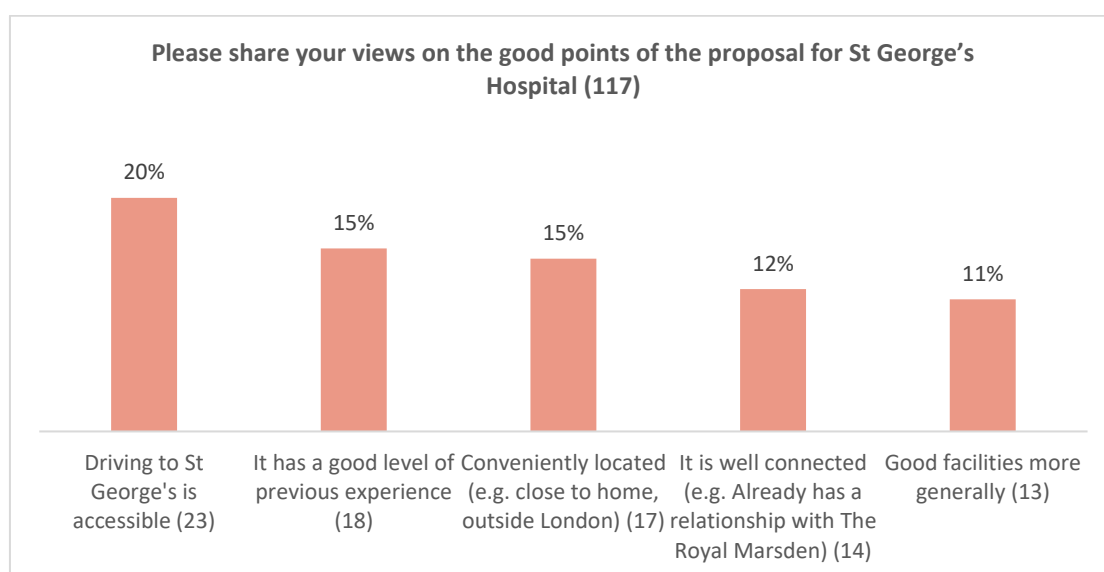


Figure 4 Family Members and Advocates, St George's Hospital, Good Points

St George's Hospital has 25 years of experience in delivering specialist children's cancer services as part of the current Principal Treatment Centre

Across all feedback types, respondents reflected on the benefit of St George's Hospital experience as part of the current Principal Treatment Centre. In terms of questionnaire responses, respondents stated that St George's Hospital already has a good level of experience (15%), particularly due to its ongoing working partnership with The Royal Marsden providing cancer care for children and young people (12%). These respondents felt that St George's Hospital was well-placed and well-equipped to take on the service. Feedback included:

- 'They've got 25 years of working successfully with The Royal Marsden and it has worked incredibly well' (Parent/carer Engagement session, November 2023)



- *‘Already have skilled dedicated staff’ (Family member or advocate of child or young person who has been affected by cancer, questionnaire response)*
- *‘Already great relationships with the Marsden - consultants rotate weekly’ (Family member or advocate of child or young person who has been affected by cancer, questionnaire response)*
- *‘Experienced staff who can guide PICU staff appropriately’ (Family member or advocate of child or young person who has been affected by cancer, questionnaire response)*

A few respondents said the hospital was already familiar to them and other families affected by childhood cancer, which was considered a benefit to them if the service moved to St George’s Hospital.

St George’s Hospital delivers a range of specialisms which already benefit patients and families, including neurosurgery

Across all feedback types, some respondents reflected on the current specialisms delivered by St George’s Hospital, which already benefit children with cancer.

- *‘In intensive care, [my daughter] used respiratory, neurology, infectious disease, cardiology, orthopaedics, endocrinology services’ (Parent, site visit to The Royal Marsden, December 2023)*
- *‘Surgical expertise in neurosurgery and dealing with brain and spinal cancers’ (Family member or advocate of child or young person who has been affected by cancer, questionnaire response)*

Family accommodation is close-by at St George’s Hospital

A few respondents talked about the relative location of Ronald McDonald House to St George’s Hospital as a benefit of the proposal. One parent talked about their long stay at Ronald McDonald House; they were able to keep the family together at Christmas, which was very important to them (Parent, public listening event, December 2023).

7.3.2 Potential challenges

Travel to and accessibility of St George’s Hospital could be challenging

Although the strength of feeling here was not as strong as it was for Evelina London, respondents still had notable concerns about travelling to St George’s Hospital. In terms of questionnaire responses,



respondents stated access by car and car parking was an issue (33%) and access by public transport was a challenge (8%). Travel time was also a concern (6%).

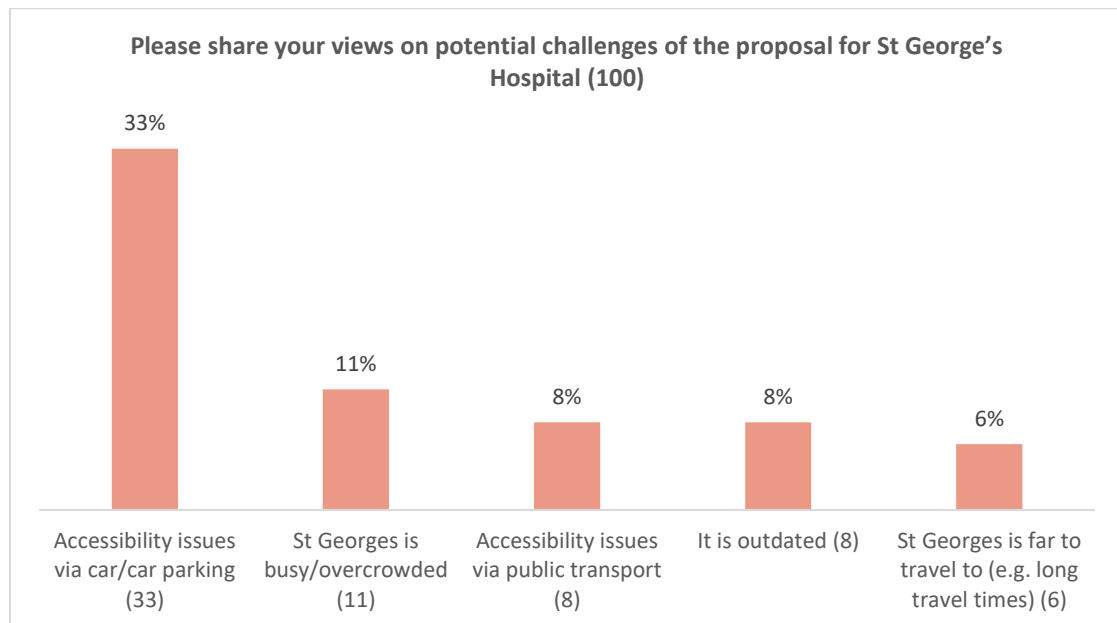


Figure 5 Family Members and Advocates, St George's Hospital, Potential Challenges

Comments included:

- *'Parking at St George's Hospital is hopeless - nowhere near enough space' (Family member or advocate of child or young person who has been affected by cancer, questionnaire response)*
- *'Traffic and parking is horrendous' (Family member or advocate of child or young person who has been affected by cancer, questionnaire response)*
- *'The location, it's a challenge. I mean, Tooting if you're lucky if you can move, you know, half a mile in two hours if you're driving in Tooting' (Parent/carer Engagement session, November 2023)*

St George's Hospital is not a dedicated children's hospital; it is outdated and not child-friendly

Feedback from respondents here mostly related to St George's Hospital not being a purpose-built environment that is tailored to the needs of children.

- *'Hospital is gloomy and makes you feel even more depressed' (Family member or advocate of child or young person who has been affected by cancer, questionnaire response)*
- *'Hospital feels 'doom and gloom' not very child friendly' (Parent/carer, site visit to The Royal Marsden Hospital, December 2023)*



- *'We had one dealing with St George's Hospital. It was like a Victorian prison, scary for the kids. The care was ok' (Parent/carer, site visit to The Royal Marsden Hospital, December 2023)*
- *'Too busy with no personalised care because it's such a big hospital' (Parent interview, December 2023)*

A few comments related to the perception that children are not necessarily prioritised if other adult patients needed urgent surgical care. Another respondent said they felt there was less of a focus on children and young people and more of a focus on teaching.

- *'Feel they can't run what they have now. Feels chaotic. Overrun with other things going on and didn't focus on children's care. Put a lot of emphasis on teaching students not on patient care' (Parent interview, December 2023)*

Perception that the infection risk is greater at St George's Hospital

Related to this, there were many comments about the large size of St George's Hospital and how it feels busy, hectic, and unsafe (in terms of infection control). A couple of comments referred to people smoking outside the hospital. The mixing of children and adult patients, with a shared entrance and shared lifts, was a real drawback for respondents who reflected on their current experience of St George's Hospital.

- *'I just feel like the fact that the building is this big, tall building rather than, you know, when you're waiting for lifts, there's all these emergencies going through the lifts you have to queue, you know. It's just a lot happening in that hospital... Obviously they say they're going to have this in a separate section, but going to the main hospital if you need surgery. So, I don't see how they're going to keep these children separate and away from all the other people, and there's loads of people' (Parent/carer Engagement session, November 2023)*

Shared facilities at St George's Hospital are poor and there is a lack of privacy

Some parents shared their past experiences of St George's Hospital. Many of these were negative experiences. Some parents mentioned the Pinckney Ward specifically; they talked about it being a shared ward, and also treating children with infectious diseases, which they worried about being an infection risk.

- *'Pinckney ward is a dump – it's shared with infectious diseases, which I hate' (Parent/carer, site visit to The Royal Marsden, December 2023)*
- *'Hospital was filthy and disgusting; staff too busy' (Parent interview, December 2023)*



Some respondents with personal experience of St George’s Hospital reflected on the poor state of shared facilities for parents and carers, including beds, showers, and kitchen facilities. In relation to this, respondents were concerned about the capacity of St George’s Hospital to take on the full Principal Treatment Centre; they would need assurances that these challenges could be overcome if St George’s Hospital was chosen as the future location of the Principal Treatment Centre.

- *‘St. Georges was dire. I mean, the staff are lovely, but the facilities are just the kitchen, it’s disgusting. You wouldn’t want to, you know, cook your own dinner in there. It was just horrible’ (Parent/carer Engagement session, November 2023)*
- *‘The shower was blocked every day and we had different staff every day. There was no consistency’ (Parent/carer Engagement session, November 2023)*
- *‘Would be absolutely horrific to have had all our treatment here. The facilities at St George’s are worse than camping! At our last stay there wasn’t any water coming out of the taps in any of the rooms on the ward (and this was in Covid!). I couldn’t shower for over one-week, horrible experience, I complained and nothing done, dirty rooms, just awful’ (Family member or advocate of child or young person who has been affected by cancer, questionnaire response)*

One parent reflected on poor sleeping provision for parents when their child went to St George’s Hospital for an operation. They were given what they described as ‘pillows placed on a hard surface’ (Parent interview, child received care at The Royal Marsden and St George’s Hospital, December 2023).

Limited capacity of the children’s intensive care unit at St George’s Hospital

A few respondents reflected on their past experience to say that they felt the capacity of the children’s intensive care unit was more limited at St George’s Hospital compared to Evelina London.

Lack of family accommodation at St George’s Hospital

Some respondents were concerned about the relatively low capacity for family accommodation at Ronald McDonald House. They questioned how the facility would cope with an increase of very sick children travelling long distances for treatment with their families. A few respondents talked about having to pay for hotel accommodation close to St George’s Hospital, which was expensive and had no fixed cost.

7.3.3 Improvements



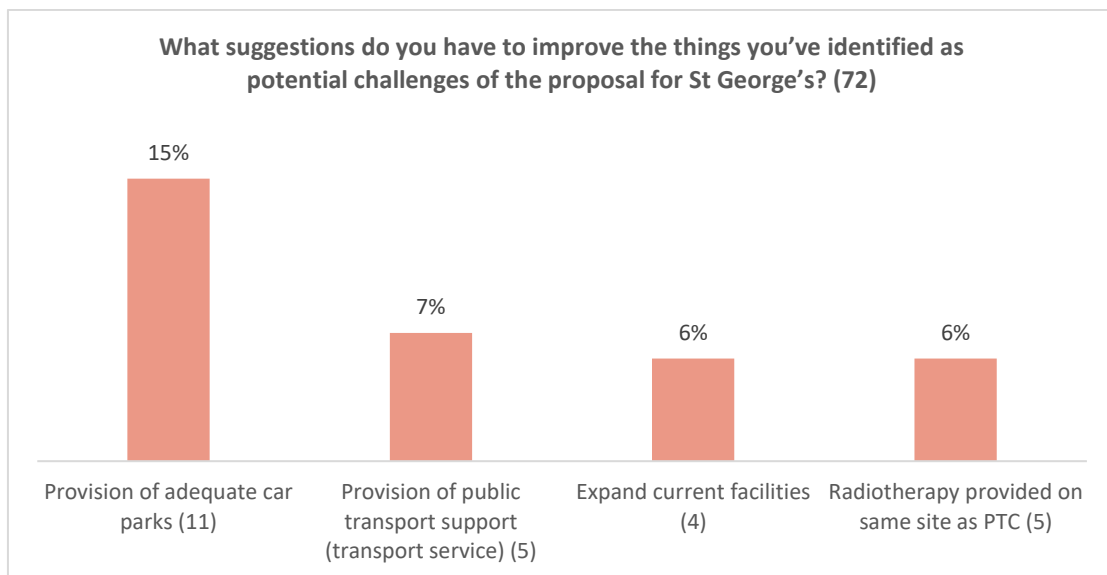


Figure 6 Family Members and Advocates, St George's Hospital, Improve Potential Challenges

The largest number of comments within the questionnaire fell outside the specific remit of the question, reiterating their wish for the service to remain at The Royal Marsden (17%). Others focused on the provision of adequate car parking facilities (15%), including dedicated spaces for families visiting children receiving treatment. Others stated that support with public transport should also be provided particularly for families outside of London, such as through shuttle busses or subsidised travel (7%).

In other feedback, the provision of a separate entrance for the new Principal Treatment Centre, which is located far enough away from other services, was emphasised as important by some respondents. They urged that the future Principal Treatment Centre should be a self-contained site, easing concerns about patients mixing with other patients and visitors, away from the busy adult hospital and emergency department (A&E)⁴².

⁴² It is important to note that St George's Hospital do plan to make the future Principal Treatment Centre a self-contained site within the hospital.



7.4 Possible challenges affecting both proposals

A lot of feedback across all engagement types focused on challenges that were common to both proposals – to Evelina London and St George’s Hospital. These are recorded here.

Neither proposal offers a single-site solution

This was echoed across different methods of engagement, with parents and carers agreeing that the proposed change does not go far enough in the co-location of essential and related services. Some feedback focused on radiotherapy in particular, as well as neurosurgery.

- *‘Neither option resolves the problem of not transferring particularly ill children because there may well be intensive care in the same hospital, but there will be no radiotherapy’ (Parent/carer Engagement session, November 2023)*
- *‘There’s still going to be a hotchpotch. So, you’re swapping one set of problems with another set of problems’ (Parent/carer Engagement session, November 2023)*

Size of the proposed hospitals will mean the loss of personalised care

Some responses also focused on the large size of the two proposed sites. These respondents questioned how the proposed sites would be able to match the welcoming, friendly, and comforting environment of The Royal Marsden for families. This was particularly discussed in relation to having a child with cancer; the level of sensitivity and care was seen to be of utmost importance.

Advice on travelling on public transport with children with cancer

Some family members and advocates reflected on advice they have been given to not use public transport to attend hospital with their child when that child was undergoing cancer treatment⁴³.

- *‘One of the things that I remember so clearly from those very early days when she was diagnosed, when everything you’re getting rushes of information, so much being told to you. One of the things that really stuck with me was if you have an immunocompromised child, you should keep them away from public transport, and it was something that was almost*

⁴³ Although please note, from NHS England’s consultation document, that The Royal Marsden, in collaboration with Great Ormond Street Hospital and University College Hospital has guidance which advises children and families that it is safe to travel on public transport for children with cancer, even with a weakened immune system. The guidance says that for some patients, it might not always be appropriate to travel in crowded areas, depending on the treatment they are received. It says clinicians should assess patients on a case-by-case basis.



drummed into us at the very beginning, keeping away from public transport. It's, you know, keeping away from busy places' (Parent/carer Engagement session November, 2023)

7.5 Views on the delivery of radiotherapy services at University College Hospital

Across all feedback types, most feedback in relation to this part of the proposal was negative. Some respondents thought the move to University College Hospital for radiotherapy services would bring accessibility issues, with patients and families having to travel further within central London.

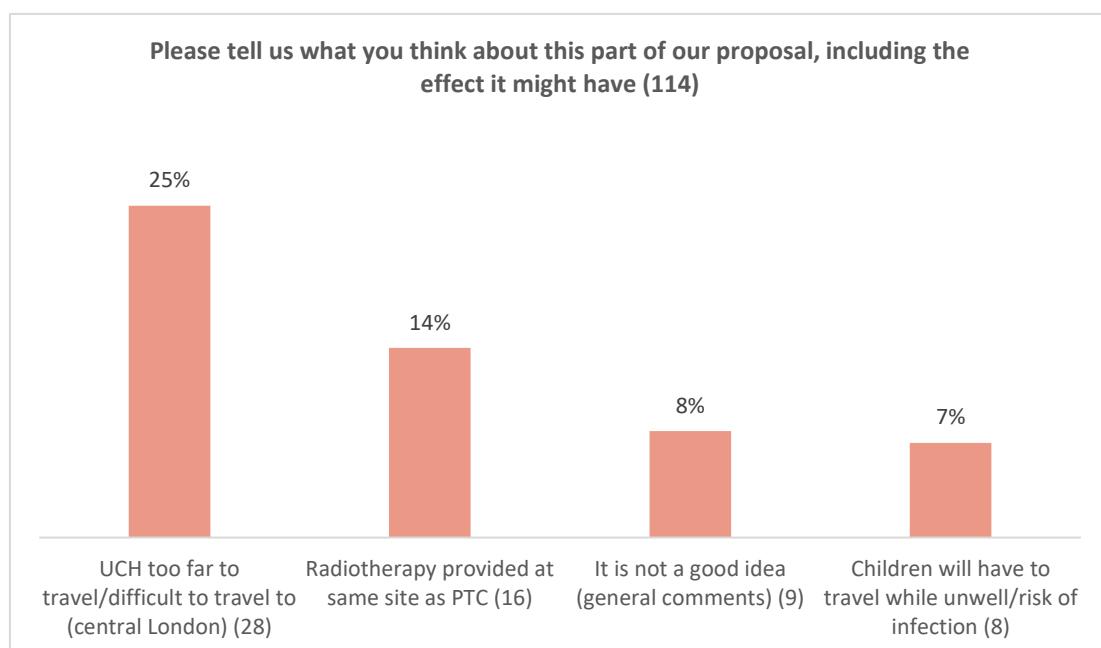


Figure 7 Family Members and Advocates, Radiotherapy Services at University College Hospital, effect it might have

Some parents and carers reflected on the reality of seeking treatment for a very sick child with cancer; having radiotherapy on a separate site was seen to compound challenges associated with travel and accessibility in central London. They called for a single-site solution.

- *'I think that it's, you know, to have radiotherapy somewhere different as well. That's yet another hospital that's even more into the middle of London' (Parent/carer Engagement session, November 2023)*
- *'You usually have to be there very, very early, like 7:00 in the morning. So, we could easily drive to the Marsden and get ready for radiotherapy every single day. She had to have a general anaesthetic. I mean, trying to get into London or anywhere else that early to do that every single day. And she did it for two weeks each time she did her stint. If that service was*



completely moved to somewhere else, it would just be really impossible to do that on a daily basis without having any kind of accommodation. Having to travel back and forth with a child who's being sick after radiotherapy' (Parent/carer Engagement session, November 2023)

- *'It feels disjointed' (Family member or advocate of child or young person who has been affected by cancer, questionnaire response)*
- *'Why break up a service and have a whole bunch of different sites across London! These are children we're talking about. They need as much stability and normality as possible. Moving from site to site, location to location plus all the travel it entails is so silly' (Family member or advocate of child or young person who has been affected by cancer, questionnaire response)*
- *'After [my child] had radiotherapy ahead of his bone marrow transplant he was wiped out, really ill. He didn't want to go anywhere, let alone move hospital. He had it for four days' (Parent/carer, site visit to The Royal Marsden, December 2023)*

Reflecting on the challenges relating to radiotherapy provision at University College Hospital, a few respondents talked about the need to offer families accommodation so they can stay overnight before early appointments; they stated that radiotherapy appointments can start at 7am. Offering accommodation at the hospital for children and families was also suggested.

There were other comments that said positive things about the proposal to move conventional radiotherapy to University College Hospital, although these were fewer in number compared to more negative comments. During a visit to Margate children's cancer shared care unit, one parent reflected on their positive experience at University College Hospital, where their child was receiving proton beam therapy over a 7.5 week period (December 2023). In particular, they talked about the excellent accommodation provided, which was a two bedroom private flat with kitchen and washing machine. The respondent felt very comfortable there as they did not have to share facilities with other families.

7.6 Future Principal Treatment Centre – what matters the most

Across all feedback types, many family members and advocates were interested in retaining the character, personalised care, and quality of care delivered by The Royal Marsden. Family facilities were also important. Feedback included:

- The welcoming, family-friendly and homely environment of The Royal Marsden should be replicated
- Separate entrance so the child is not mixing with other children and adults without cancer



- Volunteer helpers to support families move through the Principal Treatment Centre (helping with bags, securing wheelchair for child, calling lifts)
- Personalised care for the child
- Continuity of care with clinicians who have been treating your child
- Care needs to be 'as good, if not better', with experienced and knowledgeable clinical staff
- Private facilities for parents, such as working showers and comfortable beds. Kitchen facilities, including space to store food and cook meals were also important
- Good food, catering for the child's needs, preferences, and tastes
- Access to a canteen, open 7 days a week
- Food vouchers for families
- Sufficient toilets in the outpatient department
- Age-appropriate and separate spaces for older children and young people
- No mixing of children and young people of different ages on the wards
- Good quality education provision
- Dedicated play areas and education areas for children with cancer
- Paid-for wheelchair service, so families can leave the hospital on occasions
- Cancer charities have their own spaces and rooms in the ward to provide family support
- Ample parking
- Easy to access by car
- Improved network of communication between Principal Treatment Centre, children's cancer shared care units, community nursing teams, and GPs
- Improved communication of key information when a child first becomes a patient of the Principal Treatment Centre; easily digestible information and guidance
- Improved communication with the Principal Treatment Centre; so they answer your call first time you ring.

7.7 Suggestions to address challenges

Respondents also shared ideas on measures that could help minimise any detrimental effects of the proposals. In relation to both proposals, some family members and advocates focused on the need to strengthen local cancer care and treatment. There was a strong feeling that improved local services, with trained and experienced staff, should be a priority in order to mitigate the need for families to travel to London to receive care from the Principal Treatment Centre as often as they might need to. Some parents said they were unable to access chemotherapy treatment at their local children's cancer shared care units. Some parents said much more could be done to strengthen existing links between the Principal Treatment Centre and children's cancer shared care units. This included improved



communication and coordination between sites, especially if parents require flexibility in arrangements. One relative said:

- *'Until I had seen and lived through the years of treatment he had to complete, I would not have realised how important having facilities close to home was. I don't think anyone who hasn't had this experience and watched the impact on a family would be able to comprehend these problems. We were fortunate to live close by and be able to help the family, but many don't have this extra benefit. Surely the answer is to have more intensive care units rather than take facilities, which work so well, away from two hospitals which provide excellent care. As the daughter of a GP who watched as small community hospitals were closed in order to provide better facilities in big centres, I feel the lessons of the past mistakes are going to be repeated yet again' (Relative of child cancer patient, email correspondence, December 2023)*

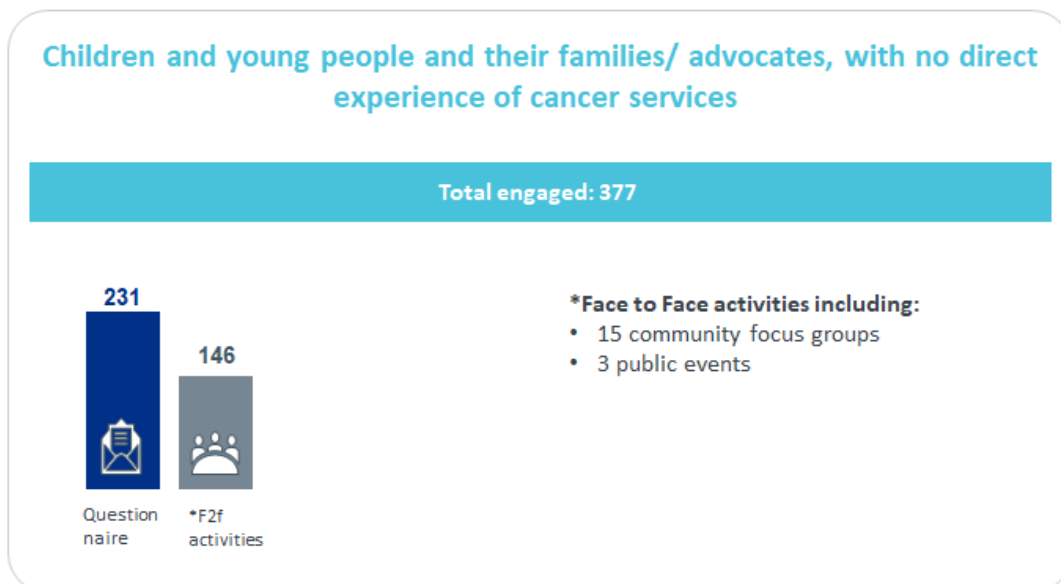
One parent advocated the use of telemedicine where appropriate, to allow specialists at the Principal Treatment Centre to remotely consult with and monitor patients in their home regions, reducing travel needs.



8 Children, young people, and their families and advocates, with no direct cancer experience

This chapter presents the findings from children, young people, and their families. It shares insight from across all feedback methods. The children and young people, and their families and other advocates, have no connection to cancer. They may have related experience, such as children and young people who have, or have had, a serious illness. Those who attended the community focus groups also represented a range of equalities groups, such as ethnic minority groups, low income households, and looked after children. Key themes in this chapter reflect those of previous chapters from across the research methods involving children, young people, and their families. As a reminder, where percentages or numbers are given, this refers to the proportion or number of comments made by individuals from this stakeholder group who answered the questionnaire only. The percentages and number of comments made refers to the specific question being addressed in that section only.

8.1 Engagement snapshot



8.2 The proposal for Evelina London Children's Hospital

8.2.1 Good points

Evelina London is a dedicated children's hospital, and has a good reputation for care

Across all feedback types, it was clear that Evelina London is recognised as, and valued for being, a dedicated children's hospital, based in a relatively new and purpose-built construction. In the questionnaire responses from children, young people, or families with no direct experience of cancer, 29% considered a strength of Evelina London's proposal that it is already a dedicated children's hospital, while others considered Evelina London's current research facilities as another key strength (17%).

- *'Staff are used to working with children. The site is set up for children' (Child, young person, or family member with no direct experience of cancer, questionnaire response)*
- *'It is a famous hospital so we think care would be good, research-led, etc' (Community focus group with children, young people, and parents, South West London, October 2023)*
- *'Impressive number of young people treated already' (Community focus group, Surrey, November 2023)*
- *'Hospital built in recent years with relatively up-to-date planning, facilities and equipment' (Child, young person, or family member with no direct experience of cancer, questionnaire response)*
- *'State of the art, modern, child-centric hospital' (Child, young person, or family member with no direct experience of cancer, questionnaire response)*

It was also noted by a few respondents that Evelina London has a children's intensive care unit, which was considered to have a good level of capacity.



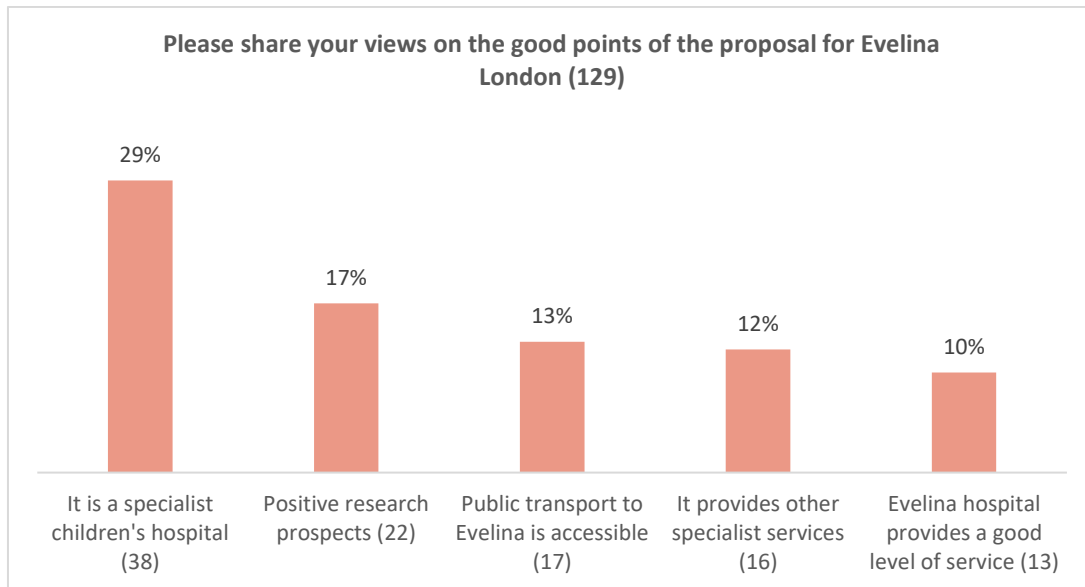


Figure 8 Children, young people, and their families and advocates, with no cancer experience, Evelina London, Good Points

Good public transport links to Evelina London

10% of questionnaire responses from children, young people, or families with no direct experience of cancer talked positively about the central location of Evelina London from a public transport perspective. However, it is important to note that several more comments were made in response to this question that highlighted respondents' concerns about accessing Evelina London. This is addressed in the challenges section below.

- *'Excellent transport links' (Child, young person, or family member with no direct experience of cancer, questionnaire response)*
- *'Easy access by major public transport links' (Child, young person, or family member with no direct experience of cancer, questionnaire response)*

Good facilities at Evelina London for patients and their families

Across the feedback types, children, young people, and family members felt that the open spaces and nearby park was an asset to Evelina London's proposal.

- *'I like the park and running around' (Community focus group, Surrey, November 2023)*
- *'Outdoor spaces' (Child, young person, or family member with no direct experience of cancer, questionnaire response)*

Respondents also talked about the more spacious and comfortable facilities available at Evelina London. Having recreational spaces for older children and teenagers was a key interest in the



community focus groups. Wi-Fi was mentioned repeatedly as a positive across the community focus groups.

- *‘There seems like there is more space for comfort – especially with the rooms for private conversations, spaces for teenagers, and outdoor spaces onsite’ (Community focus group, East Sussex, November 2023)*

Some references were made to the volunteer mobility assistants, who would be available at Evelina London to support families, which respondents agreed was a strength of the proposal.

- *‘Having volunteers to support with mobility stands out – this should be available for all children needing assistance with their mobility, particularly if there is a lone parent with other children’ (Community focus group, East Sussex, November 2023)*

Family accommodation nearby

Family accommodation was referenced across all feedback types, and it was particularly important for those taking part in community focus groups. Respondents talked about the need to keep families together, and if journey times are longer, there should be suitable accommodation available for parents, carers, and siblings.

- *‘On site accommodation definitely a good feature, to think that we’d be able to spend time with siblings and both families’ (Community focus group, Surrey, November 2023)*

8.2.2 Potential challenges

Travel and accessibility challenges associated with Evelina London



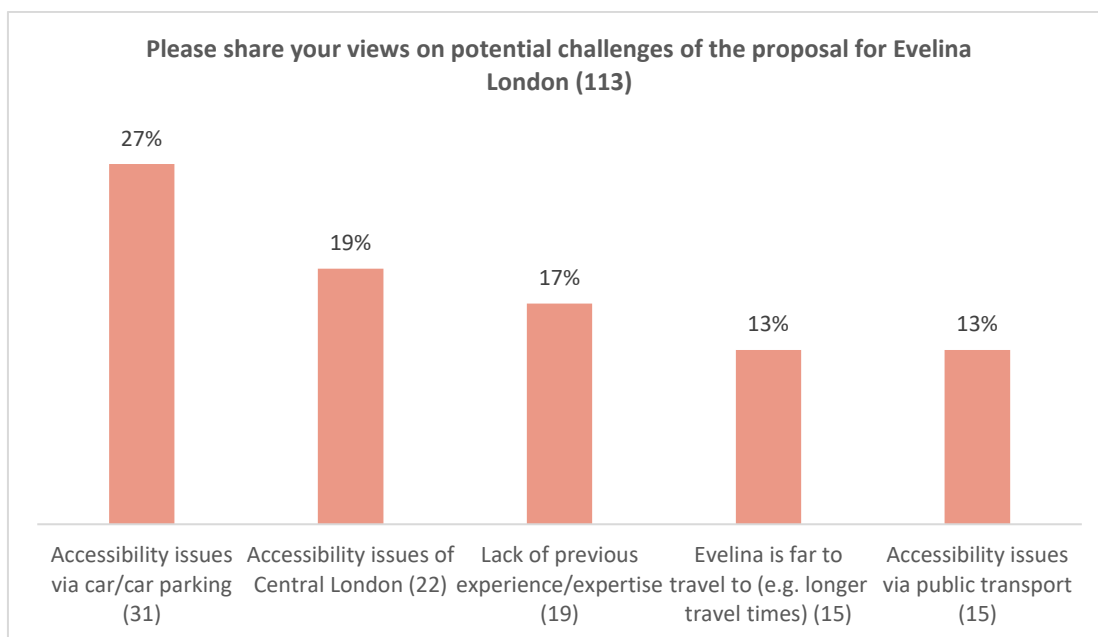


Figure 9 Children, young people, and their families and advocates, with no cancer experience, Evelina London, Potential Challenges

Across all feedback types, travel to and accessibility of Evelina London was a key concern. In terms of the questionnaire, children, young people or families with no cancer connection expressed their concern with accessing Evelina London via car (27%), particularly with the difficulty of parking onsite. Another key theme on the accessibility of Evelina London was due to its location within central London, with respondents mentioning how it is further away for most residents who will access its services (19%).

Some parents and carers within this group had personal experience of visiting Evelina London.

- *‘Having more than one child and buggy and car seats is a challenge, so parking on site would be more useful. The drop off zone isn’t useful if its full and you are driving alone’ (Community focus group, South London, November 2023)*
- *‘I think travelling on a train would be dangerous if you had cancer or were sick after an operation’ (Child, young person, or family member with no direct experience of cancer, questionnaire response)*
- *‘Extremely limited parking’ (Child, young person, or family member with no direct experience of cancer, questionnaire response)*
- *‘Parking is always hectic, and it is hard to find spaces to park’ (Community focus group, East Sussex, November 2023)*



- *'Would we have to pay congestion charge each time we travel in or visit someone there? This feels very unfair and a penalty for less wealthy families considering why we'd need to be there' (Community focus group, Surrey, November 2023)*
- *'Will there not be any support with travel for those that live in Sussex? It is pretty far and what if your parents don't have a car or only one car to share in a large family?' (Community focus group, Sussex, November 2023)*

Evelina London does not have expertise or experience in children's cancer care

Across all feedback types, children, young people, and families with no cancer connection raised their concerns about the lack of experience and clinical expertise of Evelina London in children's cancer care 17% of questionnaire responses mentioned this. There was also reference to specialisms not available at Evelina London; most notably neurosurgery.

- *'Lack of existing expertise on dealing with children/carers with cancer' (Child, young person, or family member with no direct experience of cancer, questionnaire response)*
- *'Children requiring neurosurgery would potentially need to be transferred between sites - this costs money and can be risky' (Child, young person, or family member with no direct experience of cancer, questionnaire response)*
- *'Evelina does not have the expertise or experience of treating Paediatric cancer, compared to St George's' (Child, young person, or family member with no direct experience of cancer, questionnaire response)*
- *'The thought of building new cancer services from scratch at a different site (Evelina) from the existing services (St George's/Marsden) - which was founded over 25 years ago...and delivered fantastic and life-changing successes - is quite bewildering in the current climate' (Child, young person, or family member with no direct experience of cancer, questionnaire response)*

Lack of private rooms for patients at Evelina London

Some children, young people, and families with no cancer connection highlighted their concern about the low number of private rooms for patients in Evelina London's proposal. Respondents felt negatively about the prospect of having a bed in a bay, where patients and their families would not have the level of privacy wanted and needed to feel comfortable.

- *'Families not being able to share rooms with children can be worrying' (Community focus group, East Sussex, November 2023)*
- *'Rooms are limited' (Community focus group, South London, November 2023)*



- ‘The bay areas do not seem useful when patients need specialist care – no private bathroom’
(Community focus group, South London, November 2023)

8.2.3 Improvements

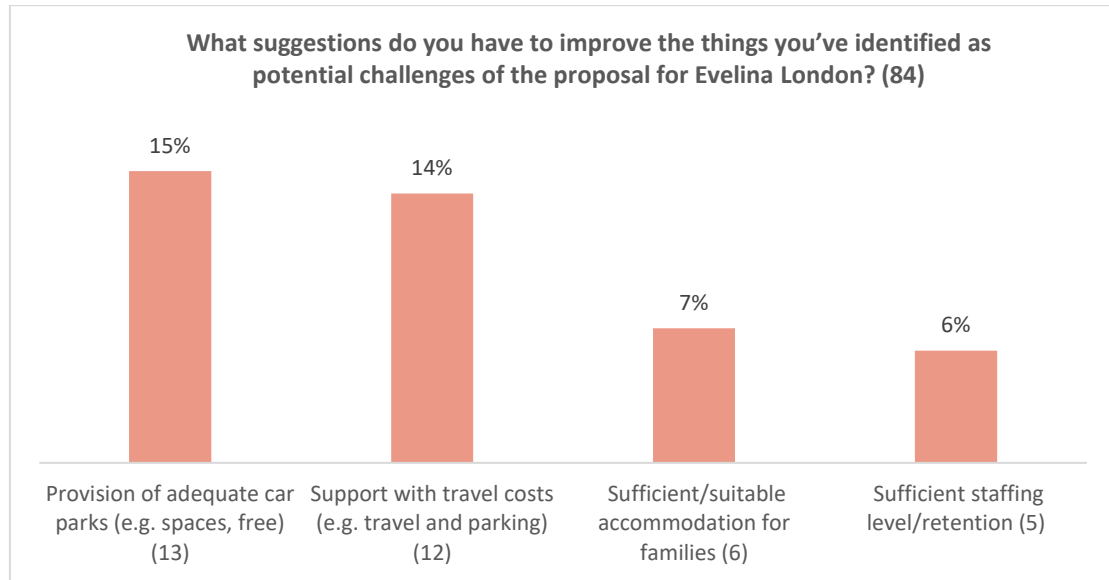


Figure 10 Children, young people, and their families and advocates, with no cancer experience, Evelina London, Improvements

In questionnaire responses, most children, young people and families with no cancer connection stated that the proposal for Evelina London could be improved through the provision of either increased on-site parking or dedicated parking spaces for families/patients (15%). This was echoed in other feedback types. As well as this, other key themes included providing support with travel costs whether this is emission zone charges, public transport or parking costs (14%) – crucially not just for one parent, but for others as well who play a caring role in a child’s support network. Others talked about accommodation – while it was seen as a positive that there is a Ronald McDonald House nearby, there were concerns about its capacity. Assurances around the availability of family accommodation was needed by some respondents.

8.3 The proposal for St George’s Hospital

8.3.1 Good points

St George’s Hospital has 25 years of experience in delivering specialist children’s cancer services as part of the current Principal Treatment Centre



Many children, young people, and families with no cancer connection consider the main strength of the proposal for St George’s to be the fact that it has experience in providing cancer care to children and young people. 32% of questionnaire responses referred to this, and this sentiment was echoed across other feedback types. Respondents talked about how this meant that clinical staff, services, and patient pathways were already established (or easier to put in place when the change happens) to help facilitate the change (17% questionnaire responses).

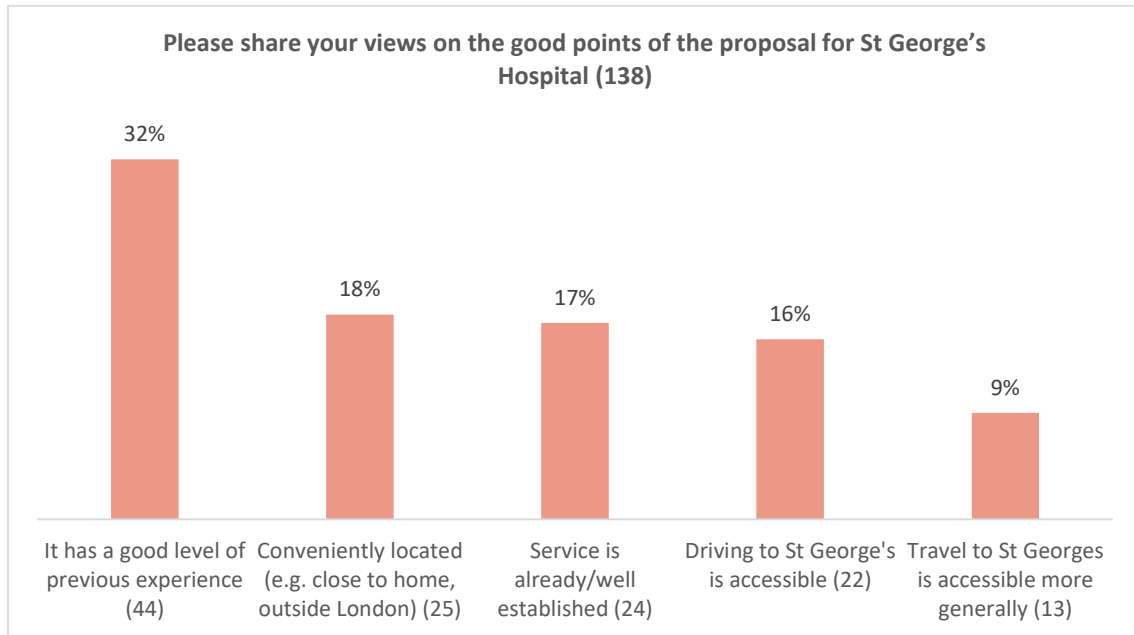


Figure 11 Children, young people, and their families and advocates, with no cancer experience, St George's Hospital, Good Points

- *‘The staff already have 25 years of experience in looking after these children’ (Child, young person, or family member with no direct experience of cancer, questionnaire response)*
- *‘Significant experience in looking after children with cancer - established pathways and relationships with the Marsden’ (Child, young person, or family member with no direct experience of cancer, questionnaire response)*
- *‘The existing children's cancer services are already delivered at St George's Hospital - thus the existing specialists are already on site and employed. Awarding the principal cancer centre status to St George's Hospital would provide the impetus to further develop the existing provision, and enable development of these services in an evolutionary way’ (Child, young person, or family member with no direct experience of cancer, questionnaire response)*

Perception that St George’s Hospital is located closer to the families in the whole catchment area that will use the Principal Treatment Centre, and it is easier to access by car because it is not in central London



Other key strengths of the proposal for St George’s Hospital for children, young people and families with no cancer connection include its perceived accessibility, with many mentioning how it is located closer to most families who will use the service, in terms of the whole catchment area (18% questionnaire responses), as well as being easier to access by car since it is located outside central London (16% questionnaire responses).

- *‘Easier to access on main roads from South Coast’ (Child, young person, or family member with no direct experience of cancer, questionnaire response)*
- *‘Easy to access, can drive or use public transport’ (Child, young person, or family member with no direct experience of cancer, questionnaire response)*

Provision of ensuite family rooms at St George’s Hospital

During the community focus groups, many comments from children, young people and families with no cancer connection reflected positively on the provision of ensuite family rooms at St George’s Hospital. Family rooms are important because they fulfil a physical and emotional need to be together, during what is a very difficult and stressful times for families.

- *‘Family suites – great to be together with all the siblings etc, especially if have a baby and breastfeeding’ (Community focus group, South West London, October 2023)*
- *‘The family rooms are a big positive, my children are very young, and I wouldn’t want to sleep away from them. I am breastfeeding my youngest and this would be a good space for this’ (Community focus group, Surrey, November 2023)*

8.3.2 Potential challenges

Travel and accessibility challenges at St George’s Hospital

Although considered to be one of St George’s Hospital main strengths by some children, young people and families who have no cancer connection, for others, its location was seen as a challenge. Respondents talked about issues with accessing the site by car and securing car parking (14% questionnaire responses), as well as difficulties accessing the site via public transport since it is located outside of central London (9% questionnaire responses). This theme was echoed in other feedback types.



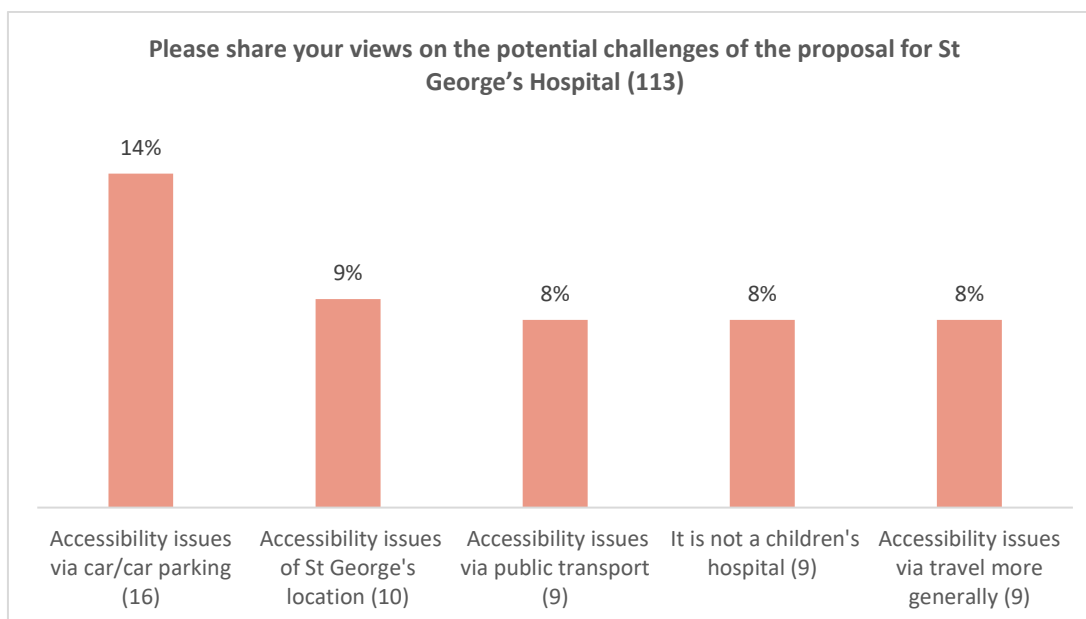


Figure 12 Children, young people, and their families and advocates, with no cancer experience, St George's Hospital, Potential Challenges

- *'Very limited overcrowded parking facilities. Difficult driving as commuter route if peak times for appointments' (Child, young person, or family member with no direct experience of cancer, questionnaire response)*
- *'The car parking is quite tight at St George's Hospital' (Child, young person, or family member with no direct experience of cancer, questionnaire response)*
- *'Parking will be a huge problem - especially as roads around the hospital have limited or no parking' (Child, young person, or family member with no direct experience of cancer, questionnaire response)*
- *'Location. It is far less convenient than Evelina. Less central and harder to get to from main line stations. Fewer alternative public transport options' (Child, young person, or family member with no direct experience of cancer, questionnaire response)*

Some families would have long journey times to reach St George's Hospital; there was some concern about this, particularly from those located near the south coast:

- *'Worried about the distance, travel is quite hard from Hastings. Would be really keen to get support' (Community focus group, East Sussex, November 2023)*
- *'It's very far away for us' (Community focus group, Brighton, November 2023)*

St George's Hospital is not a dedicated children's hospital, with old and outdated estate and facilities



Across all feedback types, some children, young people and families who have no cancer connection considered it a limitation of St George's Hospital proposal that it is not a dedicated children's hospital. Comments related to the old and out-dated estate, with older facilities. A couple of comments referred to the perceived tension between adult and children's services at St George's Hospital, and whether this would impact the level of care given to children's cancer care patients, in future.

- *'The hospital and facilities aren't nice albeit they will build a new centre' (Child, young person, or family member with no direct experience of cancer, questionnaire response)*
- *'Within an aged hospital, complex that has poor interconnectivity between departments and sections' (Child, young person, or family member with no direct experience of cancer, questionnaire response)*
- *'I'm wondering if there will be enough attention for the children at St George's Hospital as it's not just a children's hospital' (Community focus group, Surrey, December 2023)*

There was also concern from some that St George's Hospital children's intensive care unit did not have adequate capacity to take on the full Principal Treatment Centre⁴⁴.

St George's Hospital lacks some key specialisms

Some respondents in this group reflected on the key specialisms that are missing from St George's Hospital proposal, such as heart and kidney care. Neurosurgery was also mentioned, given that only a partial service would be provided.

- *'They don't have the other services you need at the level of complexity you need. Cardiology and renal really matter. Palliative care is important, and they don't have it (regardless of what your document says⁴⁵). They also don't have experience in networks / managing care across the whole region' (Child, young person, or family member with no direct experience of cancer, questionnaire response)*
- *'Doesn't seem to have the range of specialisms that Evelina has' (Child, young person, or family member with no direct experience of cancer, questionnaire response)*

Somewhat related to this, some respondents expressed concerns about St George's Hospital research capability and capacity.

- *'Research is very important for this service. The most important point is in the PCBC [Pre-Consultation Business Case] - the panel did not see the St George's Hospital proposal as*

⁴⁴ It is noted that St George's Hospital provides all the intensive care for the current Principal Treatment Centre so it already has this capacity.

⁴⁵ Although it is noted that palliative care is available at St George's Hospital.



having the same potential to sustain and enhance research and create the future facing service children with cancer need. This says it all - this service change is all about the future of care for these children and independent experts in paediatric oncology research (including at the ICR) have said St George's Hospital would not be as capable of delivering the innovative treatments they need' (Child, young person, or family member with no direct experience of cancer, questionnaire response)



8.3.3 Improvements

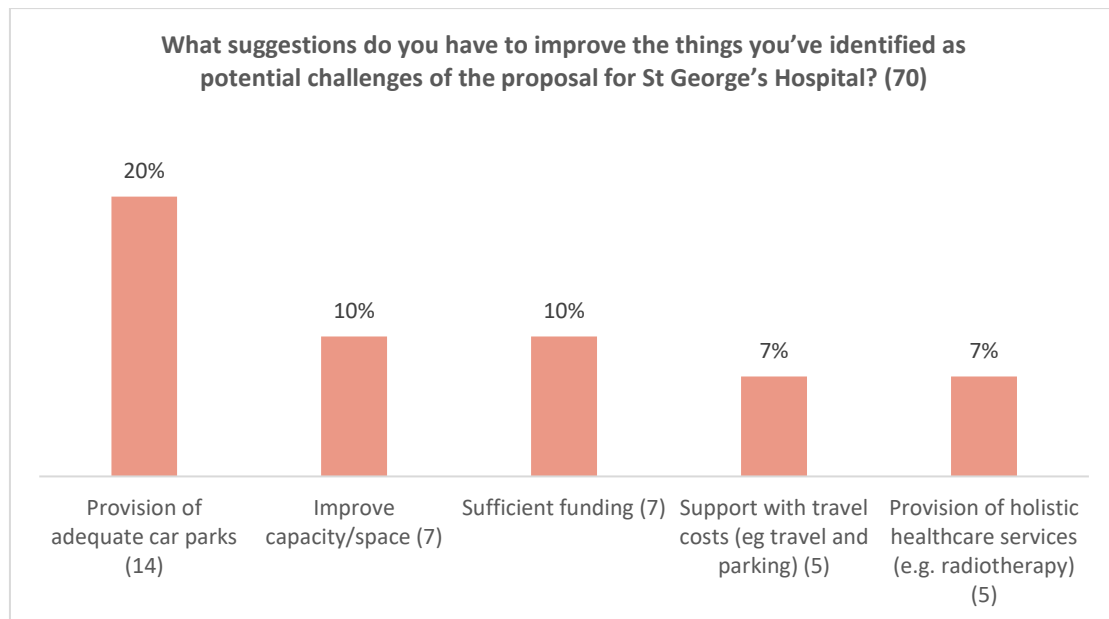


Figure 13 Children, young people, and their families and advocates, with no cancer experience, St George's Hospital, Improvements

Across feedback, a key improvement to the proposal for St George's Hospital for children and families with no cancer connection would be to improve or expand parking on site, with some suggestions including having dedicated parking bays or discounted parking for families of patients who are receiving treatment (20% questionnaire responses).

- 'Would be good if they could expand the car park, add some levels. And also give parking discounts to parents and patients during cancer treatments' (Child, young person, or family member with no direct experience of cancer, questionnaire response)
- 'Could there be an opportunity for the children's wing to have its own car park? One less thing for stressed parents to worry about' (Child, young person, or family member with no direct experience of cancer, questionnaire response)

Some also recognised that for the change to be a success then greater funding for St George's Hospital would be required, especially given its current estate and facilities.

- 'If this is the chosen option, there should be additional funding if needed to ensure that the facilities would be at least as good as those offered by Evelina' (Child, young person, or family member with no direct experience of cancer, questionnaire response)



- ‘The move should have suitable investment’ (Child, young person, or family member with no direct experience of cancer, questionnaire response)

Reference was also made to ensuring other key services were provided on-site at St George’s Hospital, such as radiotherapy.

8.4 Views on the delivery of radiotherapy services at University College Hospital

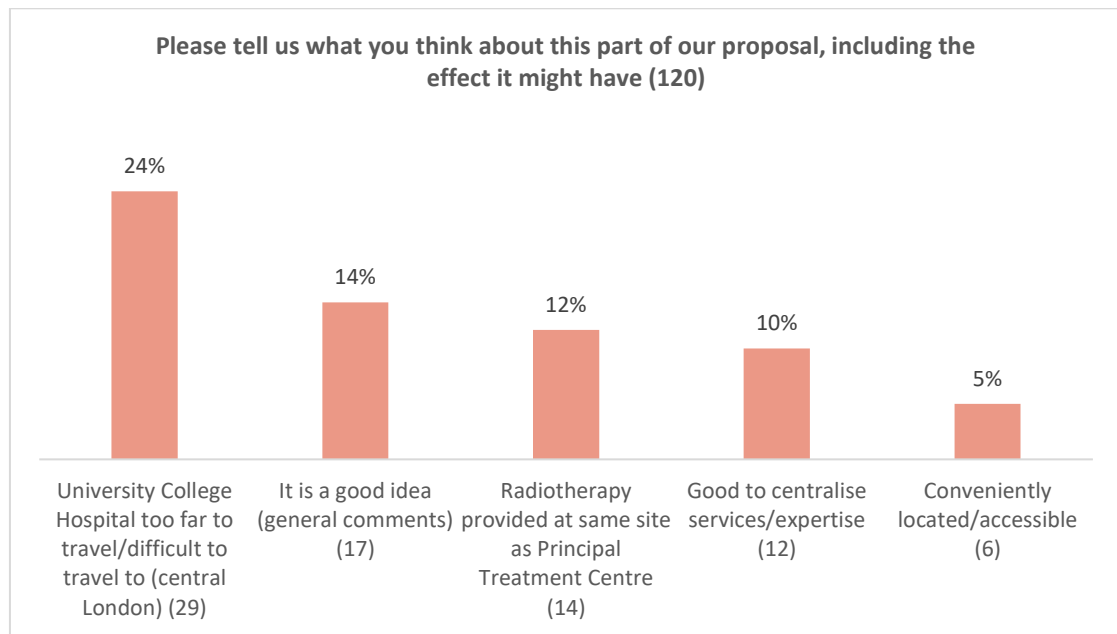


Figure 14 Children, young people, and their families and advocates, with no cancer experience, Radiotherapy Services at University College Hospital, effect proposal might have

Similarly to other stakeholder groups, a key theme from children, young people and families with no cancer connection about moving radiotherapy from The Royal Marsden to University College Hospital is that the distance is too far for patients to travel, especially for those living outside central London (24% questionnaire responses).

- ‘This change in location would make it incredibly difficult for families who live outside of London to get to’ (Child, young person, or family member with no direct experience of cancer, questionnaire response)
- ‘UCL is a long distance for residents in south west London’ (Child, young person, or family member with no direct experience of cancer, questionnaire response)



- *'Possibly make it trickier to get to central London site for those living further out in the south east' (Child, young person, or family member with no direct experience of cancer, questionnaire response)*

Some respondents talked generally about the move of radiotherapy to University College Hospital as a good one (including 14% of questionnaire responses to this question), and some reflected on the strength of the proposal to centralise radiotherapy (10% of questionnaire responses).

- *'Fine. If University College Hospital already do proton beam and other radiotherapy services that makes sense' (Child, young person, or family member with no direct experience of cancer, questionnaire response)*
- *'Any improvement to service or increase in service is very welcome' (Child, young person, or family member with no direct experience of cancer, questionnaire response)*
- *'A good proposal, if it opens up a larger service' (Child, young person, or family member with no direct experience of cancer, questionnaire response)*

Other feedback focused on the need to locate radiotherapy within the Principal Treatment Centre itself. The idea of children and families traveling to another hospital for radiotherapy was seen to be potentially stressful, disruptive, and financially costly.

- *'It should be included in the two proposed treatment centres instead' (Child, young person, or family member with no direct experience of cancer, questionnaire response)*
- *'Difficult for families to access and requires treatment to take place across multiple sites at what is already a very stressful time' (Child, young person, or family member with no direct experience of cancer, questionnaire response)*
- *'It may be unhelpful for families to have treatment across different hospitals to learn and navigate different hospitals and care teams' (Child, young person, or family member with no direct experience of cancer, questionnaire response)*

8.5 Future Principal Treatment Centre

When children, young people and families with no cancer connection reflected on what would matter most to them in a future Principal Treatment Centre, they said:

- State of the art facilities, which are clean and bright
- Child-friendly and child-focused, welcoming atmosphere
- A hospital that does not feel like a hospital



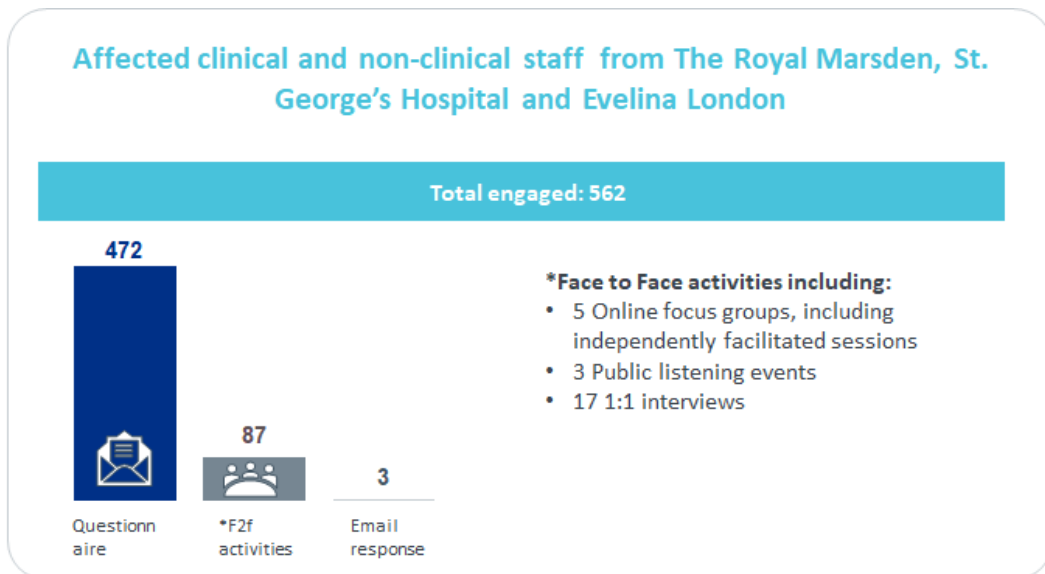
- Expertise and experience of specialist staff
- All of the specialist expertise in one place
- Groundbreaking research facilities, access to new treatments and clinical research
- Good children's intensive care unit access
- Ease of access for families by car or public transport
- Lots of parking available
- Easy and affordable family accommodation nearby
- Spaces for parents
- Located locally.



9 Affected clinical and non-clinical NHS staff

This chapter concerns feedback from clinical and non-clinical NHS staff at the hospitals where the Principal Treatment Centre is currently, or could be. We call these ‘affected staff’ – from The Royal Marsden Hospital, St George’s Hospital, and Evelina London Children’s Hospital. These respondents draw on their professional expertise and first-hand experience of delivering children services. Some staff have experience of working at more than one of the affected hospitals. It is important to note that feedback here represents personal opinion; formal responses from organisations are presented in a chapter that follows in this report. Feedback from other NHS staff members, including from University College Hospital staff, is included in the next chapter.

9.1 Engagement snapshot



9.2 The proposal for Evelina London Children’s Hospital

9.2.1 Good points

Evelina London is a purpose-built children’s hospital, with many specialities and a large children’s intensive care unit

Across all feedback types, many affected clinical and non-clinical staff felt strongly that a key strength of Evelina London’s proposal is that it is a children’s hospital. This strength was linked to its breadth and depth of specialisms on site, including heart and kidney care, the perceived expertise offered by a network of allied healthcare professionals, and expertise in palliative care for children.

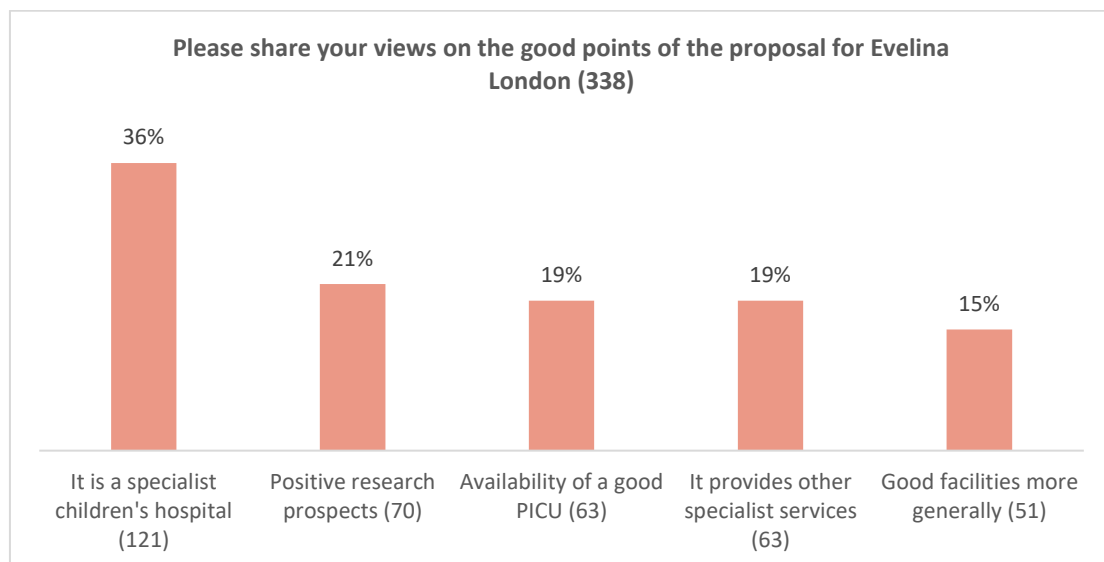


Figure 15 Affected clinical and non-clinical staff, Good Points about Evelina London

- ‘Evelina is a specialist children's hospital and are experts in providing high quality care for children with complex illnesses and disabilities. There are a large number of children specialist medical/healthcare professionals to support the development and running of this service’ (Current member of staff, Evelina London, questionnaire response)
- ‘Strength at Evelina is a large PICU and breath of specialities. Large teams, huge services with a range of specialities within, and this comes with immense expertise’ (Palliative care consultant trained in oncology, Evelina staff event, November 2023)
- ‘Comprehensive children’s hospital with PICU and other specialities’ (currently works for the Principal Treatment Centre at The Royal Marsden Hospital, questionnaire response)



- *‘Evelina London is a world-class children's hospital with strong integration of research into working of the hospital. It attracts excellent patient and family feedback, and exceptional staff feedback. It has all the required co-located clinical services and an abundance of non-clinical support facilities and services only available in a children's hospital of this size’ (Currently works for Evelina London, questionnaire response)*
- *‘Has all children’s specialties on site except neurosurgery, which King’s does’ (Staff meeting at The Royal Marsden, December 2023)*
- *‘It has a large number of paediatric specialists with a lot of expertise. Not all patients follow the textbook: it would be good to have access to extra services, not just those that are specified [in the service specification]’ (Member of staff, site visit to The Royal Marsden, December 2023)*
- *‘There is also a wealth of expertise across allied health professionals including speech and language therapists, occupational therapists’ (Evelina staff event, November 2023)*
- *‘A service that is often underestimated is the palliative care service – Evelina’s has grown a lot in the last 15 years and the care they provide is pretty remarkable and I hope this message gets conveyed’ (Evelina staff event, November 2023)*
- *‘The main advantage about Evelina is that it is a children hospital. They understand the need of the child and the parents. The journey of the child affects the whole family not just one person. They already have the background of dealing with the other aspects of the family, transport, accommodation. The hospital infrastructure is excellent to accommodate an oncology department beside the other specialities. The team seemed friendly and willing to offer the best care’ (Member of NHS staff working at the Principal Treatment Centre at The Royal Marsden Hospital, questionnaire response)*
- *‘Evelina Children Hospital - as it is mentioned in the name ‘children hospital’ - this may have positive psychological impact on parents of newly diagnosed children, that their kids will be cared for in a hospital specialising in children services. As a children’s hospital, Evelina has a more children-friendly feel, with many areas designed to appeal to children's needs’ (Member of NHS staff currently working at the Principal Treatment Centre at St George’s Hospital, questionnaire response)*
- *‘Evelina is endowed with a large Nuclear Medicine Department comprising several scanners, including the cutting-edge PET/MR (the second one in the country, with the other being at The Christie, in Manchester). Although the latter is only used for research purposes at the moment, this machinery is very promising because in the near future regular clinical*



applications could be sought" (Email response from a member of staff who currently works for the Principal Treatment Centre at The Royal Marsden and St George's)

Respondents talked positively about the hospital building of Evelina London; it was considered attractive and designed with children in mind. One particular facility, the simulator MRI scanner, was highlighted as an asset by some respondents. Radiology is considered to be cutting edge at Evelina London. Evelina London also has PET-MR, which has the potential to be used for clinical applications in the future to reduce radiation exposure in children from PET-CT, alongside a Nuclear Medicine Department.

- *'This hospital has child-friendly facilities, including an MR simulator (the only one in our country!) the huge benefits of which (reducing the rate of general anaesthetics and increasing the imaging quality by helping the children keep still in the real scanner) I know very well as I had the fortune to previously work with it abroad. Moreover, the cutting-edge interventional radiology suite and an MR scanner are next to each other allowing for a tailored and more accurate real-time biopsy in a one-stop examination' (Paediatric oncoradiologist from The Royal Marsden, email correspondence)*
- *'Same CT and MR scanners as The Marsden' (currently works for the Principal Treatment Centre at The Royal Marsden Hospital, questionnaire response)*

The perception that Evelina London has excellent research facilities with a strong track record of research

Linked to this, others commented that another strength is that Evelina London has excellent research facilities with a strong track record of research (21%). This was often referenced in relation to Guy's and St Thomas's NHS Foundation Trust (GSTT), supported by its charity, and connections to King's College London.

- *'The amount of research happening at GSTT is something important for a principal centre to have' (Currently works for Evelina London, questionnaire response)*
- *'Research into evidence-based healthcare and an ongoing desire to improve services is embedded into the culture of Evelina' (Currently works for Evelina London, questionnaire response)*
- *'While they don't have cancer research, the infrastructure is there for early trials and many of these are translatable to cancer research, all we need is expertise of those at The Royal Marsden. The Clinical Research Facility at Evelina has been renewed for another 5 years*



where delivery of child trials are key to delivery, it has capacity for this' (Evelina staff event, November 2023)

- *'Evelina is part of a prestigious and wealthy Trust supported by an efficient Charity and including outstanding research facilities without which most of our oncological cohort would not survive' (member of staff who currently works for the Principal Treatment Centre at The Royal Marsden and St George's Hospital, email response)*

Some experience relating to children's cancer care and adult oncology at Evelina London

It was highlighted by some staff across all feedback types that staff at Evelina London already work with some oncology patients and services through their existing work. A few staff from The Royal Marsden reflected on occasions of partnership working with Evelina London in relation to child oncology patients.

- *'Complex children with congenital cardiac or renal diseases who need surgery because of a neoplasm will be operated at Evelina London anyway because deemed safer than St George's Hospital due to the established expertise of the former in these conditions' (Meeting with members of staff, The Royal Marsden, December 2023)*

A few members of staff from Evelina London highlighted that care for immunosuppressed children is already routine as they care for transplant patients.

- *'When transplanted they are extremely immunosuppressed and are cared for on a non-infectious ward... Infection control is tight. They are supported by play team and psychology teams as well as nursing and medical staff. This is routine.'* (Member of staff at Evelina, email correspondence, December 2023)

Some staff said being part of Guy's and St Thomas' NHS Foundation Trust was another key strength of the proposal from Evelina London, meaning that they have direct links to adult oncology services through the Trust. This was considered particularly important in terms of research, but also helpful for young people transitioning to teenage and young adult services.

Evelina London is a good place to work

Some staff reflected on the positive work culture and strong management practices of Guy's and St Thomas's.

- *'Part of established forward thinking trust. Forward thinking management. I will feel proud working at Evelina' (Currently works for the Principal Treatment Centre at The Royal Marsden Hospital, questionnaire response)*



- *'The Trust invests heavily in upskilling and training staff to ensure they are highly skilled and knowledgeable in their fields' (Currently works for Evelina London, questionnaire response)*
- *'Hospital and team are inspiring' (Currently works for the Principal Treatment Centre at The Royal Marsden Hospital, questionnaire response)*

There was also reference to Evelina London's track record in recruiting and retaining staff.

- *'Recruitment might not be straightforward, but Evelina has good recruitment/retention rates and also good staff questionnaire results. Evelina has thoughts about how we can upskill existing staff' (Evelina staff event, November 2023)*
- *'There's a buzz you get in London, when you step out of Waterloo. It would attract a bigger pool of staff and expertise – a lot of people won't come for a job at The Royal Marsden because of its location' (Member of staff who currently works at the Principal Treatment Centre at The Royal Marsden, site visit, December 2023)*

Evelina London has existing relationships with other healthcare providers

Shared care was considered to be another strength of Evelina by some affected staff; they talked about Evelina London's experience of working with different organisations across the region including King's College Hospital and hospitals where children's cancer shared care units are based. In terms of dealing with oncology patients who require neurosurgery, staff were keen to emphasise that a relationship with King's College Hospital is already in place:

- *'I have experience where children have neurosurgery at King's and return to Evelina for rehab. We have a long-term relationship with Kings that works well from experience working within that service. This relationship is already established, and I don't see working together as a problem for the proposals' (Evelina staff event, November 2023)*
- *'Evelina runs the non-malignant service with King's and has experience of visiting King's College Hospital and seeing patients there and making plans for their care. This has expedited the care of the patient' (Evelina London staff event, November 2023)*

References were also made to Evelina London hosting the South Thames Paediatric Network (STPN), seen as a strength in terms of partnership working and links across other hospitals.

- *'Hosts the South Thames Paediatric Network which is working closely with the South Thames Children and Young People's Cancer ODN – means that network and ODN work is already closely aligned and the relationship and joint working would be strengthened from a future colocation of oncology at Evelina Childrens Hospital' (Currently works for the Principal Treatment Centre at The Royal Marsden Hospital, questionnaire response)*



Links between Evelina London and The Royal Marsden were also talked about, for example through the South Thames Retrieval Service (STRS) and the review of oncology patients from The Royal Marsden with cardiac problems.

In contrast to this, some members of staff also stated that Evelina London may benefit from not having experience in delivering cancer care for children.

- *'They have no preconceived conceptions about or experience of delivering oncology – a big benefit – this would allow the service to transfer across as it is and settle into place' (Member of staff, The Royal Marsden, December 2023)*
- *'[Evelina London are] taking time to talk to staff, acknowledging their lack of oncology experience historically, understanding the importance of tapping into our expertise in designing a new service and thinking about what strengths they offer to help develop the oncology service' (Member of staff who currently works for The Principal Treatment Centre at The Royal Marsden and St George's Hospital, email response)*

Evelina London uses the same IT system for patient records as The Royal Marsden, which was perceived as helpful to a smooth transition

Principal Treatment Centre *'The Royal Marsden also has access to Epic which would make transition smoother as using the same system' (Evelina London staff event, November 2023)*

- *'Using Epic may make a big difference when it comes to transferring patient information and chemotherapy builds' (Currently works for the Principal Treatment Centre at The Royal Marsden Hospital, questionnaire response)*

Evelina London is relatively close to University College Hospital for radiotherapy

Across feedback types, some affected clinical and non-clinical members of staff said it was an advantage that Evelina London was located closer to University College Hospital for radiotherapy compared to St George's Hospital, meaning journeys between hospitals would not be 'so long and arduous' for patients. Staff talked about both inpatients as well as outpatients who might have to manage appointments on the same day between hospitals.

There is family accommodation available at Evelina London and nearby

Thinking of the needs of patients and their families, some staff talked about the availability of parent and family accommodation.



- *'Breadth of parent accommodation, got accommodation below PICU for those acutely unwell, then a couple of others including long term solution at Ronald McDonald' (Evelina London staff event, November 2023)*
- *'From intensive care perspective, it's unusual for patients not to be accommodated at Ronald McDonald House at Evelina London' (Evelina staff event, November 2023)*

Good public transport links serving Evelina London, for patients, families, and staff

Some comments from staff related to the accessible location of Evelina London for public transport use.

- *'Evelina is far better served by public transport, for people that choose that, compared to Marsden currently' (Evelina staff event, November 2023)*
- *'Much easier to get to than St George's Hospital by public transport for The Royal Marsden staff, who mainly live in Kent, Surrey and Sussex' (Member of staff, site visit to The Royal Marsden, December 2023)*

Charitable support at Evelina London

A few respondents talked about Evelina London's access to charitable support through Guy's and St Thomas' NHS Foundation Trust.

- *'Evelina has access to resources such as charitable support... which has some of the biggest fundraising opportunities' (Evelina London staff event, November 2023)*

9.2.2 Potential challenges

Lack of expertise and experience of providing children's cancer care at Evelina London

Across all feedback types, many affected clinical and non-clinical staff considered the greatest challenge of Evelina London to be its lack of experience in treating children and young people with cancer, with many particularly mentioning the uncertainty of existing staff expertise and as to whether extra training for existing staff would be needed (including 32% questionnaire responses). These are linked to concerns about retaining staff from the current Principal Treatment Centre.

- *'The staff are not experienced in treating children with cancer. Although the facilities will be new, the key factor for cancer outcome will depend upon staff expertise in diagnosis & treatment, and it will take years, if not decades, for the current level of care to be met' (Currently works for the Principal Treatment Centre at St George's Hospital, questionnaire response)*



- *‘Many staff at Evelina do not currently have experience of looking after children with cancer: doctors and nurses, AHPs (physio, OT, SALT), radiographers, play and psychology team etc’ (Currently works for the Principal Treatment Centre at St George’s Hospital, questionnaire response)*
- *‘Surgical team not currently based there – this may make patients nervous. The nursing team don’t have any experience looking after these patients – they will need significant education’ (Member of NHS staff currently working at Evelina London, questionnaire response)*

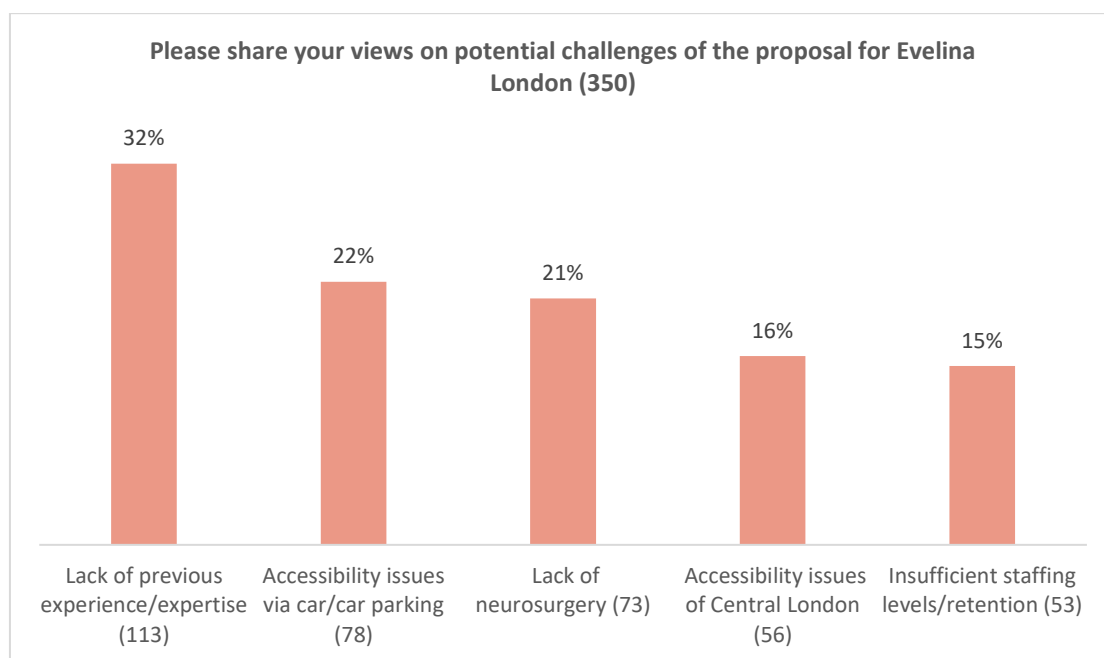


Figure 16 Affected clinical and non-clinical staff, Potential Challenges about Evelina London

Challenges relating to attracting an experienced oncology workforce to Evelina London

Some expressed concern around staffing the Principal Treatment Centre if it moved to Evelina London. This related to the challenges in retaining staff from The Royal Marsden and St George’s Hospital, and encouraging them to move to Evelina London, but also the years that would be needed to train and embed new children’s cancer care teams (if existing staff could not be retained) in a new environment.

- *‘There is a lead-time to train nurses from which they’d be starting from a low base. Nurses also need to be doing cancer all the time to maintain their competence – it’s not the same if a staff member has done it in the past’ (Meeting with nurse at The Royal Marsden, December 2023)*



- *'The building is not fit for the purpose of caring for oncology patients – absence of laminar flow cubicles. PICU has 2 laminar flow cubicles, but none have bathroom facilities (not enough for the increased burden of cancer patients). The staff have little or no expertise in this area. We are already under pressure with poor recruitment, poor workflow and inadequate number of beds' (Member of NHS staff who currently works at the Evelina London, questionnaire response)*
- *'Lack of experience of the team at Evelina, as they have NEVER managed cancer, we are talking about radiology, infectious diseases, gastroenterology, surgery' (Currently works for the Principal Treatment Centre at St George's Hospital, questionnaire response)*
- *'No existing skills in oncology is a big risk. This extends to all different workforce groups, not just nurses' (Meeting with nurse at The Royal Marsden, December 2023)*
- *'The team have no experience in managing children with cancer. Experience is vital in this group for nurses, psychologists, play therapists, intensivists, and surgeons. You cannot just import these people. The nurses with oncology experience in south London currently all work at RMH or SGH, and who knows if they will transfer. Similarly, the oncologists may not want to move' (Currently works for the Principal Treatment Centre at St George's Hospital, questionnaire response)*
- *'Staff have no oncology experience. It is a complex speciality that would need to employ a whole new team of people. Not practical in current staffing crisis' (Currently works for Evelina London, questionnaire response)*

There was also a concern that staff could be asked to work in other areas of the hospital, resulting in a loss of their oncology expertise, and having a detrimental impact on patients who need dedicated care.

It is also important to note that a few respondents talked about the competition for staff between Evelina London and Great Ormond Street Hospital (Principal Treatment Centre, North Thames area); a few clinicians expressed concern that it could impact staffing levels and quality of care in hospitals in central London. For example, one respondent said:

- *'I think that there is a disadvantage in the [Principal Treatment Centre] being so close to GOSH which may reduce staffing recruitment and retention' (Currently works for the Principal Treatment Centre at The Royal Marsden Hospital, questionnaire response)*

Travel and accessibility concerns relating to Evelina London affecting staff recruitment and retention



Some mentioned the extra distance staff would have to travel, the increasing cost of travel, the lack of financial incentive to move, and the potential detrimental impact on work-life balance, as potentially deterring existing staff from moving to Evelina London. Others questioned how experienced staff would be recruited altogether, to compensate for the lack of experience at Evelina London currently.

- *'Location is far from ideal, especially for staff unable to commute like myself. I feel I am literally being forced out of my job that I've worked hard to secure' (Currently works for the Principal Treatment Centre at The Royal Marsden Hospital, questionnaire response)*
- *'Many staff do not want to work in London/have to get the train into work. Real concerns about the retention of staff' (Currently works for the Principal Treatment Centre at The Royal Marsden Hospital, questionnaire response)*
- *'Travelling into central London for staff – additional London weighting will not bridge the gap and mean increased costs of commuting for staff' (Affected member of staff, public listening event, November 2023)*
- *'Some staff at St George's Hospital would not want to move to Evelina' (Feedback from staff at councillor visit to St George's Hospital)*
- *'Longer travelling times for staff at The Royal Marsden' (Meeting with nurse at The Royal Marsden, December 2023)*
- *'There has been no / little dialogue with staff currently delivering children's cancer care about moving to a new location. I am unsure whether the plan is to sacrifice these staff, or whether they will be asked to move (the commute is likely to be challenging)' (Currently works for the Principal Treatment Centre at St George's Hospital, questionnaire response)*

No neurosurgery delivered on site at Evelina London

Other respondents specifically mentioned the drawback of neurosurgery not being delivered on-site at Evelina London (including 21% questionnaire responses). It was highlighted that if the future Principal Treatment Centre were to be at Evelina London, it would be the only Principal Treatment Centre without neurosurgery on site. This was viewed as a missed opportunity.

- *'[Reference made to an NHS report that says] we need to have the ICU on site at all PTCs and we all agree on that. Within that report, it's very clear that paediatric neurosurgery for patients with brain tumours should be undertaken [at the PTC], you should have your PTC, you should have the neurosurgery service on site as well, and that's documented all the way through his report, and then it's backed up by experts from Great Ormond Street and at the*



time from Kings' (Staff engagement session online, member of staff at The Royal Marsden and St George's Hospital, December 2023)

- *'The lack of paediatric neurosurgery on site also feels like a huge, missed opportunity for neuro-oncology patients. As that would mean that, despite the PTC moving from The Royal Marsden, patients who become 'time-critical neuro transfers' would still need to be retrieved by STRS from Evelina to KCH or SGH, which makes the whole process a bit pointless for neuro-oncology patients (Member of staff working at the Principal Treatment Centre at The Royal Marsden Hospital and St. George's Hospital, email correspondence, December 2023)*
- *'Key interdependent services required for cancer care are missing, especially neurosurgery' (Currently works for the Principal Treatment Centre at St George's Hospital, questionnaire response)*

Layout of services at Evelina London across different buildings

Concerns were expressed by a few respondents about staff working in different areas across the Evelina London site. This could potentially affect staff and the effectiveness of team working, as well as compromise the patient experience.

- *'If staff are split up after the move this could further dent morale; there could also be an impact on multi-disciplinary working if staff aren't working all in the same location within the hospital (as they are now at The Royal Marsden)' (Meeting with nurse at The Royal Marsden, December 2023)*
- *'How would a child who has had a bone marrow transplant get to the day case unit for their procedures? Here we just wheel them along the corridor. There, it is planned to be in a different building' (Meeting with member of staff from The Royal Marsden, December 2023)*
- *'I think it would be three separate little bits and it would just be, you know, as a therapist, I'd be running between three separate bits. And with nowhere that I could see children and yeah, it doesn't gel together as a unit' (Staff engagement session online, member of staff at The Royal Marsden, December 2023)*

Family accommodation may need to expand at Evelina London

Some respondents raised their concerns about the capacity of family accommodation at Evelina London. The understanding of some respondents is that Ronald McDonald House is often at full capacity and there are no current plans to secure accommodation for families affected by cancer.

- *'Although they have a big Ronald McDonald House, beds are not currently ring-fenced for cancer families needing accommodation' (Public listening event, November 2023)*



Facilities not sufficient to accommodate the needs of cancer patients at Evelina London

Reflecting on their experiences of visiting and working at Evelina London, some affected staff members highlighted the availability of space as a challenge. This was largely mentioned in relation to dedicated recreational, educational, and therapy spaces for children with cancer, to keep them separate from other non-oncology patients.

- *‘Concerned about space at Evelina. Where would the services go? We already struggle for space for some clinics – as well as space for staff’ (Evelina London staff event, November 2023)*
- *‘One patient I’ve worked with has been in treatment for six months. The important things for them is the schoolroom and playroom. In Evelina London, they are both small and are in communal areas over a coffee area which isn’t appropriate, and this would cause parents real worries’ (Member of staff at The Royal Marsden, public listening event, November 2023)*
- *‘Space is an issue at Evelina London and having some therapy space would be really important’ (Evelina staff event, November 2023)*
- *‘The schoolroom and the playroom. They’re not sufficient for the kids we’ve got, and parents would totally freak. We’d get kids stuck in beds. We’d never get them out and being a physio, I want them out of bed, I want the eject button. There isn’t in Evelina. There is no therapy space at all as far as I’m aware’ (Staff engagement session online, member of staff at The Royal Marsden, December 2023)*



9.2.3 Improvements

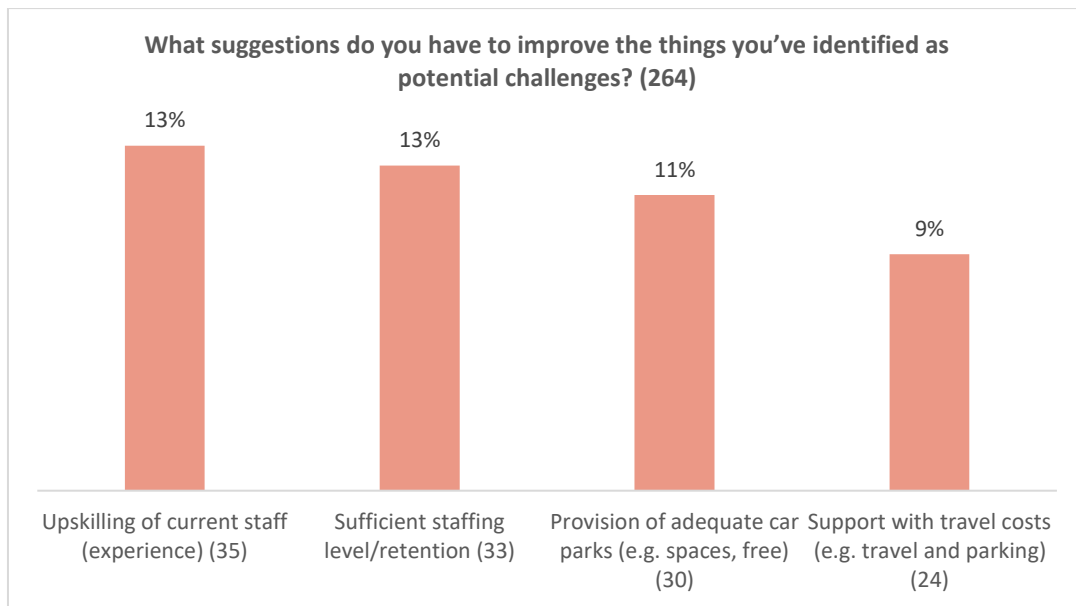


Figure 17 Affected clinical and non-clinical staff, Improve Potential Challenges about Evelina London

Despite not being an improvement of the proposal for Evelina London, some affected staff took the opportunity to state their preference for St George's Hospital. Other suggested improvements included the upskilling of existing staff at Evelina London since they do not have experience in providing care to children with cancer (including 13% of questionnaire responses to this question).

- *'Education sessions with existing PTC staff to give clinical update sessions for ELCH staff' (Currently works for Evelina London, questionnaire response)*
- *'Robust plans for how education and training can be developed and carried out' (Currently works for Evelina London, questionnaire response)*

Another improvement included the need for a clear and detailed plan for staff recruitment, and the perceived need for investment.

- *'Run a recruitment drive six months before the planned date of move. Aim would be to recruit and train staff so they can safely replace those who aren't planning to move. They would do all the oncology modules at the Sutton site and become part of the team, with a good understanding of how the service is run, ahead of the relocation. It would help to avoid risks of burn out and loss of staff' (Currently works for the Principal Treatment Centre at The Royal Marsden, site visit, December 2023)*



- *'We would need to increase staffing and huge investment in training since we will have lost most of our workforce since they will not move to Evelina' (Currently works for the Principal Treatment Centre at The Royal Marsden Hospital, questionnaire response)*
- *'Transfer of clinicians and teams to Evelina but that would still be detrimental to originating hospitals' (Currently works for the Principal Treatment Centre at St George's Hospital, questionnaire response)*
- *'Hiring more staff to face increase in demands' (Currently works for Evelina London, questionnaire response)*

In relation to this, some staff suggested retaining 'The Royal Marsden' model to help encourage staff to migrate to the new Principal Treatment Centre.

Support for travel, for staff and families, was another important theme here. This included reimbursement of costs relating to travel (with one suggesting that staff are reimbursed for the cost of travel for up to four years as part of a relocation package) and offering flexible appointment times for patients and their families. It is acknowledged that proposals already include the plan to reimburse travel for up to four years.

9.3 The proposal for St George's Hospital

9.3.1 Good points

St George's Hospital has 25 years of experience in delivering specialist cancer services as part of the current Principal Treatment Centre

This includes the children's intensive care unit and surgery. St George's Hospital already has some of the expertise in managing paediatric oncology pathways that is needed.

- *'They have extensive experience with sick patients and that service has been set up over many, many years' (Staff engagement session online, December 2023)*
- *'There is already a wealth of expertise at St George's Hospital, and it cannot be assumed that all the staff would move jobs to Evelina if offered' (Currently works for the Principal Treatment Centre at St George's Hospital, questionnaire response)*
- *'St George's are already experienced in caring for oncology patients and have existing facilities to accommodate this patient group' (NHS member of staff currently working at the Evelina London)*



- *'It has functioned perfectly well serving South London's population and has a wealth of existing expertise' (Currently works for the Principal Treatment Centre at St George's Hospital, questionnaire response)*
- *'PICU very experienced at managing children with cancer. Excellent at managing mediastinal mass caused by lymphoma when they can't breathe if they lie down – have to have anaesthetics sitting up. Not easy to deal with' (Staff engagement session online, December 2023)*

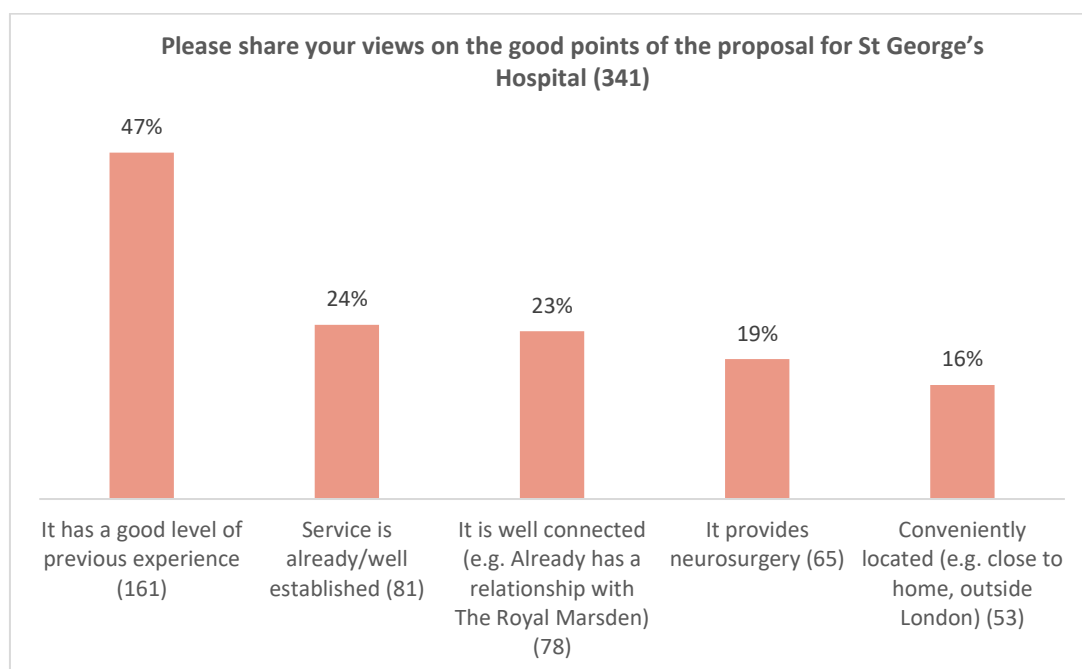


Figure 18 Affected clinical and non-clinical staff, Good Points about St Georges Hospital

Other key themes build on this, with others highlighting how services and pathways are already well established (including 47% questionnaire responses), due to the fact St George's Hospital has worked in partnership with The Royal Marsden in delivering the current Principal Treatment Centre (including 23% questionnaire responses).

- *'St George's Hospital is [part of] an excellent, well established, principal treatment centre. They have many years' experience in treating children with cancer and have a close working partnership with The Royal Marsden. They already have the facilities to provide the care and treatment required for these children with plans to expand' (Currently works for Evelina London, questionnaire response)*
- *'Existing partnership with RM / the RM model is known by St George's Hospital as well as RM staff' (Currently works for the Principal Treatment Centre at The Royal Marsden Hospital, questionnaire response)*



- *‘The teams already work together with well-established MDTs. The key inpatient specialties already deliver this work, so no transfers of personnel or expertise is needed. There is no need to move surgeons, or their teams. Most of the existing pathways can continue unchanged or with greater simplicity. There is neurosurgery on site properly, not just an acceptable compromise as Evelina option has’ (Currently works for the Principal Treatment Centre at St George’s Hospital, questionnaire response)*
- *‘St George’s Hospital is an excellent adult and children’s hospital with many strong paediatric services. It has established pathways and trained staff due to the current arrangements with The Royal Marsden Hospital’ (Member of NHS staff currently working at the Evelina London, questionnaire response)*
- *‘It feels a benefit to know that there is already in place a familiarity and good working relationship with SGH’ (Currently works for the Principal Treatment Centre at The Royal Marsden Hospital, questionnaire response)*
- *‘I would like to highlight the outstanding quality of the professionals working at St George’s Hospital that I have the pleasure of working with (nurses, pharmacists, paediatricians, surgeons, anaesthetists, radiologists, etc). Every single one of them give their very best for the patients and are always prepared to walk the extra mile for them. I only have words of praise for what I consider top-notch personnel’ (member of staff who currently works for the Principal Treatment Centre at The Royal Marsden and St George’s Hospital, email correspondence, December 2023)*

St George’s Hospital offers some neurosurgery on-site

Many comments referred to the specialist facilities and services located on site at St George’s Hospital to provide cancer care for children, such as neurosurgery (including 19% questionnaire responses).

- *‘Large number of specialties on site, including neurosurgery/cardiothoracic’ (Currently works for the Principal Treatment Centre at St George’s Hospital, questionnaire response)*
- *‘We do paediatric neurosurgery. Evelina don’t. About 25% of children’s cancers require neurosurgery. This would be a missed opportunity to bring the PTC and neurosurgery together’ (Staff engagement session online, December 2023)*

St George’s Hospital would offer a separate, standalone unit, dedicated to the Principal Treatment Centre

Some staff highlighted that St George’s Hospital unit would have a self-contained, children’s cancer unit, with its own entrance, minimising mixing between children with cancer and other patients. It



would also enable a more physically connected and coordinated workflow, to benefit staff as well as improve the patient experience.

- *‘All staff in ‘one place’; staff can more easily look after children in this model’ (Meeting with nurse, The Royal Marsden, December 2023)*
- *‘The thing that attracts me at George’s is actually a centre all in one block, Evelina is in three different bits’ (Staff engagement session online, December 2023)*

St George’s Hospital already has a strong working relationship with The Royal Marsden

Across feedback types, affected staff talked about the existing relationship between St George’s Hospital and The Royal Marsden, which has benefited from years of partnership working. This was seen as a real strength of the St George’s Hospital proposal, creating a strong foundation for the transition of the Principal Treatment Centre to St George’s Hospital, if St George’s Hospital is chosen. Related to this, there was reference to retaining The ‘Royal Marsden @’ brand.

- *‘This will make the transition more seamless (as compared to an environment (like Evelina London) when don’t know anyone)’ (Meeting with nurse, The Royal Marsden, December 2023)*
- *‘Marsden brand won’t be ‘swallowed up’ at St George’s Hospital (as it might in Evelina London). Will help enable history of RMH brand to be preserved along with clinical excellence. Maintaining this brand could help maintain closer relationships with RMH adult services’ (Meeting with nurse, The Royal Marsden, December 2023)*

St George’s Hospital is already known to some families; continuity of care will be maintained for those families

Although a short-term benefit, it was acknowledged that families under the care of the Principal Treatment Centre would maintain a sense of continuity when the transition happens.

- *‘Short term engagement would be easier with George’s and from a family point of view, going through an amazingly difficult time, changing providers may be difficult’ (Evelina London staff event, November 2023)*

9.3.2 Potential challenges

St George’s Hospital is not a dedicated children’s hospital, and lacks related specialisms

Across all feedback types, many affected staff stated that the greatest challenge of the proposal for St George’s Hospital is the fact that it is not a specialist children’s hospital (including 14% of questionnaire



responses to this question). Some of these comments related to the outdated estate at St George’s Hospital.

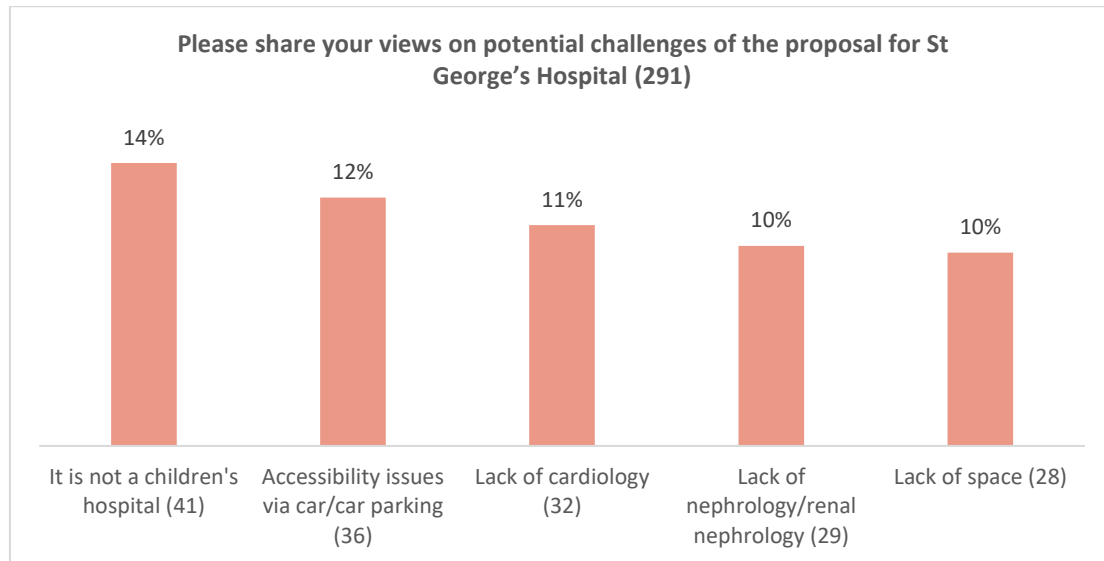


Figure 19 Affected clinical and non-clinical staff, Potential Challenges about St Georges Hospital

Others stated that St George’s Hospital lacks some specialist services that may be required to care for children with cancer, such as cardiology (11%) and nephrology (10%).

- ‘St George’s Hospital is not a dedicated paediatric hospital and as such their links to children’s networks is much lower than Evelina’s’ (Currently works for Evelina London, questionnaire response)
- ‘Lacks some specialist children’s services, including cardiac and renal, so children with these complications of cancer/cancer treatment would need to be treated elsewhere’ (Currently works for Evelina London, questionnaire response)
- ‘Limited space for current services expanding with need to consider where a purpose-built cancer service could be provided. Need for ongoing support from other tertiary services (ie cardiology/renal) for Oncology patients. Need to expand some imaging services such as echocardiography to support diagnostic treatment and management of oncology patients’ (member of NHS staff currently working for the Principal Treatment Centre at St George’s Hospital, questionnaire response)
- ‘At the moment, the haematology service at St George’s Hospital is absolute crisis. They have no paediatric haematologist at present time they’re having to buy in services from Evelina London and St. Mary’s because they have no consultant staff’ (Staff engagement session online, December 2023)



- *‘The environment at St George’s Hospital is quite depressing and the buildings look old. It isn’t a welcoming environment for children’ (Evelina London staff event, November 2023)*

Redefining St George’s Hospital as the new Principal Treatment Centre might be difficult to achieve due to financial constraints and the need to disentangle existing relationships

Some members of staff highlighted funding issues that already exist at St George’s Hospital, causing them concern about how realistic it would be to establish the new Principal Treatment Centre there. One member of staff commented that ‘they can’t get the basics right’:

- *‘St George’s Hospital has a long track record of underfunded departments, clunky internal administrative processes and many unopened paediatric oncology trials. Hence, it would be unrealistic to expect that the whole institution is going to turnaround in a matter of years to deliver world-class pioneering research and trailblazing initiatives to remain at the forefront of paediatric oncology nationally and internationally’ (Member of staff at The Royal Marsden Hospital, email correspondence, December 2023)*

In addition, and in contrast to those who think the existing links between The Royal Marsden and St George’s Hospital is a strength of the proposal, a few members of staff raised concerns about existing relationships posing a threat to positive change and innovation.

- *‘Having an established relationship could mean that a complete reset and redefinition of roles which would be needed might be difficult – it could be easier to move to something completely new rather than try to untangle established relationships’ (Staff engagement session, December 2023)*

One member of staff talked about a perceived lack of action by the management of St George’s Hospital:

- *‘I think the issue is a trust issue really. It’s a bit blunt but you know, over the years, as all of us as leaders working with George’s, we’ve heard all sorts of stuff that they promised us and they haven’t delivered on it’ (Staff engagement session online, member of staff from The Royal Marsden, December 2023)*

Travel and accessibility to St George’s Hospital would be challenging

Another key theme raised here surrounded accessibility, particularly via car and the difficulties relating to parking onsite and nearby for both staff and patients (including 12% of questionnaire responses in response to this question). It is noted that affected staff feedback about travel and accessibility concerns for Evelina London were greater in number. Some staff said that many current staff members at The Royal Marsden travel to work by car – and would want to continue to do so.



- *'Expensive limited parking' (currently works for the Principal Treatment Centre at The Royal Marsden Hospital, questionnaire response)*
- *'Not as centrally located as Evelina, further away from university hospital' (Member of NHS staff currently working the Principal Treatment Centre at St George's Hospital, questionnaire response)*
- *'Very hard to get to both driving and on public transport for staff and patients' (currently works for the Principal Treatment Centre at The Royal Marsden Hospital, questionnaire response)*
- *'It may be more difficult for our staff to get to: most people drive to work at The Royal Marsden, and public transport would mean going into central London and then out again' (Staff engagement session online, December 2023)*
- *'I just think St George is notoriously bad for parking. And that's not just for patients but for staff as well, our consultants provide an on-call service at Georges, and it is just shocking for them to even try and park anywhere. They won't give our consultants any parking permits. It's just I can't imagine Evelina will be any better, but Georges is notoriously bad. They haven't got enough parking spaces for staff, let alone visitors, and anyone who's been an outpatient appointment at Georges, you'll just have to get there well hours before just to try and get there on time. Shocking' (Staff engagement session online, December 2023)*

Perception that St George's Hospital does not have a strong research proposition

Some affected members of staff expressed their concerns about the viability of retaining the research function of The Royal Marsden if it moved to St George's Hospital.

- *'During the options appraisal process, the panel did not have the same level of confidence in St George's Hospital ability to deliver research as it did with Evelina' (Evelina London staff event, November 2023)*
- *'I've worked at St George's Hospital for 17 years – I'm not confident they would have the infrastructure to conduct research on the same level as Evelina' (Evelina London staff event, November 2023)*
- *'St George's Hospital has a poor track record in paediatric cancer trial research... failed to open several key paediatric oncology therapeutic studies they had committed to opening... This meant that patients receiving initial treatment at SGH could not be enrolled on these trials' (Currently works for the Principal Treatment Centre at The Royal Marsden Hospital, questionnaire response)*



- *'We've really struggled to run trials that really struck over the last 20 years. It's not been easy, and I do have concerns' (Staff engagement session online, member of staff from The Royal Marsden, December 2023)*

Perception that there is no strong connection to adult cancer treatment and care at St George's Hospital

A few members of staff talked about a perceived lack of connection between St George's Hospital with an adult oncology service; this is viewed as essential for research and treatment. Although it is acknowledged that St George's Hospital does provide cancer care for adults.

- *'We do see rare adult tumours in children and child tumours in adult. There needs to be a connection between paediatric and adult centres. St George's Hospital does not have an adult cancer treatment area' (Paediatric oncologist, The Royal Marsden, Public listening event, November 2023)*

St George's Hospital does not use the same IT system for patient records

St George's Hospital does not currently use the Epic system for managing patient records. The adoption of Epic has been viewed by some staff as instrumental in improving communications and patient care across hospitals. It was noted by one respondent that Epic is expensive.

- *'This would be a backward step for working in the community' (Evelina London staff event, November 2023)*

Facilities not currently suitable to meet the needs of children's cancer care patients at St George's Hospital

This specifically relates to concerns about the perceived lack of dedicated spaces for oncology patients, such as recreational (indoor and outdoor) and educational spaces at the current service at St George's Hospital⁴⁶.

- *'St George's Hospital currently doesn't have a dedicated play area/school for children with cancer -they have to share with other children and have a 'neutropenic hour' when children can use it. I would want dedicated provision in a future centre (as now in The Royal Marsden)' (Member of staff, public listening event 2)*

⁴⁶ It is important to note that comments in this section refer to the current service at St George's Hospital, given that the provision of services will be enhanced in the future with dedicated outdoor spaces for children as outlined in the consultation/proposal document.



A few comments also related to equipment, such as St George’s Hospital only having a portable PET scanner, with questions raised about the impact on the service as a result.

- *‘Did not see any mention of nuclear medicine who need these kind of scans. St George’s Hospital only has a portable PET scanner. GSTT has a PET-CT and Pet-MR. Are you taking account of this in your proposals? Needs to be more thought on how this will work’ (Paediatric oncologist, The Royal Marsden, Public listening event, November 2023)*

Family accommodation not sufficient at St George’s Hospital

Some staff reflected on the limited number of family rooms available at Ronald McDonald House.

9.3.3 Improvements

Across all feedback types, some staff (including 15% of questionnaire responses to this question) stated that funding would be required to improve and expand the current facilities offered at St George’s Hospital.

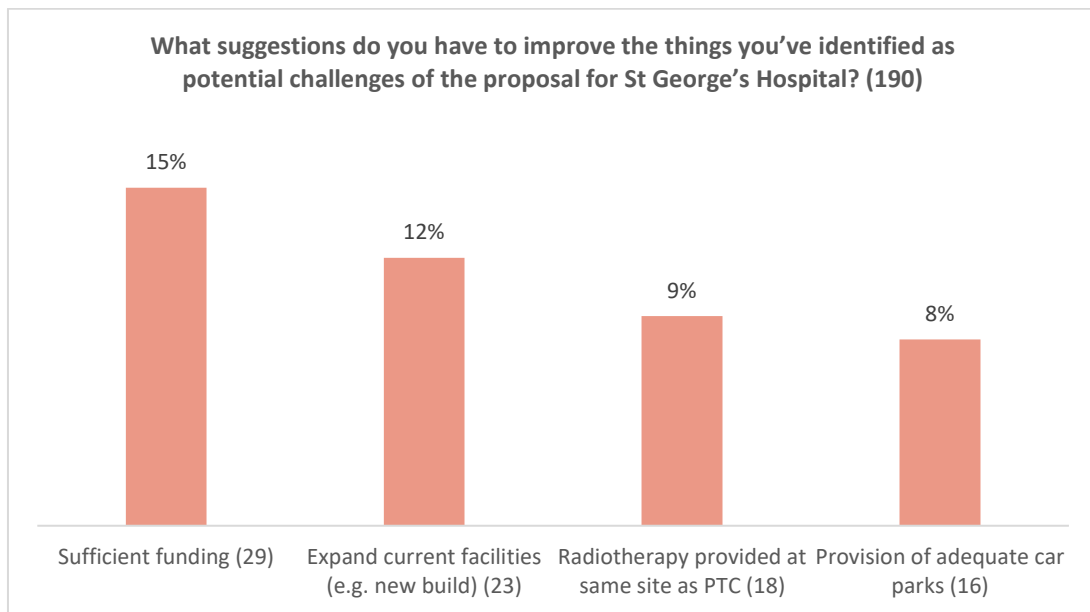


Figure 20 Affected clinical and non-clinical staff, Improve Potential Challenges about St Georges Hospital

Feedback mentioned improving the look and feel of St George’s Hospital for patients and families, as well as providing on-site accommodation and compensation for travel costs.

- *‘Money allocated to improve current facilities’ (Currently works for the Principal Treatment Centre at St George’s Hospital, questionnaire response)*



- *‘Additional funding for family accommodation and travel grants’ (Currently works for the Principal Treatment Centre at St George’s Hospital, questionnaire response)*
- *‘Would need to invest in its supporting services big time to provide anything that looks like proper specialist support’ (Currently works for Evelina London, questionnaire response)*
- *‘St George’s needs financial support to create the hospital building that children and their families deserve’ (Currently works for the Principal Treatment Centre at St George’s Hospital, questionnaire response)*

As envisaged in St George’s Hospital proposals, some staff were keen to have a truly self-contained children’s cancer centre through expanding the current facilities at St George’s Hospital with new, dedicated facilities (12%).

- *‘Keep the cancer treatment centre at St George’s Hospital and invest in new wing’ (Currently works for the Principal Treatment Centre at St George’s Hospital, questionnaire response)*
- *‘Need a solely designated paediatric ward’ (Currently works for the Principal Treatment Centre at St George’s Hospital, questionnaire response)*

As well as this, other affected staff stated that holistic care will need to be provided on site (9%). Here, respondents particularly mentioned radiotherapy, looking at whether this could be provided within St George’s Hospital without patients/families having to travel to University College Hospital.

- *‘Enable radiotherapy services for adults and children at SGH’ (Currently works for the Principal Treatment Centre at St George’s Hospital, questionnaire response)*
- *‘Radiotherapy to be brought inhouse’ (Currently works for Evelina London, questionnaire response)*

9.4 Potential challenges affecting both proposals

Some key themes were common across feedback for both proposals, affecting Evelina London and St George’s Hospital. These key themes are presented here.

Neither proposal offers a single-site solution; children’s cancer care will continue to be fragmented

This largely referred to the location of radiotherapy in a separate hospital, as well as the absence of a full neurosurgery service. Staff wanted assurances on detailed workflow planning and management to help coordinate a patient’s treatment between sites. Transporting very sick children between sites was raised as a concern.

Potential loss of the quality of care and specialist skills and services of The Royal Marsden



Some staff doubted that the new Principal Treatment Centre would be able to replicate the warm and personal care patients and their families receive at The Royal Marsden, given the relatively large size of the hospitals and the busy environment at both Evelina London and St George's Hospital. The availability of space for both proposals was also questioned:

- *'I don't think anybody's looked at the plans and said look, we've got this amount of space at the Marsden.... They've just said we've got this space available [at Evelina London/St George's Hospital], we've got this budget, let's squeeze it in here. So, I think somebody needs to look at the offices, the therapy areas, the school, the playroom, areas for parents, they're all really, really important [and how they are going to fit]'* (Staff engagement session online, December 2023)

Some feedback from staff was very specific to certain skills and services that were considered at risk if the Principal Treatment Centre moves. This included:

MIBG Scan

- *'No MIBG scanning facilities and no MIBG therapy on site for neuroblastoma patients. RMH is a national referral centre'* (currently works for the Principal Treatment Centre at The Royal Marsden Hospital, questionnaire response)

Specialist integrated haematology malignancy diagnostic service (SIHMDS)

- *'This service enables the rapid diagnosis of acute leukaemia. It would require substantial infrastructure to be set up at the relevant hospital before any move could be safely implemented'* (Affected member of staff, email response, November 2023)

Related to this, staff questioned whether charity funding would be lost, and if additional services like play therapy (which is funded by charitable donations), would be sustained in the new Principal Treatment Centre.

Staff recruitment and retention could be challenging for both proposals

Some staff expressed that there was a wider issue of staff recruitment and retention in the NHS which would affect both proposals.

- *'There is a shortage of nurses currently, there's a massive shortage of nurses in clinical practice and paediatric trained nurses are even more like gold dust. And if the staff from the Marsden choose because of the location of either site that they're not going to move, I am concerned that there will not be enough specialist oncology nurses to actually provide the services... you can't just knit an oncology specialist and it takes a number of years to gain*



that specialist knowledge. So, I think it's something that we've got a big workforce plan, national workforce planning, because we've got such a shortage of nurses across England' (Staff engagement session online, December 2023)

Plus, common to both proposals, the new Principal Treatment Centre would be located in inner London. Talking about the administrative team at The Royal Marsden, staff said:

- *'Although they're passionate about their job you know it's the big upheaval. It's time. It's the expenses, the work in London, you know, it's going to affect their salary' (Staff engagement session online, December 2023)*

Another member of staff said:

- *'Paediatric staff are saying they are not willing to move until they know more, until they understand more about what's on offer to provide some level of financial assurance for what they may lose' (Staff engagement session online, member of staff at The Royal Marsden, December 2023)*

Whether the service moves to St George's Hospital or Evelina London, there was real concern that staff would be financially disadvantaged given increased travel costs. Many comments relating to this were made by staff currently working at The Royal Marsden, although other members of staff from other hospitals acknowledged this challenge⁴⁷.

Staff also talked about having a worse work-life balance if they worked in London, including not being able to see their children in the evenings. The availability of quality childcare was also mentioned:

- *'Staff would be unlikely to be able to use hospital nursery provision (as they do now which is 'outstanding' rated and very good) which could mean putting children in private nursery which is more expensive (the current nursery is subsidised) and not as convenient (with the current nursery, you can drop children at 07:30 and pick them up at 18:00 either side of work)' (Meeting with staff at The Royal Marsden)*

Detrimental effect on the resilience of the current service at The Royal Marsden due to the potential for staffing losses

There is concern that the move of the children's and young people's cancer service to the future Principal Treatment Centre at The Royal Marsden and its ability to deliver quality care in the short to medium term. A few members of staff also expressed concern that the change will trigger early

⁴⁷ It is important to note that additional travel costs should be covered by the provider of the future Principal Treatment Centre for up to four years under staff terms and conditions.



retirement amongst key staff, including before the move. One member of clinical staff at The Royal Marsden said worry about this was keeping them awake at night.

Potential negative impact on The Royal Marsden’s teenage and young adults (TYA) service

Some staff members highlighted the risk to the TYA service when the Principal Treatment Centre moves. The service for teenagers and young adults with cancer could be inadvertently impacted by the service change, particularly young people aged 16-18 who are not formally part of the children and young people’s service and are not old enough to be classed as adults. Staff highlighted that this age group can already fall through the gap and have a longer delay in being diagnosed compared to children and young people in other age groups; there is a concern that this could worsen with the move. There was a suggestion that young people could also lose access to the palliative care service that is more appropriate to their age when the Principal Treatment Centre moves. Loss of access to an age-appropriate psychiatry service was also raised as a concern. Clinical trials for teenagers and young adults with cancer could be impacted, particularly if paediatricians who conduct research for children and young people (from which teenagers and young adults with cancer also benefit) are no longer on the same site.

- *‘The Teenage and Young Adult service will not be in the same location as the Children and Young People service – this means that the transition of care from one service to the other will be harder than it is now (where the service is in one place and it much easier for face-to-face interactions and handover)’ (Meeting with member of staff, The Royal Marsden, December 2023)*
- *‘Children do not suddenly become mature independent individuals from the minute they turn 16 years and can sign their own consent. This is a major step forward in terms of empowering them and giving them a voice at a time when most of them feel powerless and scared. But the setup, facilities, and specific staff that they benefit from cannot be matched by existing adult units... I strongly feel that the proposed split between Paediatric and The Teenage and Young Adult Services is a decision which is likely to carry a negative impact for the patients aged 16+ years currently treated in our Unit (this mainly affects neuro-oncology and sarcoma patients). This is likely to result in these young people and their families feeling ‘left behind’ and having to navigate a completely different scenario’ (Member of staff from The Royal Marsden, email correspondence, December 2023)*

The point was also raised that clinicians who treat adults may not be comfortable treating children and young people; there may be additional education, training, and support needs.



9.5 Views on the delivery of radiotherapy services at University College Hospital

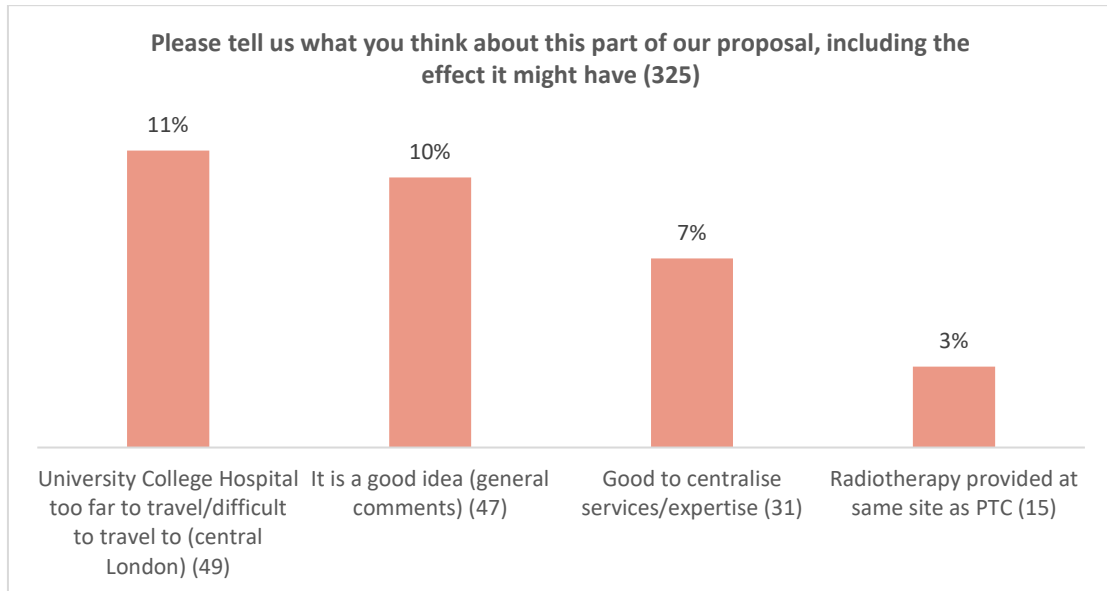


Figure 21 Affected clinical and non-clinical staff, Radiotherapy Services at University College Hospital, effect proposal might have

Across feedback types, a key concern for affected staff was the greater distance families and patients would have to travel to get to University College Hospital (11%). This creates additional unwanted journeys, transfers between hospitals, and additional stress.

- *‘Very far for patients from the south to travel’ (Currently works for the Principal Treatment Centre at St George’s Hospital, questionnaire response)*
- *‘This feels totally wrong and involving another long and difficult journey into London. Many of our patients already have to travel one to two hours just to get to Sutton. A further added journey would make life very difficult for many families already going through an incredibly stressful time’ (Currently works for the Principal Treatment Centre at St George’s Hospital, questionnaire response)*
- *‘Greater travel for families and more restrictions on travel. UCH is more difficult to get to on public transport and by car than The Marsden’ (Currently works for the Principal Treatment Centre at St George’s Hospital, questionnaire response)*
- *‘The loss of radiotherapy from RMH is a very real negative that will make services far worse for many families who will now have to travel to UCH in a future model’ (Currently works for the Principal Treatment Centre at The Royal Marsden Hospital, questionnaire response)*



10% of questionnaire responses to this question were positive about the move of radiotherapy to University College Hospital. Comments included:

- *'Seems to be a good idea and better for the children' (Currently works for the Principal Treatment Centre at St George's Hospital, questionnaire response)*
- *'I think this is a welcome change' (Currently works for Evelina London, questionnaire response)*
- *'If the service has been provided there, it makes sense to keep it there' (Currently works for the Principal Treatment Centre at St George's Hospital, questionnaire response)*
- *'I would support. It seems logical that such specialist services are focused in fewer areas' (Currently works for Evelina London, questionnaire response)*

Again, some affected staff were concerned with patients and families having to travel to University College Hospital under both proposals to receive radiotherapy, with some expressing their desire for this to be provided in-house at the selected site (3% of questionnaire responses). There was real concern about the fragmentation of care and treatment for patients over the course of their radiotherapy treatment and for those who are having concurrent chemotherapy alongside radiotherapy. Some respondents were forthright with their words. For these respondents, this aspect called into question the strengths of the proposals altogether since patients will still have to be transferred around different sites in London to receive treatment, causing additional stress for families having to travel for treatment.

- *'Unnecessary stress when patients can currently have radiotherapy treatment in the same place as other treatments at RMH. A child will have to travel to UCH for their radiotherapy treatment rather than being in a known environment with staff they've built a rapport with' (Currently works for the Principal Treatment Centre at The Royal Marsden Hospital, questionnaire response)*
- *'It feels to me as if there's not really enough discussion about how those children are going to be moved between [the future Principal Treatment Centre] and the UCH for the radiotherapy, you know, so if they're inpatients because there's going to be a lot of transporting of children around different bits of London to get the radiotherapy' (Staff engagement session online, December 2023)*
- *'Moving services to a brand new building and then have patients having to still move around London is wrong on many levels. I feel the whole proposal from NHS England is completely wrong' (Currently works for the Principal Treatment Centre at The Royal Marsden Hospital, questionnaire response)*



- *‘More patients have radiotherapy alongside chemotherapy and they would need to be moved to UCH. And yeah, and for their small number of patients that have that would need intensive care, I don’t think that that’s a good balance. I understand the need for a PICU definitely. But at the same time, they’re taking services away that that we use more regularly’ (Staff engagement session online, December 2023)*
- *‘They’re already suffering the impact of their conditioning treatment, so it isn’t ideal that patients are going to be put back on an ambulance I guess at all...and that doesn’t sit well with me because and I think that for the parents, feels like a huge contradiction. And I think that’s why they’re picking it quite a bit from a parent perspective’ (Staff engagement session online, December 2023)*
- *‘Although protons are currently not available at RMH, many of the patients we treat would not qualify for protons anyway (high grade gliomas, diffuse intrinsic pontine gliomas, leukaemia patients receiving total body irradiation as part of the conditioning pre-transplant, patients undergoing re-irradiation, palliative radiotherapy, etc). The Nuclear Medicine Unit at RMH is even more unique. It is one of the two units in the whole of the UK (the other one being at UCH) which can deliver MIBG therapy for children with relapsed/refractory neuroblastoma. With the move, the expertise in Nuclear Medicine will also disappear and as mentioned before, relying at a national level on a single centre can be dangerous when the whole system is placed under a major stress situation. To forego these two specialist units lightly feels misguided and strategically inadequate’ (Consultant Paediatric Oncologist working at The Royal Marsden Hospital, email correspondence, December 2023)*

It was also noted that there is no children’s intensive care unit at University College Hospital.

There was also concern about fragmentation of the bone marrow transplant journey, which is currently all on site apart from the children’s intensive care unit – radiotherapy, chemotherapy, stem cell laboratory – at The Royal Marsden. Here, staff questioned how exposure to infection while being moved will be minimised for bone marrow transplant patients and whether University College Hospital will have trained staff as well as appropriate rooms to look after bone marrow transplant patients.

Other feedback focused on questioning the capacity and capability of University College Hospital in taking on the radiotherapy service for the Principal Treatment Centre – as well as its resilience.

- *‘Would need to be mindful of additional transfers and therefore the sustainability and capacity of UCH’ (Evelina London staff event, November 2023)*
- *‘We treat at least 50 patients each year. All of which require complex planning and treatment plans that need highly skilled radiographers, clinicians and physicists. We are*



asked regularly, to teach our highly specialised radiotherapy techniques internationally. UCH has recently approached us to teach them about whole central nervous system (CNS) treatment and TBI (total body irradiation). We know UCH do not have capacity for these children as we are often asked to accommodate a general anaesthetic (GA) or TBI because they are unable. UCH would need an extra linear accelerator to account for the extra work from us and also to employ some more specialist paediatric radiographers. These families need lots of time to be spent with them. We have one of the best GA success rates in the country recently treating a three-year-old without GA. Our paediatric radiotherapy service is outstanding, and that standard must be upheld if not bettered by UCH' (Radiographer at The Royal Marsden, email correspondence, December 2023)

There were, however, some staff in favour of the centralisation of radiotherapy at University College Hospital. This included 7% of questionnaire responses to this question. Feedback included:

- *'It makes sense to centralise the service at UCH given the increasing use of proton beam therapy' (Evelina London staff event, November 2023)*
- *'UCH already provides radiotherapy for Southampton and Oxford, so this makes sense' (Evelina London staff event, November 2023)*
- *'Transferred a child last weekend to UCH from Evelina ICU as they came in through the emergency department. During the transfer, UCH was really good (Evelina London staff event, November 2023)*
- *'Transferring the radiotherapy to UCH will be excellent, as it will create one large paediatric radiotherapy centre, encompassing both expertise (photons and protons) and facilitating research' (Currently works for the Principal Treatment Centre at The Royal Marsden Hospital, questionnaire response)*

9.6 Feedback specifically from colleagues at The Royal Marsden

It is important to note that feedback received from clinical and non-clinical staff at The Royal Marsden was consistent with feedback from clinical and non-clinical staff at other affected hospitals. There was no clear preference for an option. In fact, many members of staff answered the consultation questions directly, acknowledging the strengths and challenges of both options, as well as commenting on the proposal to move radiotherapy to University College Hospital.

However, there was a clear strength of feeling in feedback from staff at The Royal Marsden about the proposal to move radiotherapy to University College Hospital. While a few members of staff from The



Royal Marsden talked positively about the proposal to move radiotherapy to University College Hospital, most feedback was negative. Even those who acknowledged the experience of expertise of University College Hospital caveated that with various concerns. Staff from The Royal Marsden questioned how children would be transported between sites and where they would be accommodated. Some had concerns about the capacity of University College Hospital to take on the radiotherapy service on behalf of the Principal Treatment Centre. A few comments related specifically to children who would require a general anaesthetic when receiving radiotherapy and concerns about how these children would be managed. To illustrate these points, comments included:

- *‘UCLH is an excellent provider of paediatric radiotherapy and we already send out patients there for protons. They DO NOT have the capacity to accommodate our patients they are regularly asking us to take patients usually kids under GA and TBI. They are not using advanced techniques for whole CNS treatment and total body irradiation’ (Staff member from The Royal Marsden, questionnaire response)*
- *‘My biggest and very real concern is the lack of capacity at UCL to manage the 50 children under 16 that we currently treat’ (Staff member from The Royal Marsden, questionnaire response)*
- *‘At present we know they do not have enough capacity’ (Staff member from The Royal Marsden, questionnaire response)*
- *‘I think the impact of moving all the paediatric radiotherapy patients to UCL has been grossly underestimated. It is around 50 patients a year but these are highly complex patients so cannot be considered equal to 1 adult patient’ (Staff member from The Royal Marsden, questionnaire response)*
- *‘This will mean very disjointed care. Previously we have been able to offer radiotherapy and chemotherapy and other cancer therapies for these children on one site’ (Staff member from The Royal Marsden, questionnaire response)*
- *‘I think this point has been casually mentioned in the proposals and it is actually a huge down side to the move. The whole point is to have all services on one site, but you can’t achieve that, and I feel the proposal has not been as upfront about this as it could be. It comes across as ‘we can provide everything a patient needs such as PICU, surgery, etc etc.....oh but by the way we can’t do radiotherapy’ (Staff member from The Royal Marsden, questionnaire response)*
- *‘It will remove an excellent service and fragment the paediatric oncology service so it will no longer be comprehensive. It will impact the sickest children most – daily transfer for bone*



marrow transplant patients at a time when they are very vulnerable with no familiar team members around them' (Staff member from The Royal Marsden, questionnaire response)

- *'Very young brain tumour or Wilms patients who need radiotherapy under general anaesthetic will either have to travel every day or be treated in a unit not used to treating very young patients' (Staff member from The Royal Marsden, questionnaire response)*

Associated with their comments, some staff called for the proposal to move radiotherapy services to University College Hospital to be reconsidered.

9.7 Future Principal Treatment Centre – what matters the most

Across all feedback types, below is what mattered the most to affected members of staff when they thought about the future Principal Treatment Centre.

- Child-oriented and child-friendly facilities
- Centre of excellence
- A children's intensive care unit on site
- Age-appropriate recreational and therapy spaces
- Play spaces suitable for families and siblings
- Education provision on-site as well as supporting return to local schooling arrangements
- Accommodation for families to stay in the Principal Treatment Centre or very close by
- Easy to access by car or other transport modes for staff and families
- Ample parking for staff and families
- Everything under one roof, all services, including radiotherapy
- Must provide the same high standards of service as now – no compromise
- Rapid access to efficacious diagnostics and treatment
- Must have its own occupational therapists, dietitians, play team, kitchen staff, just for children's cancer care, and not shared with other specialties
- Must keep expertise and skills of staff; maintaining close teams
- Must offer exceptional training and development opportunities for staff
- Good culture and leadership
- Open to innovation
- Must maintain the excellent research track record of The Royal Marsden
- Policies and reputation of the current Principal Treatment Centre are maintained
- Access for patients to clinical trials and drug development – being part of oncology research is important



- Must have accommodation where patients can stay if they need multiple appointments to minimise the need to travel back and forth from home
- Must support patients with timing of appointments and the cost and practical issues with access, such as offering reliable and effective patient transport
- Supports the transition to care closer to home to ensure continuity of personalised care and support.



10 Other clinical and non-clinical

NHS staff

This chapter presents findings from feedback received from other NHS clinical and non-clinical staff. These members of staff do not work in the Trusts most concerned, but many work in the wider system, including at University College Hospital, Great Ormond Street Hospital and in the provision of care to children with cancer in children's cancer shared care units. Many of these respondents work in the wider catchment area. They draw on their clinical expertise and experience in their personal responses to the consultation.

10.1 Engagement snapshot



10.2 The proposal for Evelina London Children's Hospital

10.2.1 Good points

Evelina London is a dedicated children's hospital, with many specialisms

Many of the other clinical and non-clinical staff (including 26% of questionnaire responses to this question) consider a main strength of the proposal for Evelina London to be the fact that it is already a specialist children's hospital.

- *'Already a specialist children's hospital which provides great clinical care' (member of NHS staff – who works for another part of the NHS, questionnaire response)*
- *'Great dedicated children's hospital with specialist support' (Member of NHS staff – who work for the Paediatric Operational Delivery Network, questionnaire response)*
- *'Lots of services, such as cardiology which is very relevant. Also, respiratory services associated with Royal Brompton. I'd move towards Evelina as a preference, but it is very subjective' (North and South Thames Paediatric Networks meeting)*
- *'Well-established dedicated children's hospital for London and Kent/Surrey/Sussex, with many services which would support paediatric oncology already in place. Many of subspecialties currently based at Evelina Hospital work with paediatric units in South London/Kent/Surrey/Sussex' (Member of NHS staff – who works for a Paediatric Oncology Shared Care Unit in London or the south east, questionnaire response)*
- *'Dedicated children's hospital, lots of specialisms, so expect in terms of children's workforce, it will be larger, and more expertise and allied health professionals' (GOSH focus group, December 2023)*



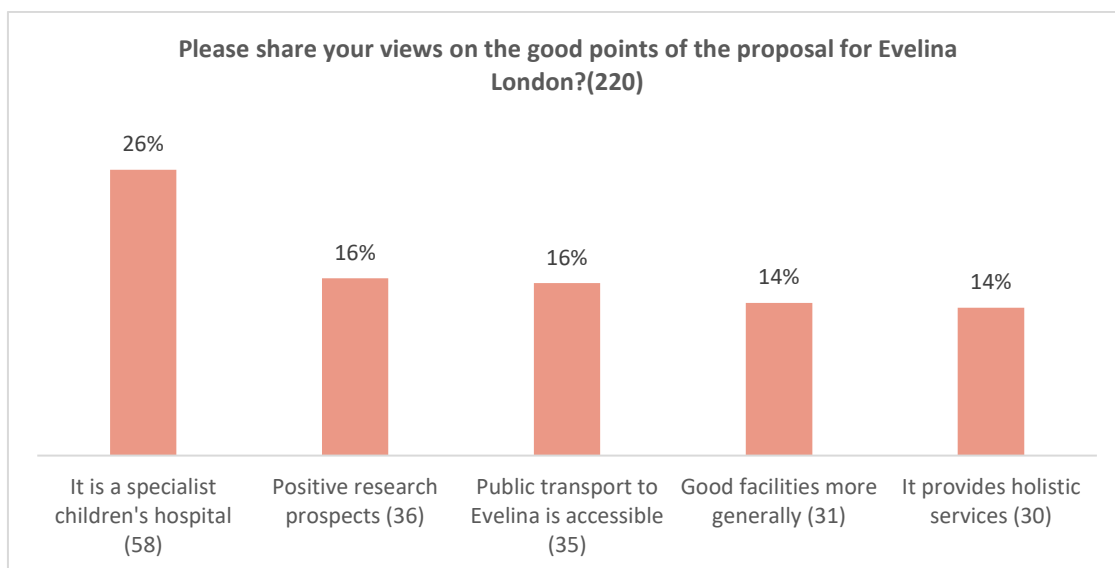


Figure 22 Other clinical and non-clinical staff, Good Points about Evelina London

The perception that Evelina London has strong research capabilities

Other key strengths included Evelina London's strong research capabilities. This was supported by 16% of questionnaire responses to this question.

- *'Good research capabilities' (Member of NHS staff – who works for another part of the NHS, questionnaire response)*
- *'Evelina London is rated as internationally excellent for research performance, people and place. This provides excellent opportunities to develop children's cancer research in partnership with ICR, the internationally recognised research teams and leadership including research into immune therapies. The infrastructure to support this included two dedicated research wards, many industry partnerships, and education and training for researchers' (Member of NHS staff – who works for another part of the NHS, questionnaire response)*

Evelina London has good public transport links

Other members of staff talked about its accessibility via public transport, given its location in central London (16% of questionnaire responses). Reference was also made to Evelina London's geographical proximity to Great Ormond Street Hospital, which could be beneficial for partnership working, as well as links to Guys and St Thomas's adult oncology service (Great Ormond Street Hospital Focus group, December 2023).

Evelina London provides holistic services



Other comments from staff related to how Evelina London is able to provide a number of different specialist services related to cancer care on one site.

- *‘One stop multi- speciality hospital. Excellent paediatric speciality services. PICU and IR on site’ (Member of NHS staff – who works for a Paediatric Oncology Shared Care Unit in London or the south east, questionnaire response)*
- *‘Dedicated children’s hospital so already has excellent facilities for children and their families. Everything needed (except radiotherapy) would be on site’ (Member of NHS staff – who works for another part of the NHS (for example, other NHS trust, primary, community or mental health provider, commissioner of services etc) questionnaire response)*
- *‘It is a good point to provide many services to children in one single big hospital’ (Member of NHS staff – other members of staff supporting children’s services, questionnaire response)*

10.2.2 Potential challenges

Travel and accessibility challenges of Evelina London because of its central London location

A key issue identified by other clinical and non-clinical staff was issues with access to Evelina London for patients and staff travelling by car (including 19% of questionnaire responses to this question) given the hospital’s location in central London. Associated with this, parking availability on site was a common concern. Journey time was also highlighted as problematic; if the Principal Treatment Centre moves to Evelina London, some staff and families could find their journey times extended – and some journeys are already considered long. Some staff noted that families are advised not to use public transport at all when a child is immunocompromised.

- *‘Lack of enough parking places for staff, families and visitors’ (Member of NHS staff – other members of staff supporting children’s services, questionnaire response)*
- *‘Being in Central London, it is somewhat easy to access but lacking parking spaces and often crowded, which is something that seriously ill patients with immune illness would wish to avoid’ (Member of NHS staff – who works for another part of the NHS, questionnaire response)*
- *‘I think one of the main issues is it’s in central London. Although transport links are good. Oncology patients are advised to not go on public transport at all. Driving through central London, a lot of parents don’t like doing and can cause great stress. Another thing is that traffic in these times may result in patients being late and treatments not on time. This will ultimately affect the flow of the service’ (Member of NHS staff – other members of staff supporting children’s services, questionnaire response)*



- *‘GOSH families have reported that travel is very difficult, especially when appointments coincide with rush hours. People end up driving and parking at great expense, and or getting stuck in rush hour traffic. Pushchairs on public transport are especially difficult’ (Meeting with representative of Surrey children’s cancer shared care units)*

ODN staff, including some staff in children’s cancer shared care units, provided anecdotal evidence that staff at The Royal Marsden may not move with the service as they do not want to travel into central London. They called for more information to be shared with staff in terms of the practicalities of the move.

- *‘A lot of staff at RMH come from further away not central London, so moving to Evelina is a no, and a potential yes for St George’s Hospital. They might look to move elsewhere instead. In terms of staff transferring, might come down to when decision is made – people will start to make plans. It’s a bit chicken and egg at the moment. People will want to see what their job will look like and the practicalities. NHS England (London and South East regions) should sort out the staff groups sooner rather than later’ (ODN staff focus group, December 2023)*

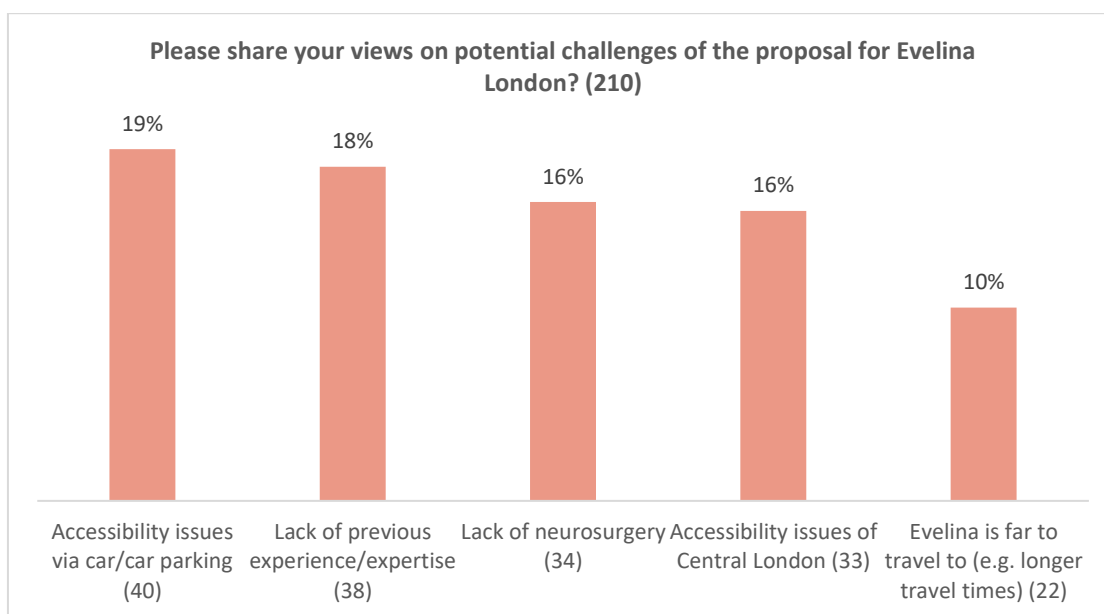


Figure 23 Other clinical and non-clinical staff, Potential Challenges about Evelina London

Lack of experience and expertise in children’s cancer care at Evelina London

Here, clinical and non-clinical staff answering the questionnaire were concerned that Evelina London lacks experience or expertise in caring for children with cancer (including 18% of questionnaire responses), with some within this theme explicitly mentioning how Evelina London does not provide neurosurgery on site.



- *'No previous experience of working with children with cancer, not even a POSCU. No co-located neurosurgery which will be highly detrimental to providing joined up cancer services. This will mean that cancer services for children will continue to be fractured' (Member of NHS staff – who works for a Paediatric Oncology Shared Care Unit in London or the south east, questionnaire response)*
- *'It does not provide services such neurosurgery, which will still need to be at St George's Hospital' (Member of NHS staff – who works for another part of the NHS, questionnaire response)*
- *'What's worrying is the neurosurgery and central nervous system (CNS) tumours. It's those children, as well as transplants, who need to go to PICU and don't know how this would be feasibly managed at Evelina? Would it be as safe as being treated at St George's Hospital?' (Focus group with ODN staff, December 2023)*
- *'Evelina London is not a cancer specialist hospital and therefore cannot be rated outstanding in relation to the specific treatment and specialisms required. Neurosurgery not available on site at Evelina' (Member of NHS staff – who works for another part of the NHS, questionnaire response)*

A couple of members of staff questioned whether Evelina London would be able to provide an adequate number of rehabilitation beds for very sick children.

Some staff held the perception that if Evelina London is chosen as the location for the Principal Treatment Centre, then it would be a 'steep learning curve' for the hospital and its management – with associated risks.

- *'No expertise in oncology surgery at Evelina. It would be risky to ask Evelina team who have never performed this type of highly complex surgery to suddenly take it on. Even if they think that can do it, they will not be as expert as the teams (such as at St George's Hospital) who have a great deal of experience in doing this' (Focus group, ODN staff, December 2023)*
- *'Unless every member of specialist staff is moving from RMH, the institution has a massive amount of work to do. The whole service, including staff will have to move' (Focus group with ODN staff, December 2023)*

'I find it incredulous moving to a hospital [Evelina] which has never given chemotherapy' (Focus group with ODN staff, December 2023)

'Evelina does not have a culture of looking after children with diagnoses. Marsden team would help establish that, but it's not just a lift and shift' (North and South Thames Paediatric Network meeting)



Staff recruitment and potential impact on other nearby NHS services

Some staff talked about the NHS staff recruitment crisis, reflecting on the shortage of nurses, doctors, and surgeons. They talked about Trusts struggling to recruit and retain staff. For some staff, their view was that having another Principal Treatment Centre in central London could dilute the workforce and increase the competition for securing members of staff.

- *‘There is a concern at GOSH that with Evelina being geographically close, if the service was to move there, there would be competition and poaching of staff from GOSH PTC’ (Great Ormond Street Hospital focus group, December 2023)*
- *‘Maintaining staffing at GOSH is extremely difficult because you’ve got highly specialised staff coming into Zone 1, which adds additional travel costs. These highly specialised staff are difficult to replace – as such GOSH are short staffed: not enough nurses, and not enough doctors (normally 20 doctors per rota, in August there were only 10). If there is not enough staff at the new PTC, there will be attempts to recruit staff from GOSH to provide cover at Evelina, and this will destabilise both sites’ (Great Ormond Street Hospital Focus group, December 2023)*

There was also concern about the impact on St George’s Hospital and other services it provides if key staff are lost and not replaced.

10.2.3 Improvements

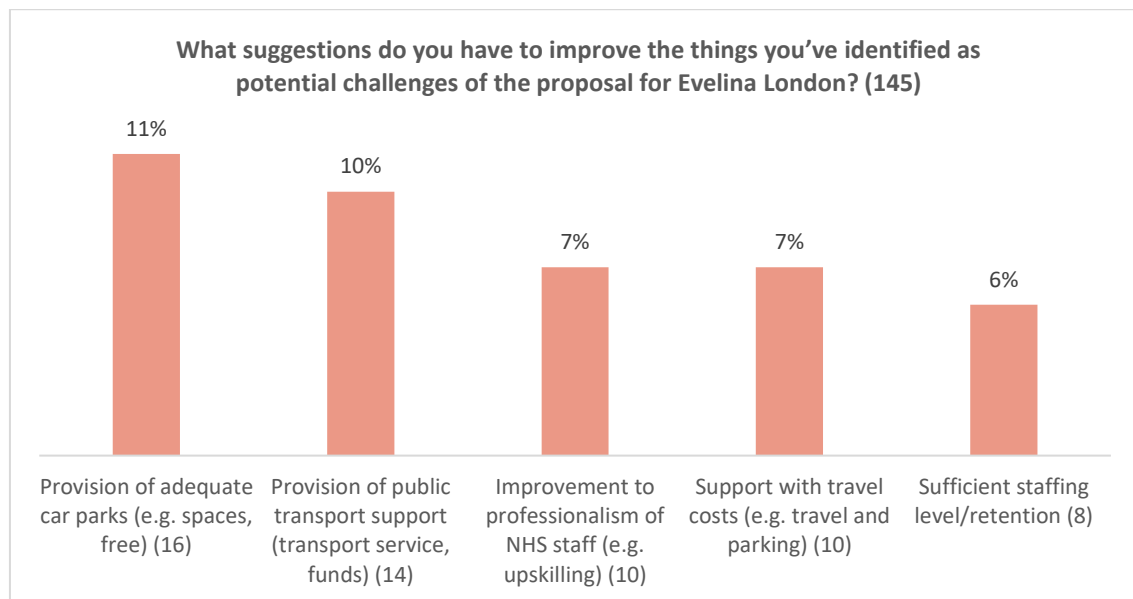


Figure 24 Other clinical and non-clinical staff, Improve Potential Challenges about Evelina London



Suggestions specifically on the proposal for Evelina London focused on accessibility, particularly via parking (11%) with many wanting to see the expansion of car parking on site or the provision of dedicated parking for patients and staff as well as an option of free parking. Others wanted greater support with public transport to the site, whether this is offered directly to families/patients to get to the hospital (like a shuttle bus) or compensation is offered for greater costs incurred for having to travel further on public transport (10%).

- *'Provide free parking for parents attending with patients on treatment'* (Member of NHS staff – who works for a Paediatric Oncology Shared Care Unit in London or the south east, questionnaire response)
- *'Facilitate financial travel support and parking facilities for the patients and their relative'* (Member of NHS staff – who works for another part of the NHS, questionnaire response)
- *'Provision of parking at Evelina for those families with children with cancer'* (Member of NHS staff – who works for a Paediatric Oncology Shared Care Unit in London or the south east, questionnaire response)
- *'Offering patient transport'* (Member of NHS staff – who works for another part of the NHS, questionnaire response)
- *'Just provide a shuttle bus service from a local tube station so cancer patients are not walking up to the hospital when they are immunocompromised'* (Member of NHS staff – who works for another part of the NHS, questionnaire response)
- *'The public transport links to be highlighted and help given to those who simply cannot take public transport, such as subsidised or free parking'* (Member of NHS staff – who works for another part of the NHS, questionnaire response)

Other suggested improvements related to:

- Ensuring adequate funding is allocated, both capital and revenue were mentioned. A couple of comments related to investment in a new build to accommodate the new Principal Treatment Centre at Evelina London
- Considering neuro-oncology being co-located with neurosurgery at King's
- Providing neurosurgery at Evelina London.

10.3 The proposal for St George's Hospital

10.3.1 Good points



St George's Hospital has 25 years of experience in delivering specialist care for children with cancer as part of the current Principal Treatment Centre

Similarly to affected staff, other clinical and non-clinical staff also consider the main strengths of the proposal for St George's Hospital to be its previous experience in providing care to children with cancer (including 38% of questionnaire responses to this question), as well as its strong relationship with The Royal Marsden (including 23% of questionnaire responses to this question). Some staff thought this would lead to less disruption for patients and staff. References to St George's Hospital providing neurosurgery were also notable. Thoughts on this included:

- *'Experienced staff and it already has the infrastructure in place. Already established networking of teams including PICU, surgery and oncology' (Member of NHS staff – who works for a Paediatric Oncology Shared Care Unit in London or the south east, questionnaire response)*
- *'It is part of the current Principal Treatment Centre and has lots of experience of looking after children with cancer who need intensive care, surgery' (Member of NHS staff – who works for another part of the NHS, questionnaire response)*
- *'Already have had children's cancer services at STGH for the last 25 years and it works well, established relationships with other hospital in place already' (Member of NHS staff – who works for another part of the NHS, questionnaire response)*
- *'There would be almost no disruption with this move as these relationships and pathways are already in place' (Focus group, ODN staff, December 2023)*
- *'They have a 12-bed more-or-less POSCU site already' (North and South Thames Paediatric Network meeting)*
- *'One of the really strong things about St George's Hospital is the infectious diseases – they have fantastic support particularly for oncology patients, which has grown from their experience working with transplant patients. Not sure if Evelina have anything to match this' (North and South Thames Paediatric Network meeting)*
- *'From medical point of view, expertise, transport, surgeons – St George's Hospital seems to be the better proposal' (Member of staff, Great Ormond Street Hospital focus group, December 2023)*



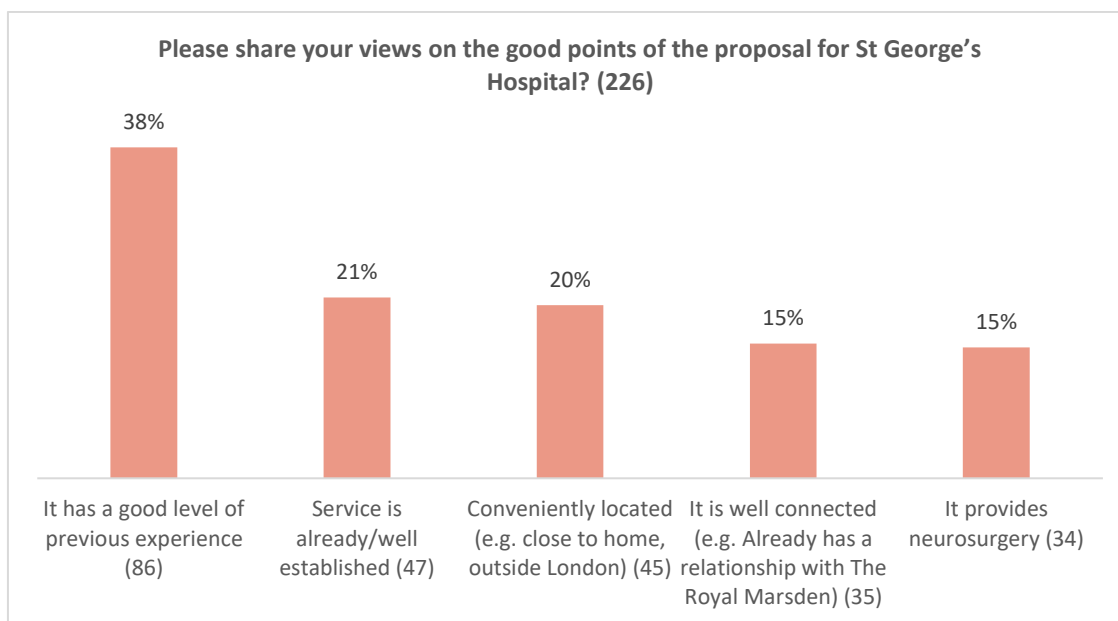


Figure 25 Other clinical and non-clinical staff, Good Points about St George's Hospital

St George's Hospital is perceived to be accessible for staff and families who live further away

Other key strengths included St George's Hospital location, since it is closer than Evelina London to many staff and users of its services (including 20% of questionnaire responses to this question). A member of staff at Epsom and St Helier's children's cancer shared care unit in Surrey noted that St George's Hospital is relatively accessible for their patients, adding that the catchment area served is relatively deprived. Other comments included:

- 'Excellent location for all of SW London, south London and Surrey and Sussex. Right next to a tube Tooting Broadway, so does not have a long walk from public transport' (Member of NHS staff – who works for another part of the NHS, questionnaire response)
- 'Keeping the service local and more easily accessible to patients, children, families and staff' (Member of NHS staff – other members of staff supporting children's services, questionnaire response)
- 'St George's Hospital is much easier to get to for both staff and patients especially when travelling from further afield' (Member of NHS staff – other members of staff supporting children's services, questionnaire response)

Familiarity for patients and families with St George's Hospital

This was recognised as an advantage for the St George's Hospital proposal; given that patients and families will have existing relationships and familiarity with St George's Hospital when the move happens.



10.3.2 Potential challenges

St George's Hospital is not a dedicated children's hospital

A common area of concern for other members of staff (including 9% of questionnaire responses to this question) was the fact that it is not a dedicated children's hospital, with many suggesting that services might be more limited as well as not being designed specifically for children and young people.

- *'Not a dedicated children's hospital so services presumably more limited and more in competition with other services within the hospital' (Member of NHS staff – who works for another part of the NHS, questionnaire response)*
- *'This is not a dedicated children's hospital so not everything is designed with them in mind – such as support services which care for adults as well' (Member of NHS staff – who works for another part of the NHS, questionnaire response)*
- *'Not a dedicated children's hospital so not as good as Evelina option' (Member of NHS staff – other members of staff supporting children's services, questionnaire response)*

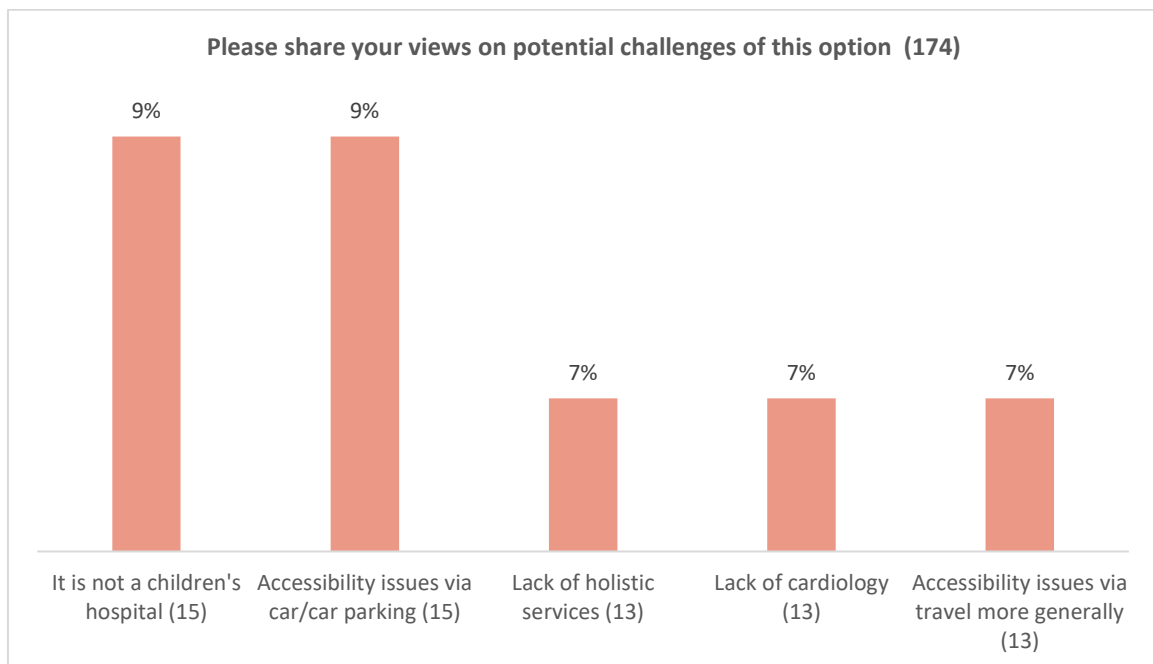


Figure 26 Other clinical and non-clinical staff, Potential Challenges about St George's Hospital

St George's Hospital would be challenging to access by car

Staff also talked about accessibility issues for patients and staff travelling via car (9%), relating to congestion (and the impact of this on journey times) and parking availability.



Some specialists are not offered at St George’s Hospital

Others mentioned that there is a lack of holistic services at St George’s Hospital with some specifically mentioning cardiology services (7% of questionnaire responses to this question), meaning that a number of patients may have to travel to other sites to receive specialist care.

- ‘Still the need for some referrals to Evelina for services such as cardiology etc’ (Member of NHS staff – who works for a Paediatric Oncology Shared Care Unit in London or the south east, questionnaire response)
- ‘Doesn’t have all specialities so children may need to access services off site’ (Member of NHS staff – who works for a Paediatric Oncology Shared Care Unit in London or the south east, questionnaire response)

There was also a perception by some that St George’s Hospital did not have adequate capacity to run the Principal Treatment Centre.

- ‘St George’s Hospital have identified two ICU beds for the service – this wouldn’t be enough to manage capacity’ (Great Ormond Street Hospital Focus group, December 2023)

10.3.3 Improvements

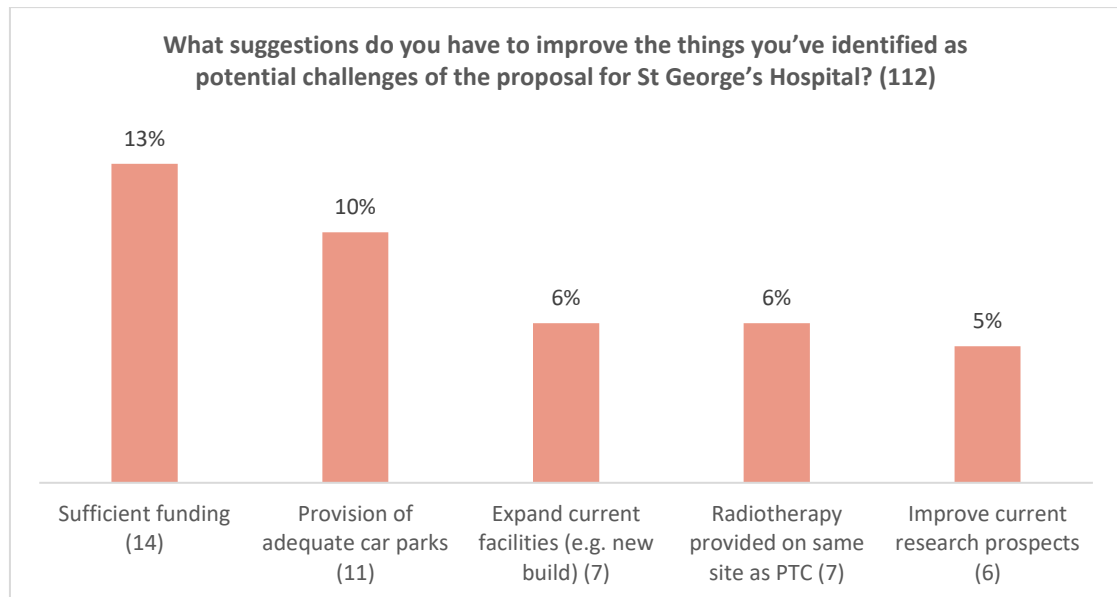


Figure 27 Other clinical and non-clinical staff, Improve Potential Challenges about St George’s Hospital

Suggested improvements to St George’s Hospital proposal were mixed with some leaving comments relating to the importance of funding to ensure the successful delivery of services (13%), while others recognised the need to expand car parking availability on site for patients and staff (10%).



- *‘Similar to Evelina option regarding funding, which needs to be provided in full (both capital and revenue) and not in part’ (Member of NHS staff – other members of staff supporting children’s services, questionnaire response)*
- *‘Money needed to alter the infrastructure’ (Member of NHS staff – other members of staff supporting children’s services, questionnaire response)*
- *‘Protected and allocated parking for patients visiting the service’ (Member of NHS staff – who works for another part of the NHS, questionnaire response)*
- *‘Extend the onsite parking by using the consultants parking area for the families’ (Member of NHS staff – who works for another part of the NHS, questionnaire response)*

10.4 Potential challenges affecting both proposals

A number of challenges were identified by staff that related to both proposals. Some staff wanted more detail to help them make a judgement on each option; in some cases, the detail wanted was in relation to a specific challenge. For example, feedback received from one focus group highlighted:

- *‘Concerns of both bids is the detail {or lack of detail provided}’ (ODN focus group, December 2023)*

These challenges are outlined below.

- Both hospitals are larger hospitals than The Royal Marsden; it can be difficult to find contacts in a large centre
- Age of transition between child and adult services is a challenge. The age of transition is not consistent across services and no plans have been shared relating to transition arrangements – particularly for children needing individualised care and those with special needs
- Capacity for isolation children’s intensive care unit beds is a concern, as well as a concern for other beds in the children’s intensive care unit
- Continuity of access to clinical trials is a concern – without compromising this – including patients aged 16-18
- The significant changes needed to patient pathways will need great consideration, particularly how the changes will affect other NHS services
- Concern about the transplant service and how that would be affected
- Concern about the leukaemia journey and how that would be affected
- Lack of JACIE accreditation, and the time it would take to set it up, could have an impact on other NHS services



- Laboratory capacity for all tests that would be required is a concern
- Infrastructure required for chemotherapy manufacturing, given it is bespoke for almost all patients; it is not known how each proposal would handle this
- Communication between the Principal Treatment Centre and children’s cancer shared care units is a concern, with questions about how this would be improved
- Access to childcare on-site for staff was raised as a concern
- Access to amenities including coffee shops, restaurants, and small shops, is a concern.

10.5 Views on the delivery of radiotherapy services at University College Hospital

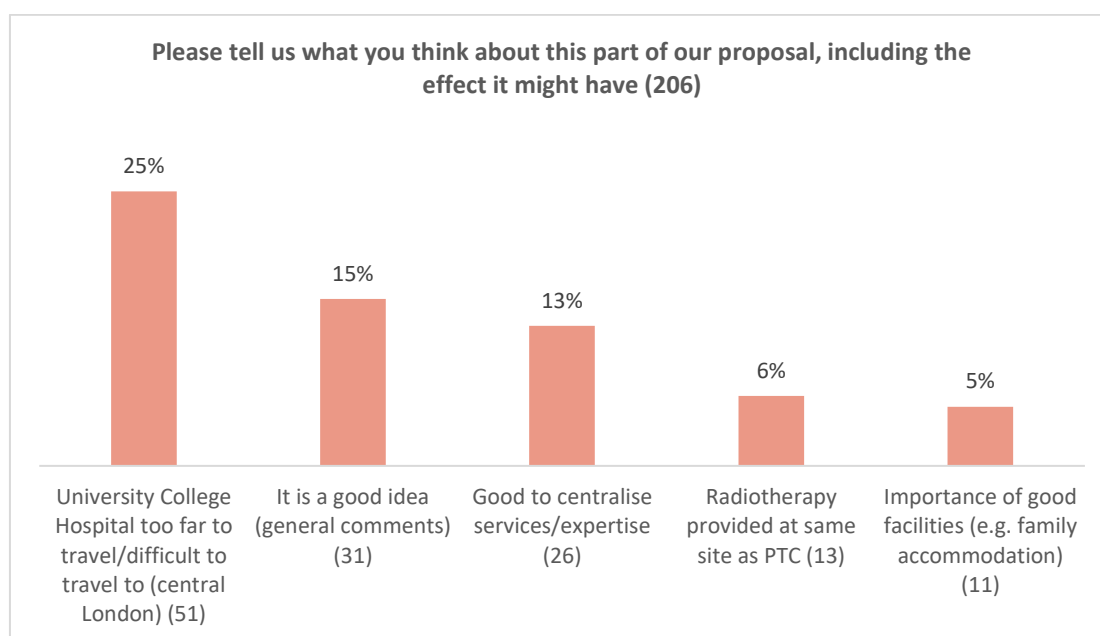


Figure 28 Other clinical and non-clinical staff, Radiotherapy Services at University College Hospital, effect proposal might have

Some staff highlighted a key limitation in the proposal to move radiotherapy to University College Hospital was the distance patients and their families would have to travel to access these services (including 25% of questionnaire responses).

- *‘While UCH is likely a better facility as it provides all relevant specialities in one hospital, this is significantly further away for patients from the SE, and for patients receiving regular radiotherapy, this will put strain on already stressed families’ (Member of NHS staff – who works for another part of the NHS, questionnaire response)*



- ‘Yet again the travel from south London to north London is very time consuming and stressful for the patients and family alike’ (Member of NHS staff – who works for another part of the NHS, questionnaire response)
- ‘It is good to have expert specialised care within one dedicated unit to ensure safe and sustainable treatment and care. The challenge remains access to a mid-London site’ (Member of NHS staff – other members of staff supporting children’s services, questionnaire response)
- ‘Cancer Alliances are concerned about the resilience of having radiotherapy services consolidated into one location. What would happen ‘if the machine is down’? They are also concerned as to whether there is enough capacity’ (ODN South Thames, December 2023)

Some other clinical and non-clinical staff left comments to say that the proposal is a good idea (including 15% questionnaire responses). This included:

- ‘I think this will be a great part of the proposal, being able to offer a wider range of services to our patients is amazing and will benefit the patient care experience immensely’ (Member of NHS staff – who works for a Paediatric Oncology Shared Care Unit in London or the south east, questionnaire response)
- ‘This would be a good progression. Many shared care patients already receive treatment at UCLH’ (Member of NHS staff – who works for a Paediatric Oncology Shared Care Unit in London or the south east, questionnaire response)
- ‘This seems like a sensible idea’ (Member of NHS staff – who works for another part of the NHS, questionnaire response)
- ‘Sounds sensible, if they have the staff and facilities there’ (Member of NHS staff – who works for another part of the NHS, questionnaire response)

Another consistent theme which has come through across all questions for other clinical and non-clinical staff is the importance they stress for radiotherapy to be provided on the same site where possible (including 6% questionnaire responses for this question). Again, respondents discussed the added stress this could cause to patients and families who would have to travel across London to receive this treatment.

- ‘Surely it makes more sense for all services to be provided on one site, as it is now at Marsden with chemo and radio given in the same place’ (Member of NHS staff – who works for a Paediatric Oncology Shared Care Unit in London or the south east, questionnaire response)



- *'I think it will be confusing and stressful for patients to not only adapt to receiving the majority of their care at either Evelina or St George's Hospital, and then have to travel to another new location in order to receive radiotherapy – particularly as all of these facilities are in the heart of London. Whereas it is currently all based at one location, which is a lot more convenient for patients'* (Member of NHS staff – who works for another part of the NHS, questionnaire response)
- *'Ideally radiotherapy would be located on same hospital site'* (Member of NHS staff – who works for another part of the NHS, questionnaire response)

10.6 Future Principal Treatment Centre

Other members of clinical and non-clinical staff shared similar views to those of affected clinical and non-clinical staff in terms of what they would value the most in the future Principal Treatment Centre. There was particular emphasis given to the provision of holistic and integrated services at the Principal Treatment Centre (including radiotherapy), improved communications between the Principal Treatment Centre and other NHS services, such as children's cancer shared care units, and a shared recognition that staff and patients should be supported with travel times and costs.

There was also discussion across different feedback types about the importance of local centres, such as children's cancer shared care units, in the provision of treatment and care to children closer to home, and how this could be further developed in the future.

- *'Families should never travel with very sick children – children's cancer shared care units should be the first port of call'* (Great Ormond Street Hospital focus group, December 2023)
- *'What services could people access at children's cancer shared care units to prevent them having to use multiple hospitals to care for one patient? Currently patients could be under the care of up to six different hospitals for different specialities. Could this be reduced and how?' (Meeting with representative of Surrey children's cancer shared care units)*



11 Equality groups

This chapter focuses on feedback from specific equality groups. This includes:

- 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
- Traveller communities
- Refugees
- Migrants
- 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.

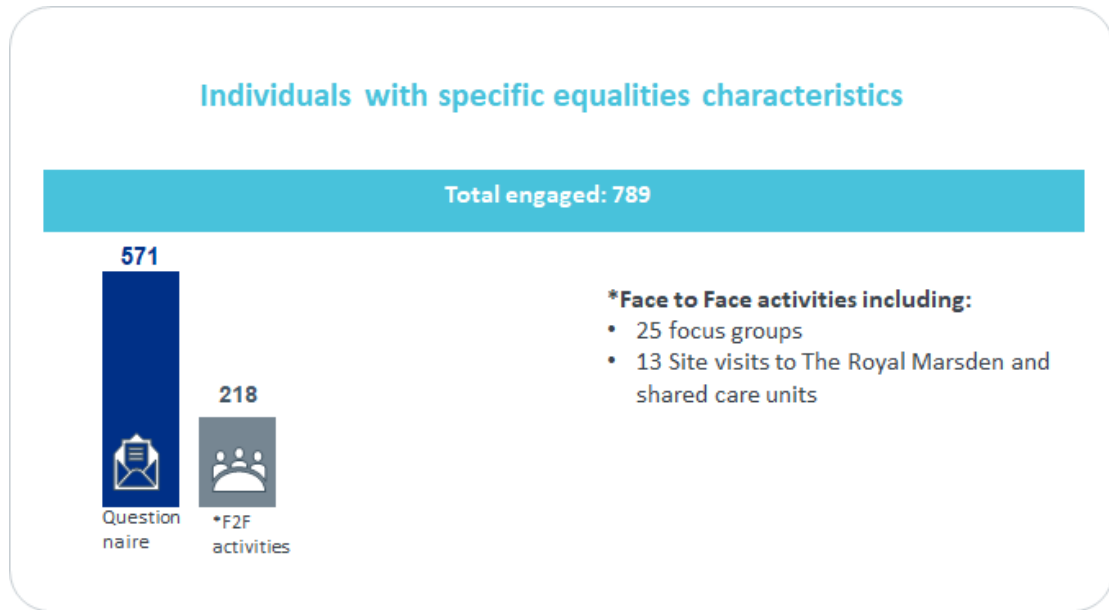
The inclusion of respondents in this chapter depends on their disclosure of personal circumstances, such as completing the demographic questions in the questionnaire, or identifying themselves as a member of a particular equality group when volunteering to participate in qualitative research activity. Please note that feedback here includes respondents from all stakeholder groups (such as family members, affected staff, other staff, members of the public); what these individuals have in common is their membership of one or more equality group.

Much feedback from respondents in this chapter echoes findings already identified in this report; as such, this chapter focuses on strength of feeling as well as any key differences in how members of equality groups talk about the proposals. In terms of questionnaire responses, this chapter includes key findings from ethnic minority groups and respondents with a disability as it was possible to identify their responses. The chapter also includes feedback from organisations where they specifically talk on behalf of an equality group, based on relevance and experience. Key themes from ethnic minority groups (not including white minorities) and those with disabilities have been presented in graph format below. Questionnaire responses from other equality groups such as those from deprived areas have not been included due to an inadequate provision of post code data, with only the first half of postcode



data being provided in the majority of cases and the variability of deprivation that exists within these areas.

11.1 Engagement snapshot



11.2 The proposal for Evelina London Children's Hospital

11.2.1 Good points

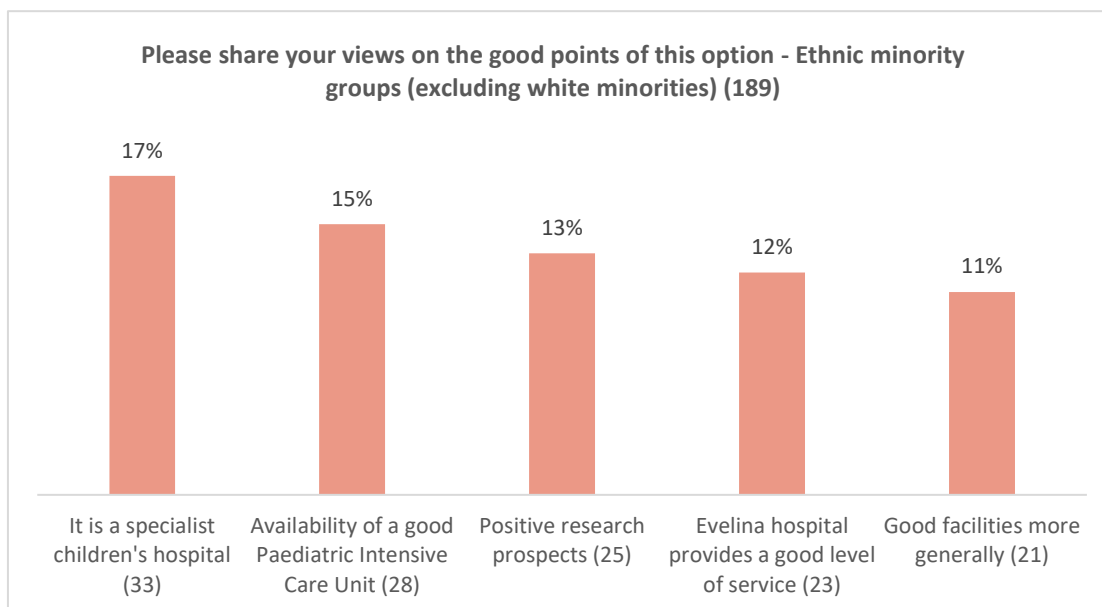


Figure 29 Equality Groups Ethnic Minority Groups, Good Points about Evelina London

Key strengths of Evelina London proposal identified by respondents from ethnic minority groups reflected those of other stakeholder groups. These included Evelina London being a children's hospital (including 17% of questionnaire responses), with a good children's intensive care unit (15% of questionnaire responses). Other comments focused on Evelina London having a good research proposition, with other good facilities and provision of a good service (12% of questionnaire responses).



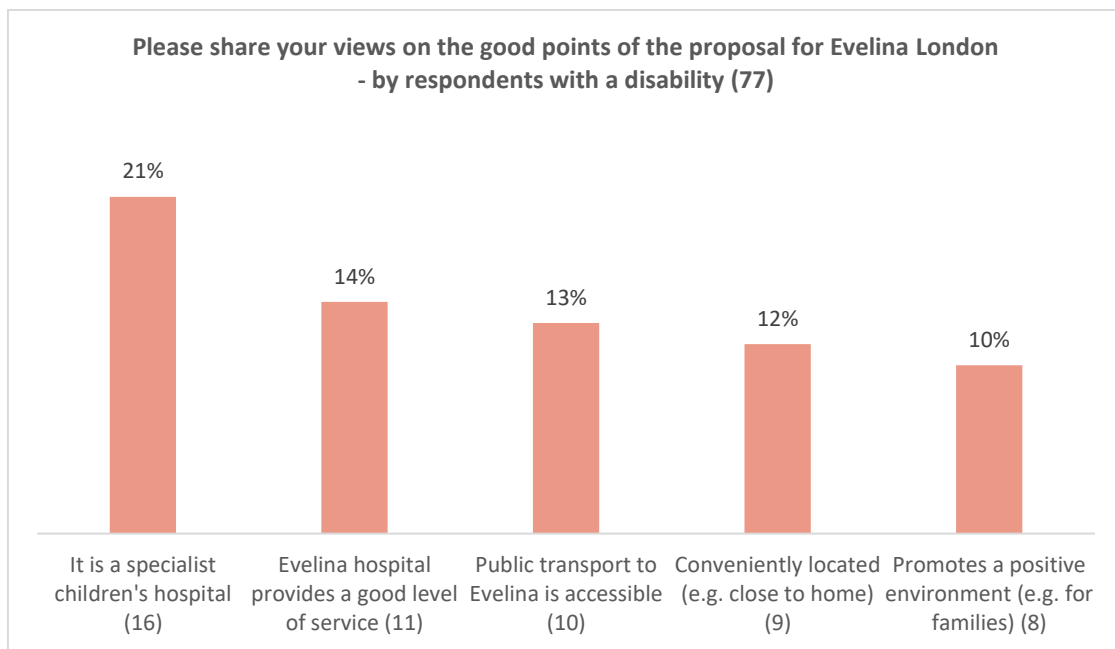


Figure 30 Equality Groups Respondent with a Disability, Good Points about Evelina London

For respondents with a disability, they agreed that the strengths of Evelina London include it being a dedicated children's hospital (21%) and that it offers a good level of service already (14%). Respondents also focused on good public transport links to Evelina London (13%) and that it is conveniently located due to its central London location. Respondents also thought it was a strength that Evelina London promotes a positive environment, such as being bright with spaces for children to play.

11.2.2 Potential challenges



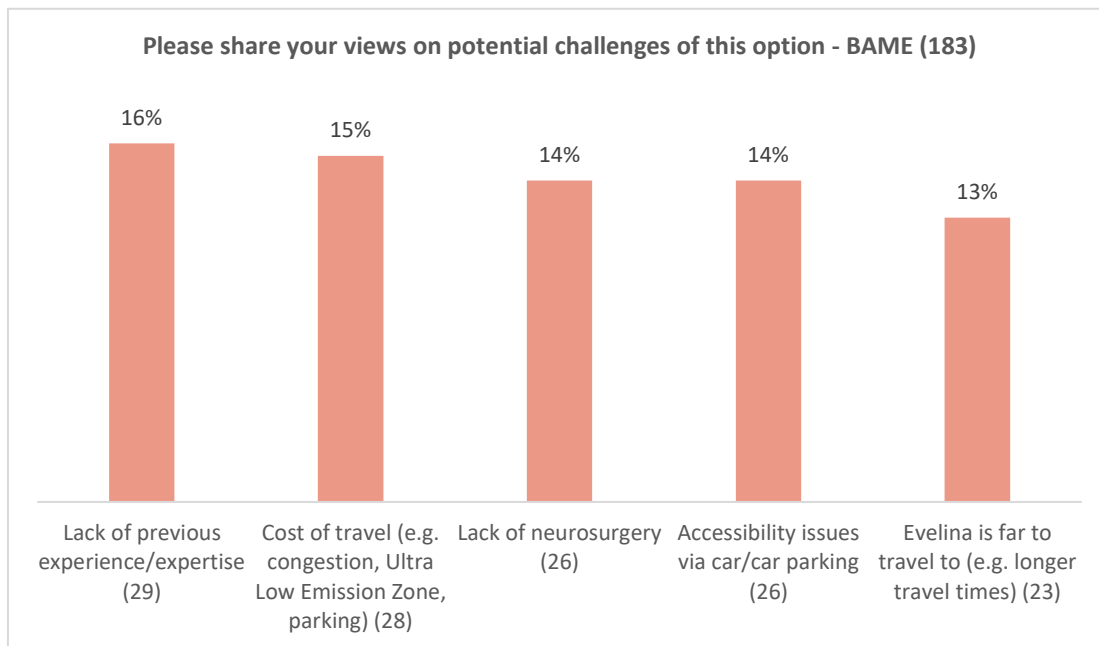


Figure 31 Equality Groups Ethnic Minority Groups, Potential Challenges about Evelina London

Key challenges identified by those from ethnic minority groups included the lack of experience and expertise in children’s cancer care at Evelina London (16%) and the lack of neurosurgery on site (14%). Accessibility was also identified as a key challenge, with comments relating to the cost of travel (15%) as well as issues with car parking (14%) and increased journey times (13%).

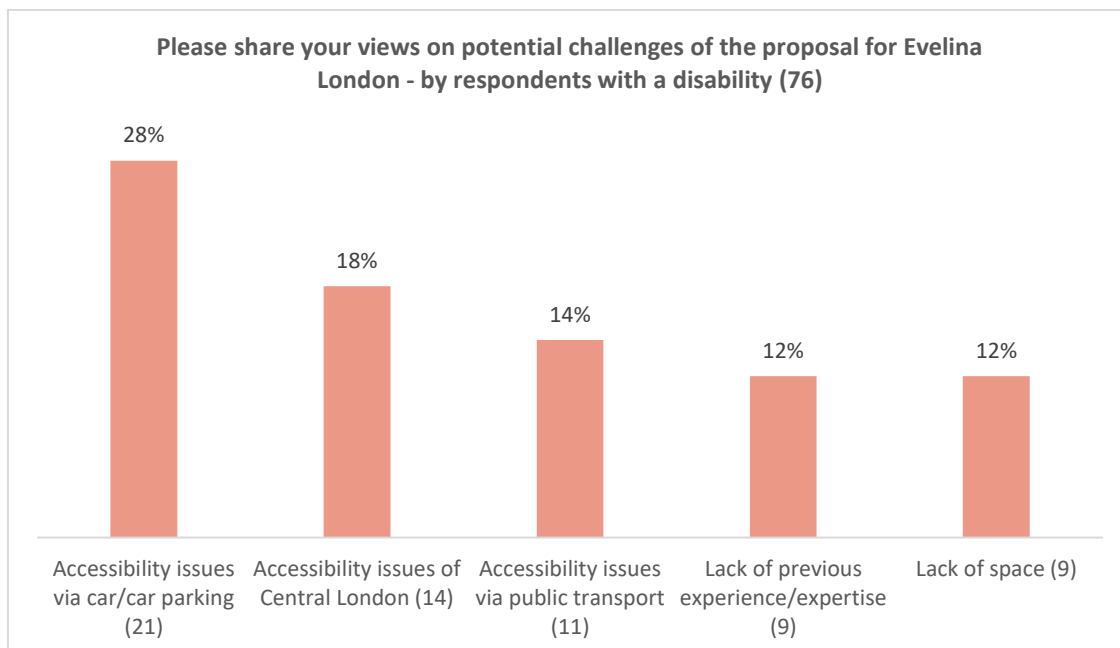


Figure 32 Equality Groups Respondent with a Disability, Potential Challenges about Evelina London



For respondents with a disability, accessibility was an overwhelming concern when considering the proposal from Evelina London with the majority of comments left by this stakeholder group referencing accessibility.

- *‘This is in heart of London – more traffic, congestion charge and would have been too far for us to travel’ (Respondent with a disability, questionnaire response)*
- *‘The hospital is very inaccessible to people from the south. The traffic is terrible on the car route as well as being long and the public transport options can add an hour to your journey’ (Respondent with a disability, questionnaire response)*
- *‘Too difficult a journey from Surrey with a sick child’ (Respondent with a disability, questionnaire response)*

Other comments centred around the lack of space on the hospital site for expansion, whether this be for expanding parking or accommodation onsite as well as capacity of the hospital in general.

- *‘Lack of space on the hospital site – already a problem’ (Member of NHS staff – who currently works for Evelina London who is disabled, questionnaire response)*
- *‘The hospital site area is limited for expansion’ (Member of the public with a disability, questionnaire response)*
- *‘Limited space for accommodation or parking’ (Member of NHS staff – who work for the Paediatric Operational Delivery Network, questionnaire response)*

11.2.3 Improvements



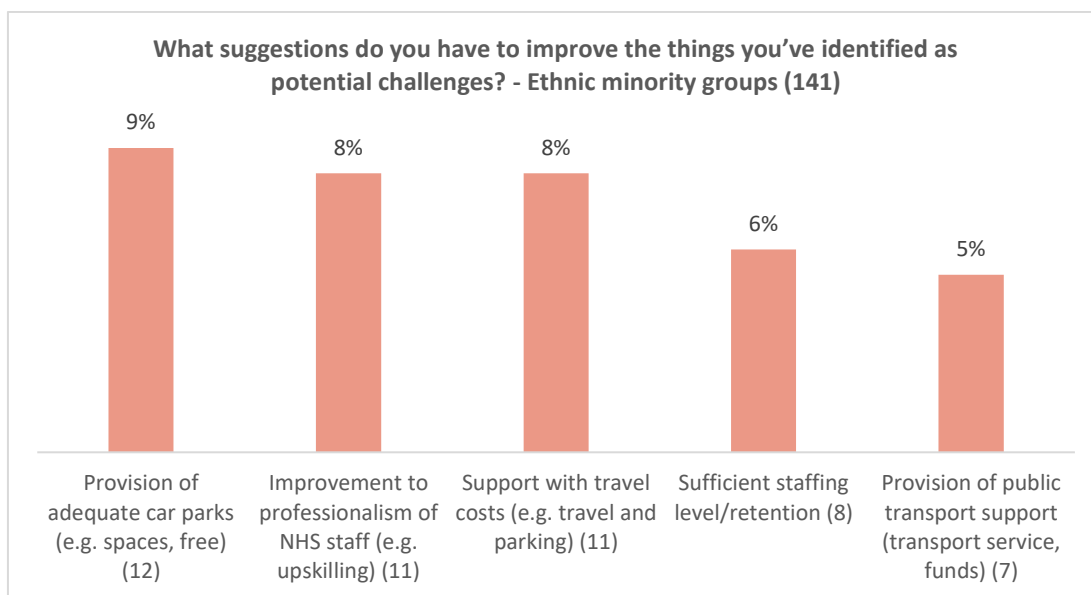


Figure 33 Equality Groups Ethnic Minority Groups, Improve Potential Challenges about Evelina London

Improvements to Evelina London’s proposal suggested by respondents from an ethnic minority group included providing adequate car parking for patients and staff (9%), as well as supporting patients and staff with travel costs (8%). Training or upskilling existing staff (9%) was also mentioned with comments of this nature usually touching on training staff in either specific aspects of children’s cancer care to more broader themes such as empathy, or collaboration.

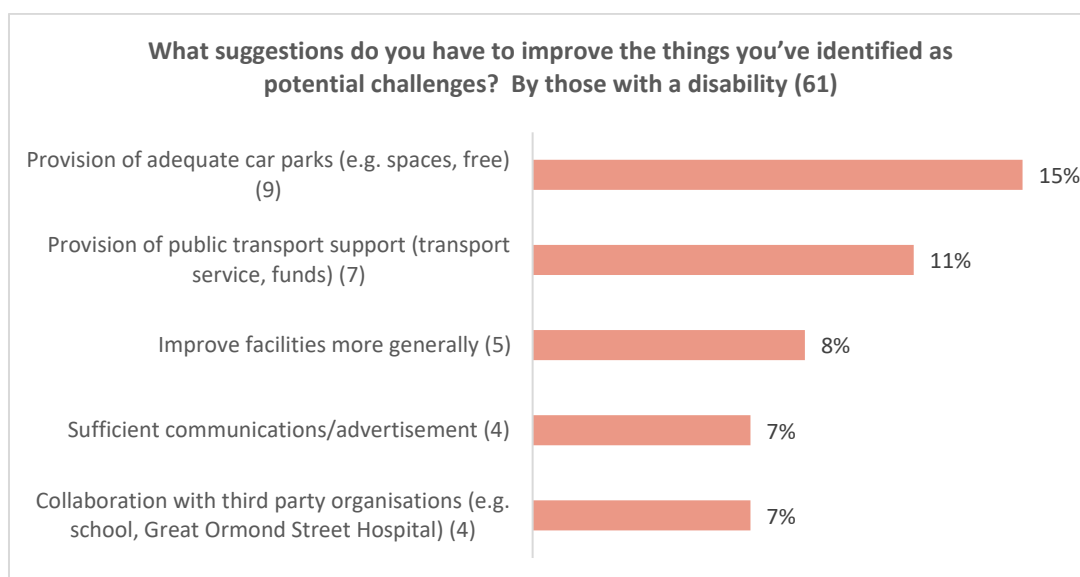


Figure 34 Equality Groups Respondent with a Disability, Improve Potential Challenges about Evelina London

Respondents with a disability stated that one key improvement should be made to parking provision (15%). Public transport support was also important to this group (11%).





11.3 The proposal for St George's Hospital

11.3.1 Good points

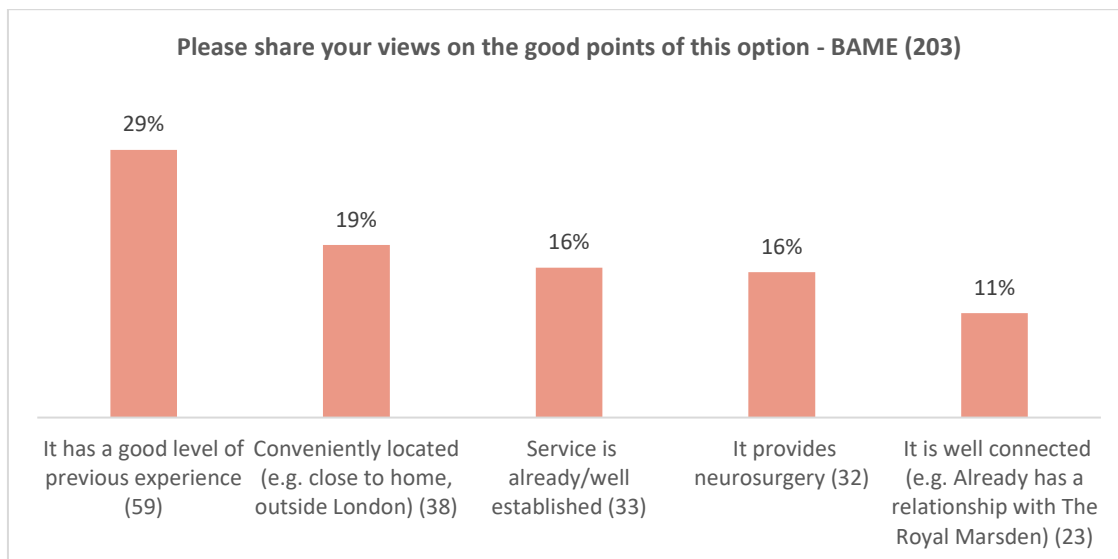


Figure 35 Equality Groups Ethnic Minority Groups, Good Points about St George's Hospital

Key strengths of St George's Hospital proposal identified by respondents from ethnic minority groups included its current experience and expertise of running part of the Principal Treatment Centre (29%) as well as the service being already well established there (16%), with a good relationship with The Royal Marsden (11%). Neurosurgery was also considered a strength (16%). The location of St George's Hospital was also noted by respondents, with some respondents feeling that it is conveniently located outside the centre of London (19%).



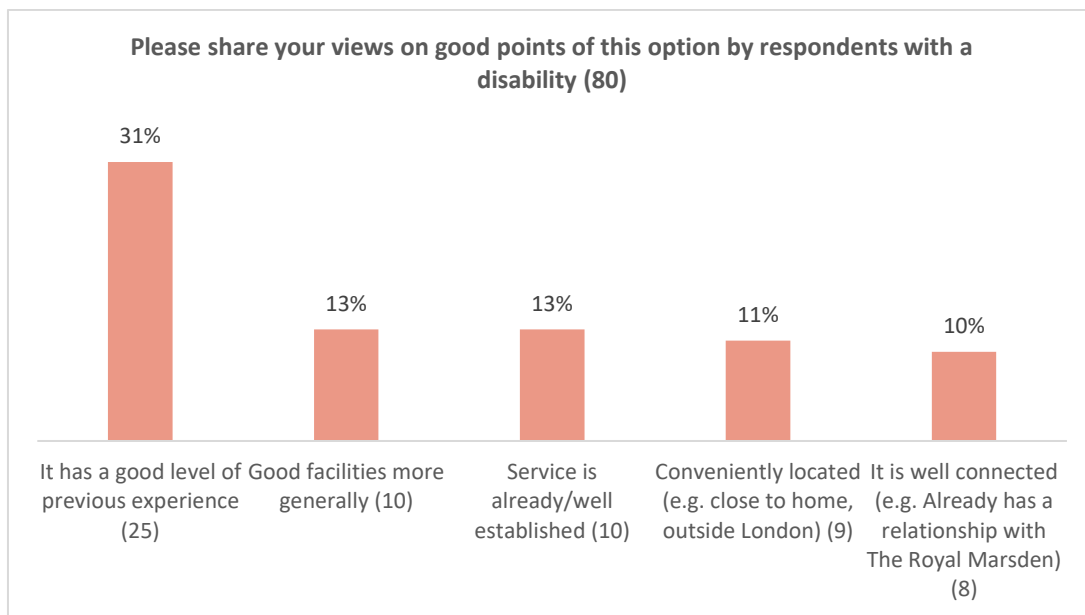


Figure 36 Equality Groups Respondent with a Disability, Good Points about St George's Hospital

For respondents with a disability, their views on the strengths of St George's Hospital were similar to other groups. They talked about the experience and expertise of St George's Hospital as part of the current Principal Treatment Centre in partnership with The Royal Marsden (31%) as well as the service being already well established (13%). Good facilities at St George's Hospital was also cited (13%). The location of St George's Hospital was noted by respondents, with some feeling that it is conveniently located outside the centre of London (11%).



11.3.2 Potential challenges

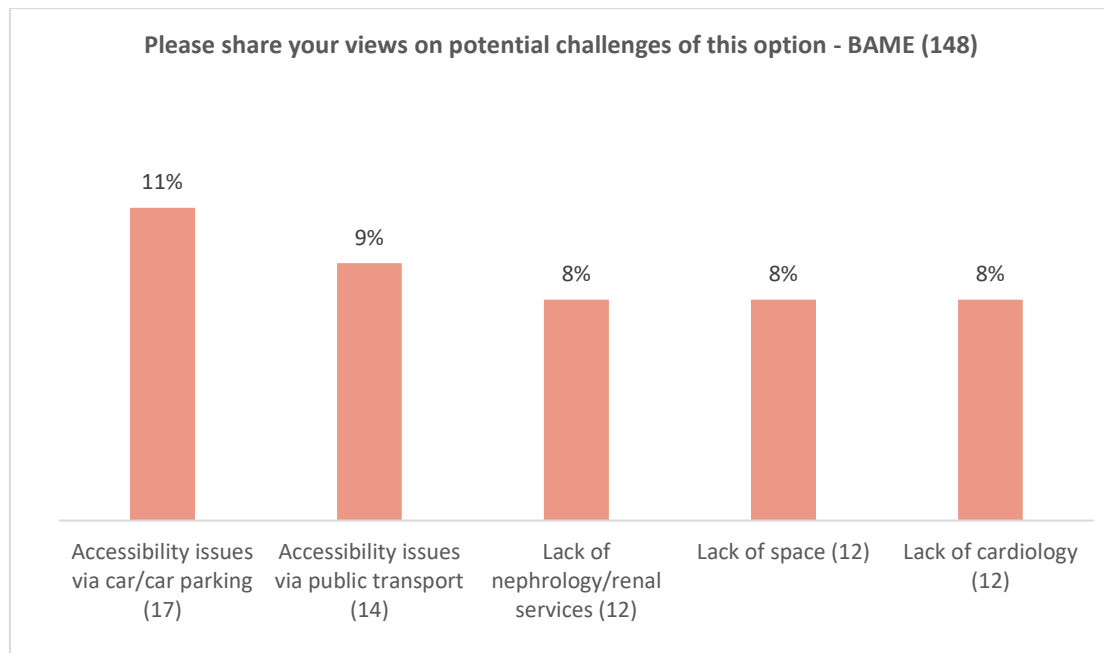


Figure 37 Equality Groups Ethnic Minority Groups, Potential Challenges about St George's Hospital

Key challenges to the St George's Hospital proposal as identified by respondents from ethnic minority groups include accessibility to the site by car (11%), accessibility by public transport (9%), and the absence of specialist nephrology (8%) and cardiology (8%).

- *'Still a lot further for patients and families to travel than it is to travel to Sutton. Expensive limited parking' (Respondent ethnic minority groups, questionnaire response)*
- *'Difficult to get to by car (due to traffic) and parking is a problem' (Respondent ethnic minority groups, questionnaire response)*



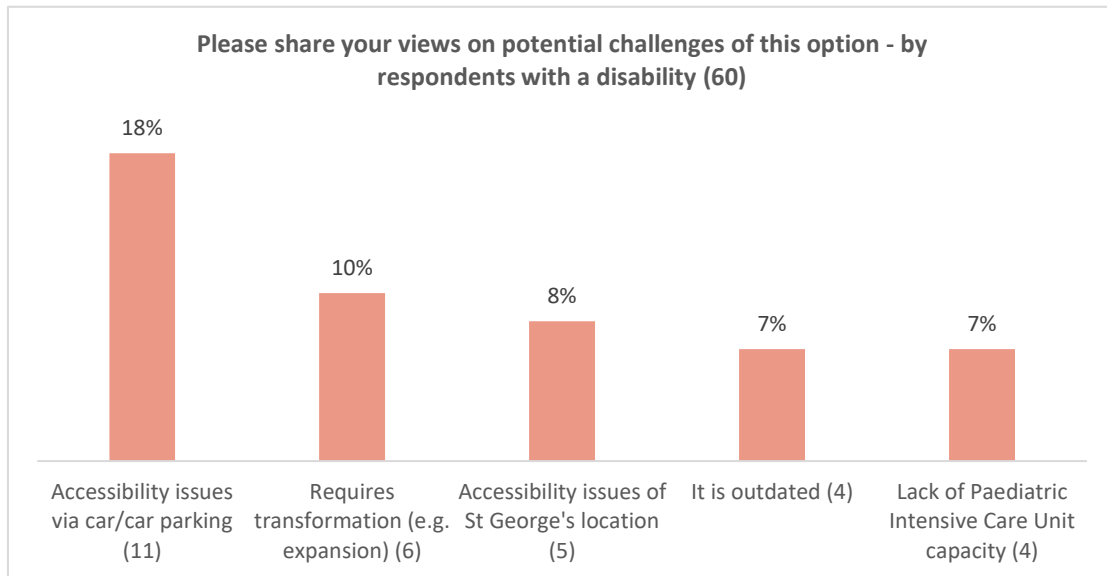


Figure 38 Equality Groups Respondent with a Disability, Potential Challenges about St George's Hospital

Those with a disability agreed that a key challenge to the St George's Hospital proposal was accessibility by car (18%). This group also identified the need to update facilities as another key challenge (10%).

- 'Where can you put a unit the size of the one at RMH? There isn't enough space for the services they have. The roads to the hospital are gridlocked for most of the day' (Respondent with a disability, questionnaire response)
- 'Where it is – a complete pain to get to from most of London. A huge rambling site half of it looks like it needs replacing' (Respondent with a disability, questionnaire response)
- 'Investment in the building without disruption to the hospital' (Respondent with a disability, questionnaire response)



11.3.3 Improvements

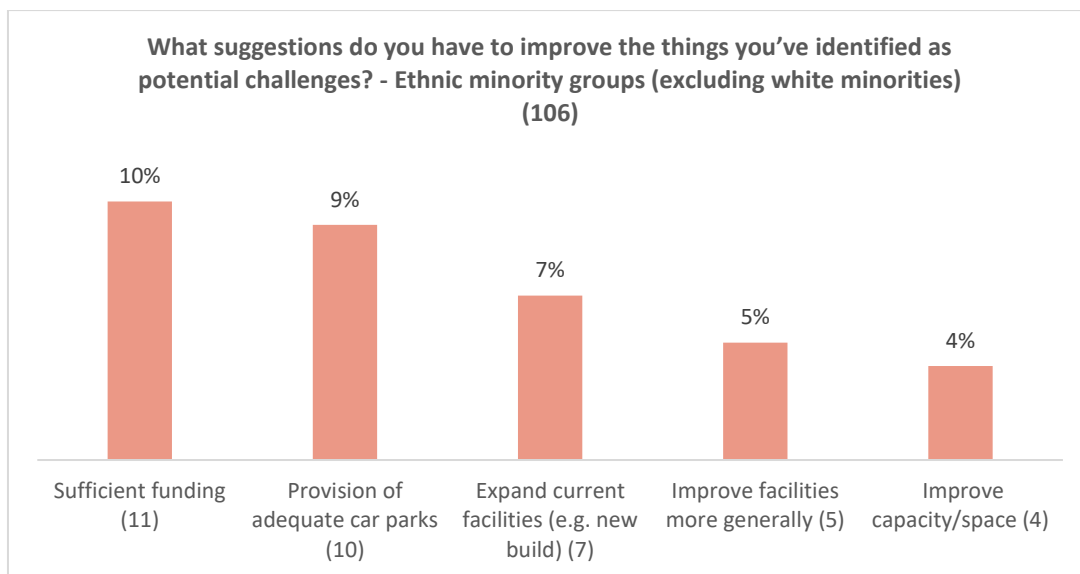


Figure 39 Equality Groups Ethnic Minority Groups, Improve Potential Challenges about St George's Hospital

Respondents from ethnic minority groups highlighted the need to secure sufficient funding to ensure St George's Hospital overcomes the identified challenges (10%), the need to provide additional car parking (9%), and the requirement to expand current facilities (7%).

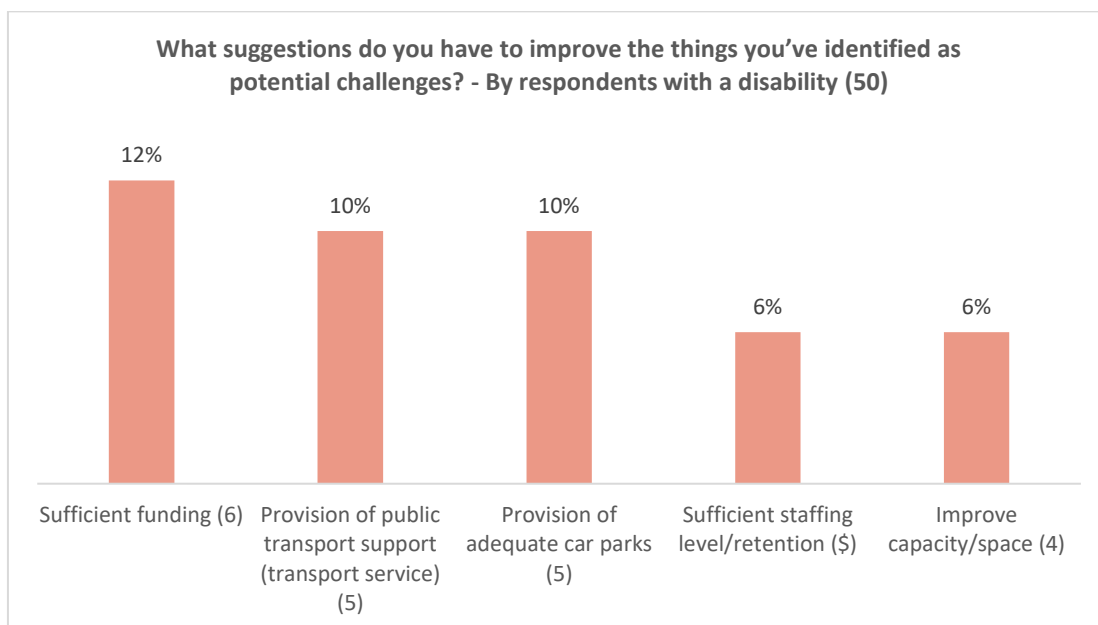


Figure 40 Equality Groups Respondent with a Disability, Improve Potential Challenges about St George's Hospital



Improvements identified included the need to secure sufficient funding to ensure the St George’s Hospital proposal is a success (12%) and the need to provide public transport support, such as a transport service (10%).

11.4 Views on the delivery of radiotherapy services at University College Hospital

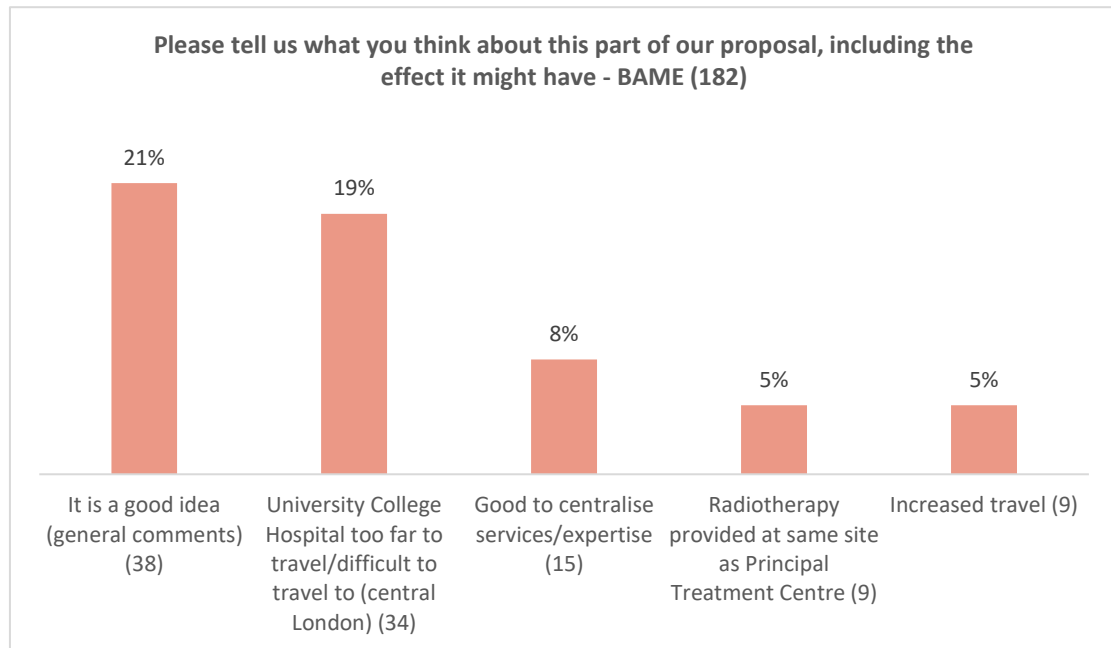


Figure 41 Equality Groups Ethnic Minority Groups, Radiotherapy Services at University College Hospital, effect proposal might have

Comments made by the greatest number of respondents from ethnic minority groups were general positive comments about the proposal to move radiotherapy services to University College Hospital (21%). Others highlighted the accessibility challenges related to travelling to University College Hospital, particularly given its central London location (19%).



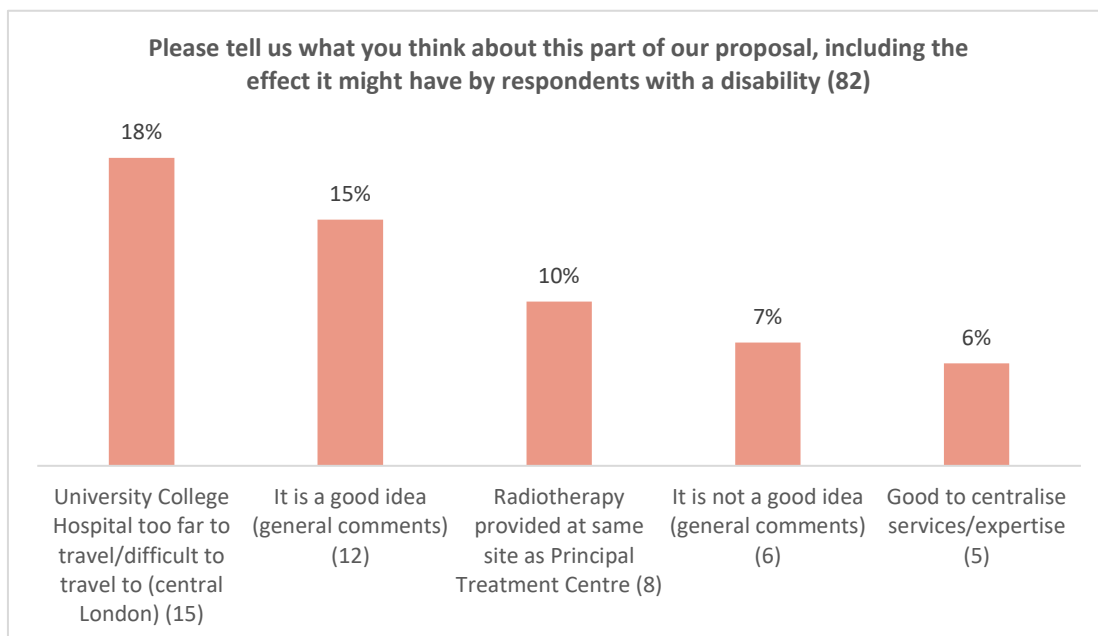


Figure 42 Equality Groups Respondent with a Disability, Radiotherapy Services at University College Hospital, effect proposal might have

Similarly, most respondents with a disability highlighted their concerns about the accessibility of University College Hospital in central London (18%). Some respondents expressed concerns about this part of the proposal in relation to the fragmentation of services (8%), whereby radiotherapy would no longer be provided on site.

- *‘It makes financial sense to site at a hospital which already has the infrastructure’ (Respondent Ethnic minority groups, questionnaire response)*
- *‘This will become costly for some families and inconvenient to access’ (Respondent Ethnic minority groups, questionnaire response)*

As well as this, other respondents considered radiotherapy services being provided at University College Hospital as being a good idea (15%), with comments here relating to the benefit of having a range of services available to patients.

- *‘That sounds exciting and sensible. A wider more targeted range of treatments should be less frightening and more reassuring’ (Respondent with a disability, questionnaire response)*
- *‘With faster computer communication between various units in individual hospitals it seems at the moment ideal to concentrate all the radiotherapy services in one hospital. I realise it is a huge expense to have all the services, particularly the proton beam service, in every hospital so until the NHS is properly funded and these services are available in every hospital*



altogether this is a good solution' (Member of the public with a disability, questionnaire response)

- *'I think this will be a great part of the proposal, being able to offer a wider range of services to our patients is amazing and will benefit the patient care experience immensely' (Member of NHS staff – who works for a Paediatric Oncology Shared Care Unit in London or the south east, questionnaire response)*

11.5 Future Principal Treatment Centre

Respondents identified the following features as essential in a future Principal Treatment Centre:

- As many services as possible under one roof
- Funding for innovative and advanced treatments
- Access to cutting edge diagnostics and treatment facilities
- Access to the most relevant and up to date research
- Staff who are experienced in treating children with cancer, who have experience of working together
- Autism and neurodiversity friendly
- Accessible in terms of disability parking, ramps, access to an interpreter if needed
- Child-friendly environment with age-appropriate facilities, located in a separate unit
- Adequate transport facilities and connectivity to facilities, including children's schooling, carers' workplaces and rest and entertainment facilities
- Access to play specialists
- Accessible by car or public transport; easy to get to; good transport links
- Access to free hospital transport

11.6 Challenges faced by and mitigations to consider for marginalised groups

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



Infographic 1: Summarising the challenges faced by marginalised groups



People from ethnic minority groups and people who speak English as an additional language

During the meeting with members of the Lewisham Refugee and Migrant Network, it became clear that individuals did not always understand how the NHS worked. They relied on their GP to navigate clinical pathways on their behalf. They felt they were often misunderstood by healthcare workers in terms of being listened to and comprehension of their speech. Many described being dismissed or ignored. Some said they resorted to taking an English speaker with them as an advocate. Those in attendance at the Belvedere Asian Women's Group also talked about their experiences of language barriers and needing translated information (Punjab).

Reflecting on the proposals, members of the Lewisham Refugee and Migrant Network acknowledged that both options were located relatively close by, but some would still need support with travel. Free hospital transport would be preferred. Some said they have no access to a car and very limited money to use in advance of a journey by public transport, so any solution would need to provide reimbursement in advance of making a journey. Women from the Belvedere Asian Women's Group said they thought the criteria for accessing hospital transport were too strict, thus preventing those who would benefit most from accessing it.

In contrast, representatives for Gypsy, Roma and Traveller ethnic groups, mentioned that travel to and parking at hospital was not a concern. For them, having bedside family accommodation was important, so the family can stay together as a close unit. Women from the Belvedere Asian Women's Group thought that separate, private rooms would be preferable to a ward setting, but if attendance on a ward was required, then children should be grouped according to age.



Clinical staff from Great Ormond Street Hospital commented that an increasing number of families who do not speak English are relying on costly taxis to travel to hospital. Staff said that this was because families lack the confidence to navigate public transport. Nurses try to show them the route on mobile phones.

Food was important to those at the Belvedere Asian Women's Group and the Lewisham and Refugee and Migrant Network they said their vegetarian diet (which also excludes egg and fish) is often overlooked in healthcare settings. They thought attention and sensitivity to this would help in cases where children were sick and not eating.

Maintaining a child's education while undergoing cancer treatment was also important to those in attendance from the Belvedere Asian Women's Group. They also valued reference to outdoor spaces in the two proposals.

People with mental health difficulties

Emphasis here was on providing affected families with early notice of any change and supporting them in negotiating that change. Suggestions included:

- Create videos that feature parents, carers, and staff, so communications are relatable and familiar
- Offer affected families the opportunity to visit the future Principal Treatment Centre to meet staff there; this could be in the form of community engagement sessions that are conducted in advance of and during the transition
- Allow for time to have repeated conversations with individuals who may need repeated assurances about the change.

Families and staff on low incomes

Across engagement activity, feedback related to accessibility challenges for families on low incomes. This included travel costs. During a focus group with Great Ormond Street Hospital clinical staff, they said consideration needs to be given to a different payment model if families are incurring additional costs due to the change in location of the Principal Treatment Centre. A few respondents who completed the questionnaire talked about the reimbursement process, particularly in relation to the speed and method of reimbursement. They thought this should be a quicker process. One respondent talked about the need for a review of staff wages to support with increased travel costs.

- *'Fast reimbursement if required' (Other respondent receiving universal credit, questionnaire response)*



- *'All issues with expenses to be dealt with at Reception of the new treatment centre' (Parent, carer or advocate for a child or young person – who is currently having treatment for cancer receiving Employment and Support Allowance, questionnaire response)*
- *'Review of wages and an increase to help with the increased costs of getting to work' (Member of staff at The Royal Marsden, questionnaire response)*

Other issues flagged as requiring attention included:

- Affordable accommodation, to minimise the cost impact of the proposal
- Affordable amenities in the surrounding area, with families being away from home and needing to use cafes and takeaways
- Childcare costs
- Impact on job security and household income, acknowledging that additional support might be needed.

People with physical disabilities

Challenges identified here related largely to accessibility and suggestions were made by some respondents. These included:

- Access ramps and working lifts
- Flexibility in appointment times (offering appointments later in the day to give enough time for travel)
- Disabled parking, and ample parking available
- Support with the cost of transport
- Hospital transport available
- Communications and hospital signage suitable for those with sight impairments.

People with learning disabilities:

It was acknowledged that not all staff are trained or experienced in dealing with patients or parents and carers who have a learning disability. One respondent talked about disability liaison nurses who provide good support, but who are not always available in healthcare settings (Disability group meeting, December 2023). Key points included:

- Good communication including the need to slow down and explain the issue properly, speaking in plain English and no jargon, and avoiding being condescending
- Longer appointments to enable time for people to process information



- Support to navigate new or unfamiliar healthcare spaces, in particular when thinking about the transition to the new Principal Treatment Centre
- Hospital Passports work well when used
- Having menus with photographs
- Easy read is sometimes too dumbed down and does not cater for those with less severe learning disabilities.

People with autism

In one focus group, some respondents who had autism talked about the risk of becoming overstimulated in hospital environments. They raised the importance of having quiet rooms available; safe spaces where patients or visitors can go, where staff understand what is happening and can provide appropriate support.

Children with special needs

There was also reflection on the needs of children who have autism or have a learning disability when they undergo hospital care. Key points here included:

- 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
- Letting parents or carers into treatment rooms
- Allowing children to listen to music or watch video as a distraction
- 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
- Offering sedation for children who struggle with scanners; offer numbing cream for injection sites
- Thinking about the transition to teenage and young adult services.

Looked after children

For looked after children, continuity of care is vitally important; one child described the importance of the relationship with staff during their treatment while they were still waiting to be placed in foster care. This child stated that retaining the Principal Treatment Centre at The Royal Marsden was very important to them; they felt the environment there was much more peaceful and calming than St George's Hospital where they were currently receiving treatment. The young person said:

- *'The Royal Marsden looked after me as if I was their own' (Young person, 13 years old, play specialist session at St George's Hospital, November 2023)*



In terms of feedback from looked after children who took part in a community focus group, accessibility for visitors was important.

- *‘Visitors can come easily otherwise it would be demotivating, inconvenient and annoying’ (Looked after child or young people, community focus group, December 2023)*
- *‘It’s important to be accessible for visitors and families’ (Looked after child or young people, community focus group, December 2023)*

Access to outdoor space was also important for looked after children during the community focus group. It was seen as an opportunity to connect with friends.

- *‘[Talking about Evelina London] I like the fact it has a park opposite so if you wanted to go outside for fresh air, that is nice. And just going out with friends, exploring nature – I would want them to visit’ (Looked after child or young people, community focus group, December 2023)*

Rural families

Accessibility was highlighted as a potential issue for families living in rural areas, especially if they were travelling greater distances as a result of the Principal Treatment Centre moving from The Royal Marsden. This was discussed at a few community focus groups. In terms of the questionnaire, responses were typical of other feedback, with more general reflections on travel and accessibility concerns, not specifically relating to rurality but nonetheless linked.

- *‘There isn’t a [bus] service after 6pm and so being discharged later in the day would be even more problematic for those travelling locally. There are no buses to some villages, and they are very isolated so would need to rely on taxis which are expensive and unsustainable. What happens if a child is really sick?’ (Disability group meeting, December 2023)*
- *‘[Both hospitals are in built up, congested areas] unsuitable for those coming from a rural area’ (Other, prefer not to say, questionnaire response)*



12 Members of the public

This chapter draws together feedback from respondents who identified themselves as members of the public. This means that they do not necessarily have a connection to cancer (via immediate or extended family and friends) or work in healthcare. Like other chapters, feedback is presented for each proposal (Evelina London and St George’s Hospital), followed by reflections on the proposal to move radiotherapy to University College Hospital.

12.1 Engagement snapshot



12.2 The proposal for Evelina London Children's Hospital

12.2.1 Good points

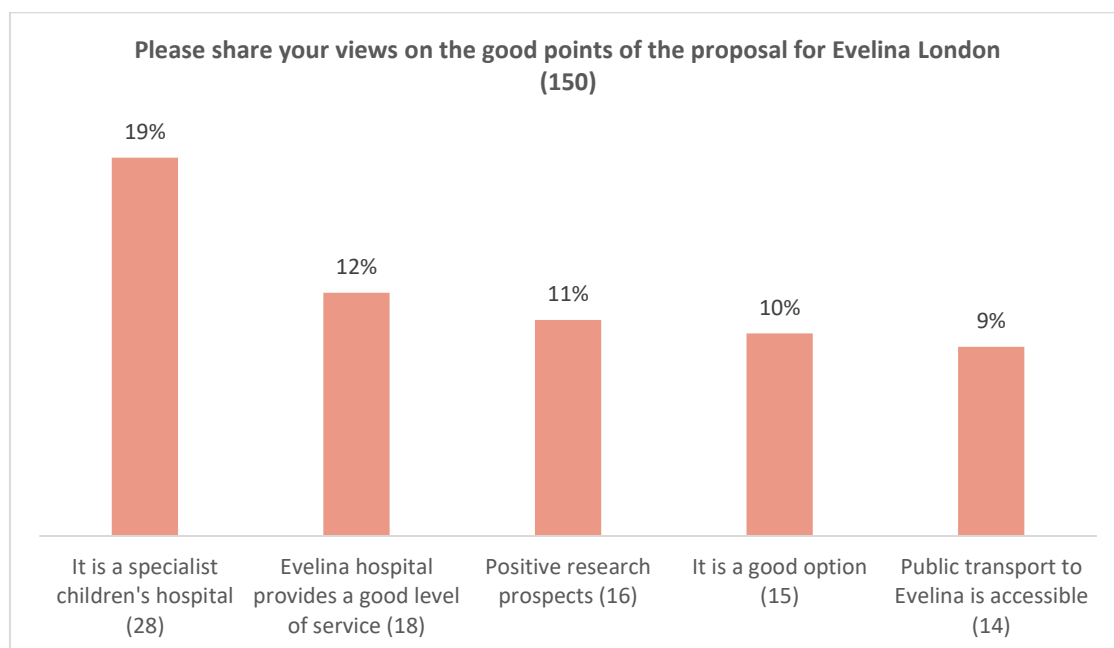


Figure 43 Members of the Public, Good Points about Evelina London

Evelina London is a dedicated children's hospital

The comments made by the greatest number of members of the public stated that the main strength of the proposal for Evelina London is that it is already a dedicated children's hospital (19%) as well as it being renowned for the excellent level of service it provides (12%).

- *'The fact that Evelina is comprehensive in all paediatric care and experienced in all levels of care'* (Member of the public, questionnaire response)
- *'Centre of excellence with very high standards of care. Evelina Children's hospital is a dedicated hospital delivering children's health care & the environment is child friendly'* (Member of the public, questionnaire response)
- *'A comprehensive children's hospital on a large scale. A large and comprehensive PICU. 24/7 services across the full range of paediatric specialties. Purpose built and dedicated facilities that are modern. A large range of some of the best medical technology and equipment for the diagnosis and treatment of sick children'* (Member of the public, questionnaire response)



- *'Evelina London is renowned as a centre of excellence and is in a central London location with easy access from all parts of the area it serves'* (Member of the public, questionnaire response)

Evelina London has a strong research proposition

Members of the public also acknowledged the strong research proposition of Evelina London (11%).

- *'Research is very important to them enabling new treatments to be developed or trialled for multiple conditions. It is part of Guy's and St. Thomas' NHS Foundation Trust which has the largest complex cancer centre in London and is research intensive'* (Member of the public, questionnaire response)
- *'Excellent staff, research and environment. Lots of funding, investment and research'* (Member of the public, questionnaire response)

Evelina London is well connected by public transport links

Members of the public also talked about how Evelina London is easy to reach by public transport, given its location in central London (9%).

- *'Public transport links are good'* (Member of the public, questionnaire response)
- *'Its central location is ideal because transport links are so good'* (Member of the public, questionnaire response)

12.2.2 Potential challenges



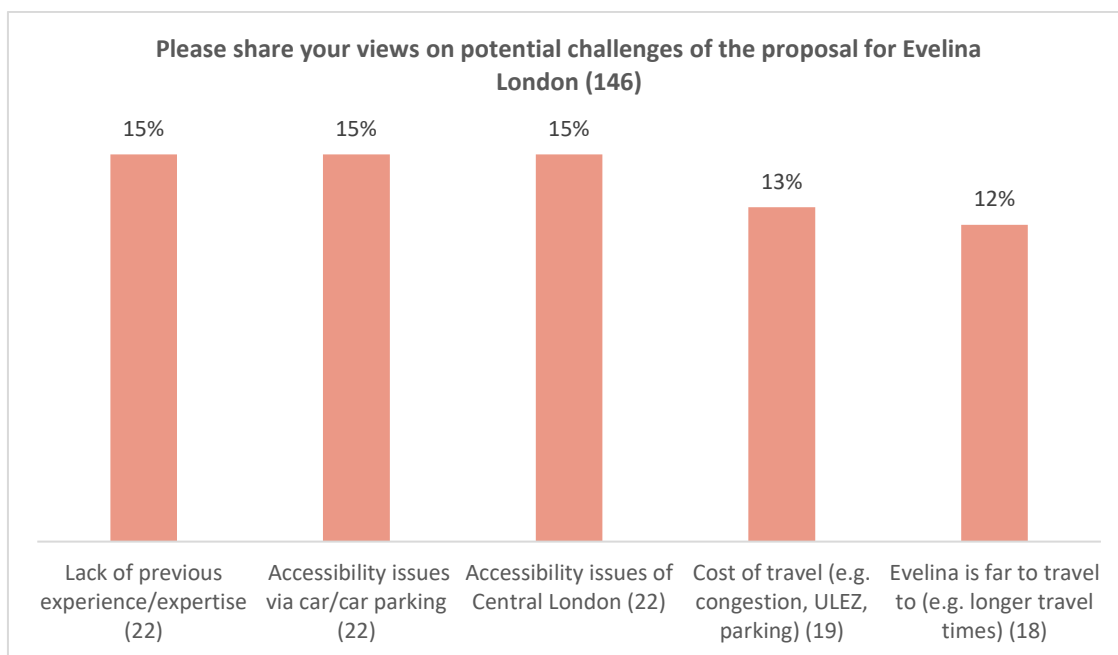


Figure 44 Members of the Public, Potential Challenges about Evelina London

Evelina London does not have experience or expertise in children’s cancer care

Like other stakeholder groups, members of the public identified Evelina London’s lack of experience or expertise in children’s cancer care as a key challenge (15%).

- *‘Evelina Hospital does not have an existing cancer service’ (Member of the public, questionnaire response)*
- *‘Does not have the long history and experience of children cancer. Smaller than St George’s Hospital and not a holistic solution’ (Member of the public, questionnaire response)*
- *‘Lack of Paediatric [oncology] experience, St George’s Hospital has 25 years’ experience’ (Member of the public, questionnaire response)*

Travel and accessibility challenges of Evelina London

Accessibility of Evelina London was a key concern for members of the public. Members of the public talked about the difficulties in accessing Evelina London by car and finding car parking (15%), as well as other issues relating to its central London location including journey times and congestion (15%), and the cost of travel (13%). It was also stated that Evelina London was a long way for many families to travel (12%).

- *‘Evelina is in a congestion zone, which will be costly for families preferring to take car/private vehicle’ (Member of the public, questionnaire response)*



- *'Travelling with a sick patient is not easy and moving to Evelina will have a big impact to the community, especially in Surrey area' (Member of the public, questionnaire response)*
- *'Not suitable for patients not living in the area. No parking having to use expensive public transport exposing already vulnerable patients to more environmental pollution' (Member of the public, questionnaire response)*



12.2.3 Improvements

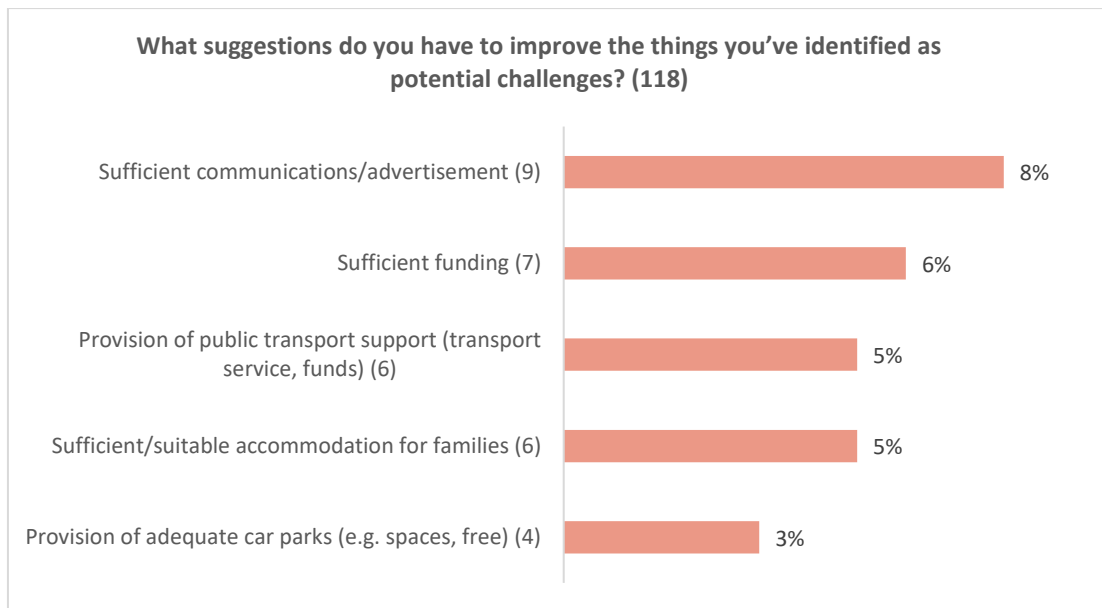


Figure 45 Members of the Public, Improve Potential Challenges about Evelina London

The greatest number of comments left by members of the public centred on ensuring affected families are communicated with about the change (8%). Here, some mentioned that families need to be provided with guidance from a personal point of contact about travel and travel costs into London.

- *'Could be mitigated with personal point of contact and transparent communication'*
(Member of the public, questionnaire response)
- *'Parents need guidance about travel costs, alternatives and speed of access to the hospital'*
(Member of the public, questionnaire response)



12.3 The proposal for St George's Hospital

12.3.1 Good points

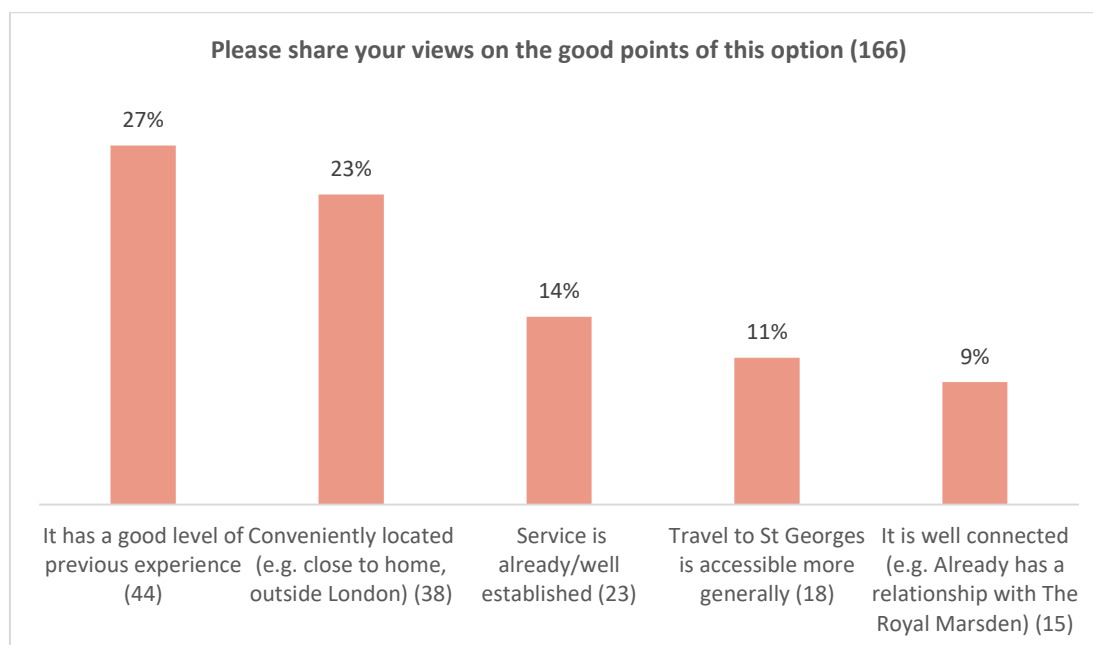


Figure 46 Members of the Public, Good Points about St George's Hospital

St George's Hospital has 25 years of experience in delivering specialist children's cancer services as part of the current Principal Treatment Centre.

When thinking about the strengths of St George's Hospital proposal, members of the public talked about its experience in delivering services to children with cancer (27%), and the fact that the hospital is already part of the current Principal Treatment Centre in partnership with The Royal Marsden (14%).

- *'Provides specialist children's services. 25 years' experience of caring for children with cancer' (Member of the public, questionnaire response)*
- *'Patients and their families are already established at St George's Hospital and already receive excellent care. St George's Hospital provides a vital service in assisting those in South East England and South West London' (Member of the public, questionnaire response)*

The location of St George's Hospital is convenient, and it is easy to access



Accessibility was another key strength of St George’s Hospital proposal for members of the public, citing its convenient location outside central London (23%) and the ease with which families can get there (11%). However, it is important to note the overrepresentation of respondents living in South West London who comprise members of the public, meaning St George’s Hospital is closer and therefore more accessible to them due to their geographical location.

- ‘Closer to more patients, less traveling’ (Member of the public, questionnaire response)
- ‘Close knit transport links’ (Member of the public, questionnaire response)
- ‘Easy to access. Lots of buses and tube nearby’ (Member of the public, questionnaire response)

12.3.2 Potential challenges

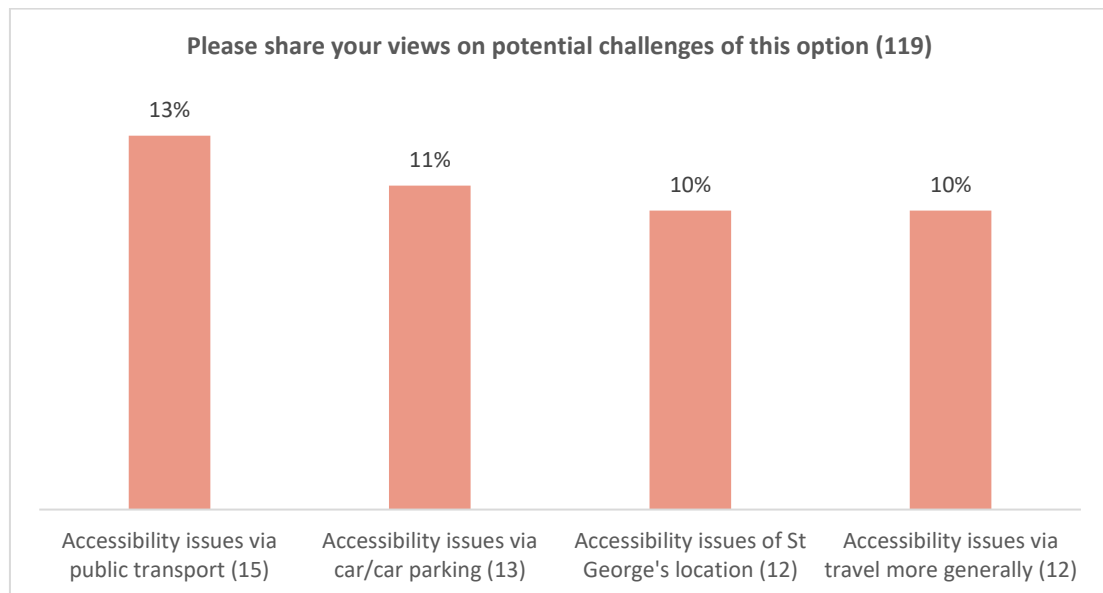


Figure 47 Members of the Public, Potential Challenges about St George’s Hospital

Travel and accessibility challenges relating to St George’s Hospital

When asked to consider challenges relating to St George’s Hospital proposal, members of the public focused on accessibility. This included difficulty in accessing the hospital by public transport (13%), and the challenge associated with travelling by car and finding a parking space (11%).

- ‘When I visit St George’s it feels like a site bursting at the seams and when it comes to parking, it’s a nightmare’ (Member of the public, email correspondence, October 2023)



- *'Location of St Georges is difficult for many employees, patients and resource suppliers in London and parts of the South East of England' (Member of the public, questionnaire response)*
- *'Nightmare to get to by road and public transport, especially with a sick child susceptible to infection' (Member of the public, questionnaire response)*

12.3.3 Improvements

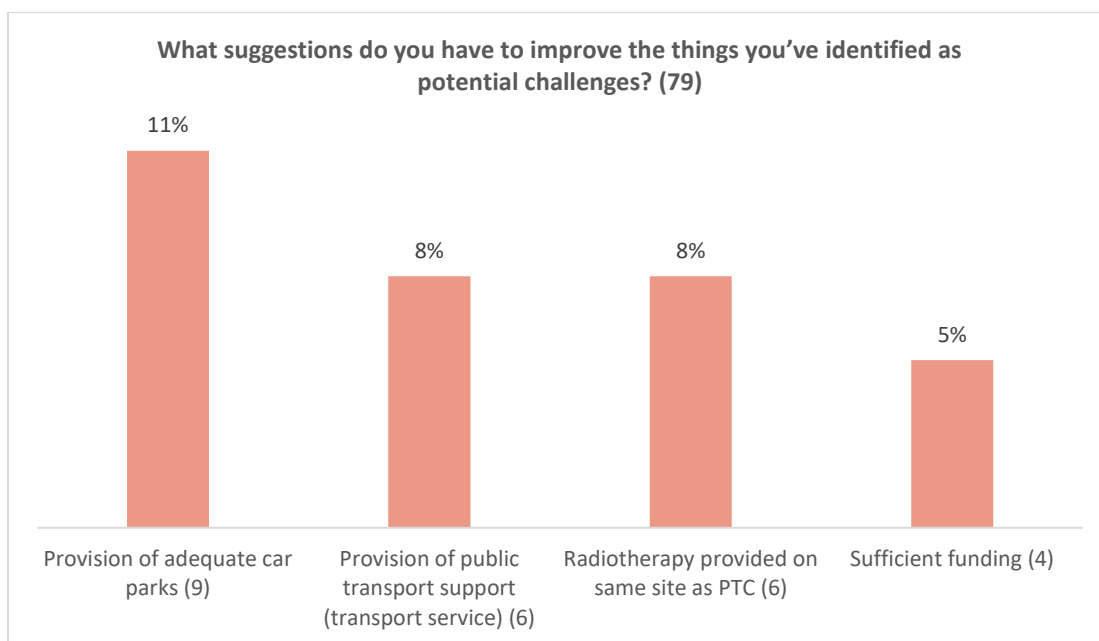


Figure 48 Members of the Public, Improve Potential Challenges about St George's Hospital

In terms of improvements that could be made to the St George's Hospital proposal, members of the public talked about improving the availability of car parking (11%) and providing public transport support (8%).

- *'Support with transport, dedicated car service' (Member of the public, questionnaire response)*
- *'Provide a shuttle service' (Member of the public, questionnaire response)*

There was also an emphasis on providing all related services in the new Principal Treatment Centre, including radiotherapy, cardiology, and nephrology.

- *'Move all the services to one site' (Member of the public, questionnaire response)*
- *'Kidney and heart services should be located with the cancer centre at St George's Hospital' (Member of the public, questionnaire response)*



12.4 Views on the delivery of radiotherapy services at University College Hospital

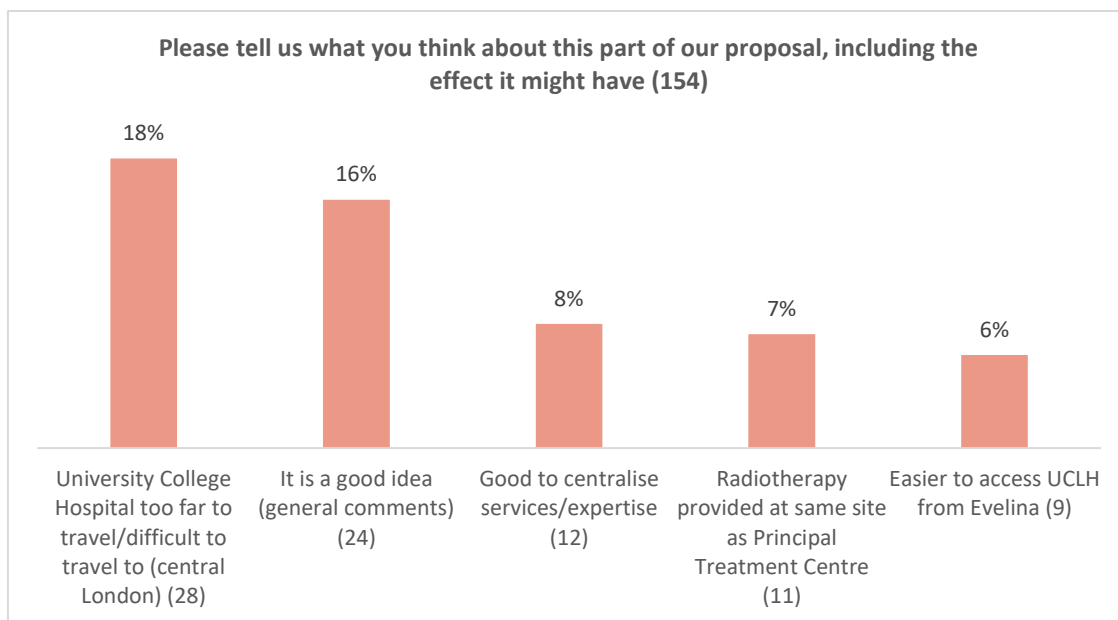


Figure 49 Members of the Public, Radiotherapy Services at University College Hospital, effect proposal might have

The comment made by the greatest number of members of the public about the proposal to move radiotherapy to University College Hospital was that it would be too far or difficult to travel to (18%).

- *‘[Reflecting on the advantage of having radiotherapy on the same site as the Principal Treatment Centre] I’ve worked near UCH for many years in the past, parking there is insanely difficult making it inaccessible by private car, but who would want to put a child going through radiotherapy through the hell of commuting into town. Transportation link for patients needs to be a priority, one that doesn’t involve the joys of the Northern Line and changing at Kennington’ (Member of the public, questionnaire response)*
- *‘Getting to UCH would result in adding additional time through congested and polluted streets and/or underground, potentially in peak travelling times. The proposal is not helpful for patients and their families at all’ (Member of the public, questionnaire response)*
- *‘Radiotherapy requires regular visits by ill people, the distance for Tooting locals to travel to UCH is unacceptable’ (Member of the public, questionnaire response)*

Others gave more general comments that it was a good idea (9%).



- *‘Consolidating small, specialised services and expensive equipment is sensible if children are to receive pioneering technology to support their care’ (Member of the public, questionnaire response)*
- *‘Advantage of specialist team and equipment’ (Member of the public, questionnaire response)*

12.5 Future Principal Treatment Centre

When asked what they would most value in a future Principal Treatment Centre, members of the public talked about:

- Modern facilities, purpose-built, child-friendly, and child-focused
- All services based in one location, including neurosurgery and radiotherapy
- Ease of access by both car and public transport, with plentiful free parking
- Proximity to one’s home
- Access to pioneering treatment
- Excellent and experienced staff, who are kind and caring
- Integrated experienced multi-disciplinary team with a well-established system of working together
- Reputation and track record of providing excellent care in children’s cancer care
- Excellent communication
- Excellent research facilities on site
- Good parent and family facilities, including affordable accommodation

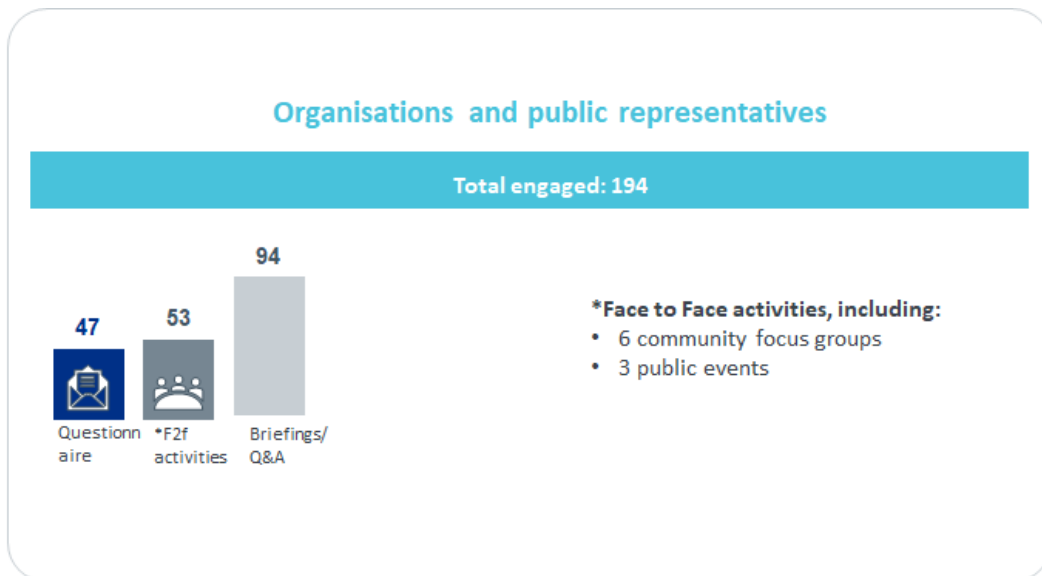


13 Organisations and public representatives

This chapter includes feedback from respondents who identified themselves as representing public bodies, voluntary organisations, research organisations, children’s cancer charities, and other not-for-profit organisations, as well as public and political representatives. Feedback comes from a range of engagement methods. In addition to these formal responses, a number of respondents submitted responses via the survey or email where they mentioned their organisation but did not identify themselves as representing it. These responses have not been separately identified here but the feedback received has been included in the analysis and is reflected in the findings of this report. The first part of this chapter deals with feedback on the two options (Evelina London and St George’s Hospital) including the proposal to move conventional radiotherapy services to University College Hospital. This draws on feedback gathered during a range of engagement activities, including the questionnaire, meetings, and discussions. Formal responses submitted on behalf of organisations are recorded separately in the second section of this chapter. Organisations ranging from healthcare bodies and local authorities to charities and research organisations, provided formal responses. These formal responses varied in length and level of detail provided. Each formal response is summarised in the dedicated section below. Full copies of formal responses from organisations have been provided separately to this report.



13.1 Engagement snapshot



13.2 The proposal for Evelina London Children’s Hospital

13.2.1 Good points

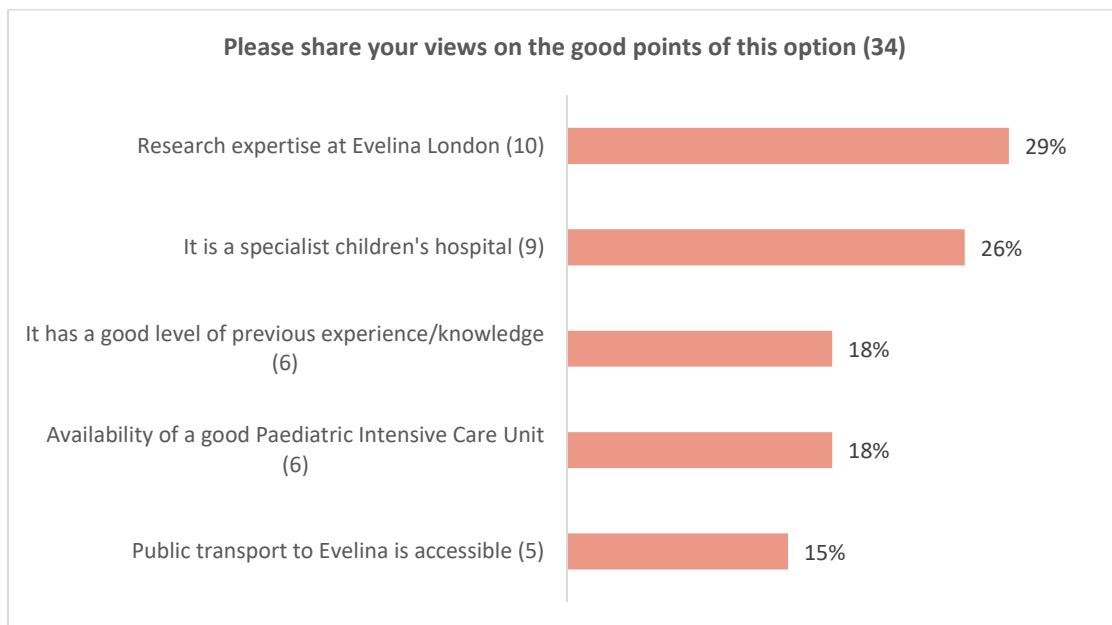


Figure 50 Organisations and Public Representatives, Good Points about Evelina London

Evelina London is a dedicated children’s hospital

In terms of positive comments about the Evelina London proposal, the fact that Evelina London is a dedicated children’s hospital was cited across feedback from this stakeholder group.

- *‘There are enormous benefits to children of dedicated children’s hospitals, and their families benefit too. Children with cancer will benefit from having most of the treatment they need provided in the same familiar and welcoming place’ (Voluntary organisational representative, questionnaire response)*
- *‘Seriously unwell children deserve the best possible care, in a place that is purposefully built and designed with children in mind and delivered by world class teams offering dedicated care. Evelina Hospital is co-designed by children and their families to be bright, friendly and with plenty of spaces to play’ (Other public body/stakeholder/political representative, questionnaire response)*



Research expertise at Evelina London

There was consideration given to the research track record at Evelina London, with reference made to the fact that researchers there are working on more than 180 children's research studies with academic and industry partners. There was also reference made to the independent assessment made by a panel of research experts which stated that Evelina London had the best potential for enhancing children's cancer research. In addition, in email correspondence from the Director of Guy's and St Thomas' Clinical Research Facility, it was stated that the facility is one of very few NHS Phase 1 Units accredited by Medicines and Healthcare Products Regulatory Agency (MHRA), and the only one to be delivering early phase cancer trials. The point was made that this facility, as well as the associated governance infrastructure, would be available to Evelina London paediatric oncologists if the move goes ahead.

- *'I understand that the research team at Evelina London is working on more than 180 children's research studies, along with academic partners worldwide and to international acclaim. Two research wards, and approvals for early-stage clinical trials... access to the vast expertise and experience of their colleagues at Guy's and St Thomas' NHS Foundation Trust, Kings College London University and across Kings Health Partners' (Other public body/stakeholder/political representative, questionnaire response)*



13.2.2 Potential challenges

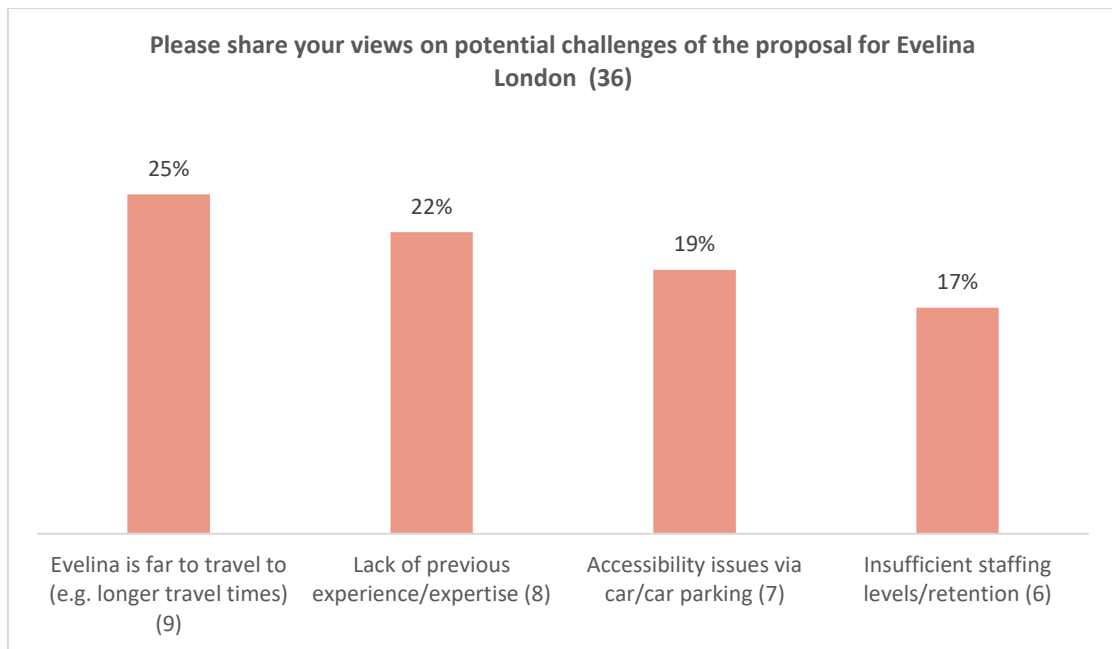


Figure 51 Organisations and Public Representatives, Potential Challenges about Evelina London

Travel and accessibility challenges of Evelina London for patients and their families

Across feedback from organisations and associated representatives, there was significant concern about the accessibility of Evelina London for patients and their families. Concern focused on the additional travel time that would be required for many families and the additional costs that would be incurred (as a result of the Ultra Low Emission Zone and the congestion charge). However, it is important to note that under the proposal, Evelina London would support with people getting Ultra Low Emission Zone congestion charges reimbursed if eligible due to their financial circumstances⁴⁸.

Although some respondents recognised Evelina London's good public transport links, it was acknowledged that many parents would prefer to travel by car and that even the journey from Waterloo Station by public transport can be 'arduous' (Children's charities focus group).

- *'Trying to access it with a sick child is just unnecessarily difficult, if not impossible. I presume if parking isn't available the NHS will be providing private ambulances but even so it will add hours of travel and unnecessary stress to the families and more importantly to very sick children' (Children's cancer charity, questionnaire response)*

⁴⁸ It is noted that financial support with travel costs would be available to one parent or carer of a child receiving cancer care, if they meet the financial eligibility criteria.



Lack of experience and expertise in children’s cancer services at Evelina London

Organisational representatives also expressed a view that Evelina London does not have experience or current expertise in children’s cancer care. This was viewed as a risk to the future of the Principal Treatment Centre, particularly in terms of the continuation of its excellent track record.

- *‘No established relationships with Principal Treatment Centre team⁴⁹’ (Research organisation, questionnaire response)*
- *‘No neurosurgery or established surgical teams’ (Research organisation, questionnaire response)*

Challenge in recruiting a specialist cancer workforce at Evelina London

The issue of recruiting a specialist cancer workforce at Evelina London was raised by a number of organisations. They would have to transfer staff from the current service, or look for specialists from elsewhere, which was considered to be a challenging endeavour which could take years. It is important to highlight that staff will be transferred from the current service to the new site under both proposals, however, it is of course still possible for staff to find another employer during this process.

13.2.3 Improvements

Suggested improvements from representatives of organisations included:

- A plan to provide a holistic service for children with cancer, under the same roof, including radiotherapy and neurosurgery
- Utilising Guy’s and St Thomas’ NHS Foundation Trust’s existing teenage and young adults cancer service as an opportunity to strengthen the clinical pathway and patient experience
- A rigorous financial plan for sustaining the service at Evelina London
- Financial support for families
- Ensuring sick children do not have far to travel for radiotherapy.

Other comments related to leaving the Principal Treatment Centre at The Royal Marsden (for its experience, expertise, and research track record) or moving the Principal Treatment Centre to St George’s Hospital.

13.3 The proposal for St George’s Hospital

⁴⁹ This is a perception; Evelina London staff provides a joint heart service with The Royal Marsden to discuss, care for, and monitor individual patients with cancer.



13.3.1 Good points

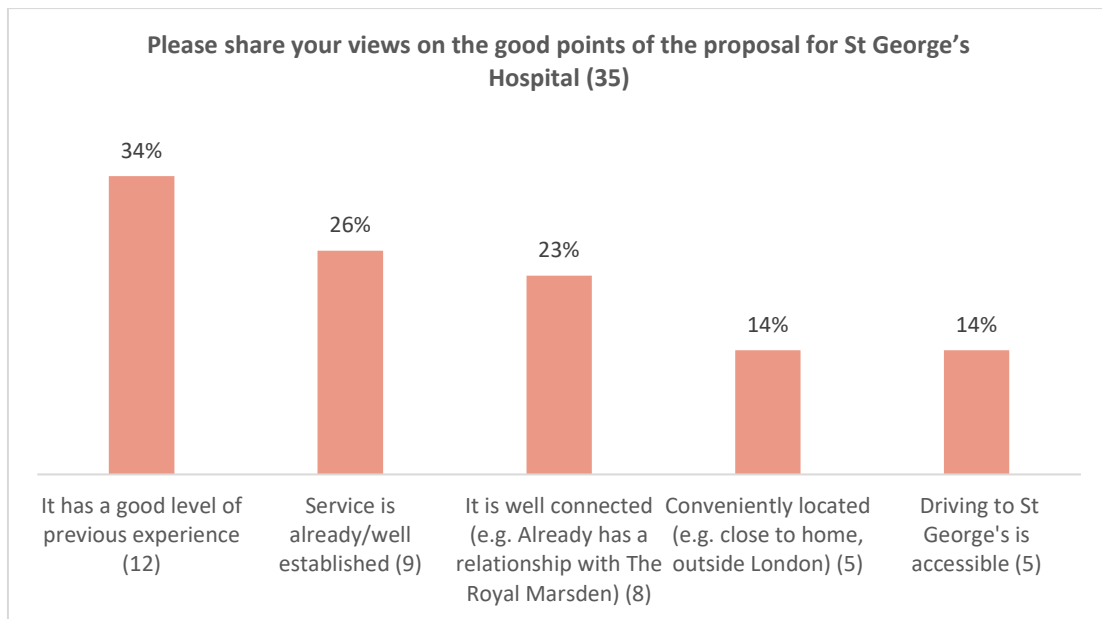


Figure 52 Organisations and Public Representatives, Good Points about St George's Hospital

St George's Hospital has expertise and experience in children's cancer care, including children's cancer care surgery

Respondents reflected on the fact that St George's Hospital has a good level of experience (34%) of questionnaire responses, due to the fact that it already delivers the current Principal Treatment Centre service in partnership with The Royal Marsden (23%). In terms of children's cancer care surgery, a surgeon at Bristol Children's Hospital, who responded to the consultation, favoured St George's Hospital proposal, given this very specialised area is not currently available at Evelina London.

- 'Established PTC relationship and connection' (Research organisation, questionnaire response)
- 'Already rated as Outstanding by the CQC. Lengthy experience of treating children with cancer. Experienced, skilled and dedicated clinicians and caring staff' (Research organisation, questionnaire response)

Travel and accessibility for families is good at St George's Hospital

Comments from some respondents focused on the more convenient location of St George's Hospital compared to Evelina London for many families, especially for families living outside London. The availability of parking was also seen as a strength of the proposal.



St George’s Hospital offers some neurosurgery on site

A few responses talked about the value of having neurosurgery co-located with the Principal Treatment Centre, acknowledging that St George’s Hospital provides the service to some patients. The Paediatric Lead for the Tessa Jowell Brain Cancer Mission noted that not having neurosurgery on site is a missed opportunity.

- *‘Specialist experience especially neurosurgery which is often needed by children with cancer’ (Other public body/stakeholder/political representative, questionnaire response)*
- *‘St George’s Hospital provides the key service of neurosurgery: one in four children with cancer have neuro-oncological cancer, and children with other cancers can need neurosurgery in emergencies’ (Other public body/stakeholder/political representative, questionnaire response)*

13.3.2 Potential challenges

St George’s Hospital is not a dedicated children’s hospital

A common theme across stakeholder groups, it was again highlighted, that St George’s Hospital is not a dedicated children’s hospital.

- *‘St George’s Hospital is not a specialist children’s hospital, and would be unlikely to become the centre of excellence that the NHS should be hoping to develop with this initiative’ (Voluntary organisation, questionnaire response)*

Travel and accessibility challenges relating to St George’s Hospital

While some respondents looked favourably at St George’s Hospital location, others were concerned that families would struggle to access it by car or by public transport.

- *‘Geographically inaccessible to patients outside South London area’ (Research organisation, questionnaire response)*
- *‘Journeys by public transport (e.g. by train) from East Sussex may be a little more complex’ (Other public body/stakeholder/political representative, questionnaire response)*

13.3.3 Improvements

Comments made by organisational representatives in terms of improvements that could be made to St George’s Hospital proposal included:



- Supporting families with travel costs
- Offering accommodation on site
- Ensuring the hospital has adequate funding to develop and sustain the service in the long-term.

A few organisational representatives raised the concern that if St George's Hospital was not selected as the location for the Principal Treatment Centre, then this could result in a negative impact on other paediatric services at St George's Hospital, as well as a negative impact on the financial wellbeing of South West London Integrated Care Board.

- *'Paediatric oncology at St George's Hospital is closely intertwined with other specialties. A range of specialists at St George's Hospital deliver children's cancer care as part of their wider caseload, including neurology, paediatric neurosurgery, gastroenterology, haematology, paediatric intensive care, paediatric surgery, paediatric acute medicine, infectious disease, and clinical support services such as paediatric pathology and radiology. The surgeons at the hospital who operate on children with cancer also operate on other children from across South West London and Surrey. If the children's cancer service were to move to Evelina, a large number of the other specialties at St George's Hospital would be impacted, and could be weakened. There would be particularly significant impacts on paediatric pathology and paediatric surgery' (Other public body/stakeholder/political representative, questionnaire response)*

13.4 Views on the delivery of radiotherapy services at University College Hospital

Much of the feedback on the proposal to move radiotherapy services to University College Hospital highlighted concerns about splitting the services across sites and requiring children to travel for conventional radiotherapy.

- *'In both options radiotherapy services would be provided by University College London Hospitals NHS Foundation Trust, as such clinical services wouldn't all be on one site, still requiring children to travel' (Research organisation, questionnaire response)*
- *'I want to make sure that local children don't have to travel too far for radiotherapy when they are sick. I am worried that if radiotherapy services are no longer available at St George's Hospital, children in Croydon will be travelling for hours to get to the alternatives and back' (Other public body/stakeholder/political representative, questionnaire response)*



- *‘For the greater majority of ‘normal’ radiotherapy, having it available closer to the patients’ home would be desirable’ (Other public body/stakeholder/political representative, questionnaire response)*
- *‘Better if radiotherapy is transferred to St George’s Hospital rather than a split site services’ (Voluntary organisation, questionnaire response)*

However, organisational support for the move of radiotherapy services to University College Hospital can be found in individual formal responses, which are detailed later in this chapter.

13.5 Potential challenges affecting both proposals

It is worth noting here comments made by organisational representatives that highlight concerns that affect both proposals. One of these concerns relates to the absence of a single site solution, notably that radiotherapy will be provided at University College Hospital, and therefore children will still need to travel between hospitals when they are very sick.

- *‘We are not solving the issue of children needing transfers? We are just further complicating a system that works’ (Scrutiny Committee meeting)*

Another concern was about the lack of detail provided in the proposals, including financial detail and charitable funding. Others highlighted the enormous importance of clinical trials for children with cancer and of ensuring they continue.

- *‘It is critically important that the facilities to deliver these trials, and to accommodate children travelling from across the UK to participate in these trials, are part of whichever of the two proposed sites is selected as the new London centre. Loss of this facility would have an enormous impact on the UK’s ability to deliver experimental cancer medicine trials for children and would result in a highly significant reduction in the opportunities for UK families to take part in these trials’ (National lead for the Experimental Cancer Medicines Centre (ECMC) Paediatric Network, email correspondence, December 2023)*

13.6 Future Principal Treatment Centre – what matters the most

Organisational representatives talked about the following features as essential in a future Principal Treatment Centre:

- High quality expert cancer care responsive to the specific needs of children with cancer



- Access to specialist children’s services in one place
- Child-friendly purpose-built facilities
- Safe and comfortable environment, isolated from other children’s non-cancer care
- Access to play opportunities
- Access to mental health therapy
- Easy transport access and parking
- Effective help for parents and families
- Dedicated spaces for parents and families
- Practical support to accommodation and travel
- Access to counselling, financial and community or charitable support
- Opportunities for patients to take part in clinical trials
- Strong research facility
- Clear referral and discharge pathways and processes
- Good communication between the Principal Treatment Centre and related services.

13.7 Formal responses

Formal responses were submitted by letter, email, and the questionnaire. A summary is provided of each organisation’s response to the consultation⁵⁰. Formal responses are organised by organisation type. These types are:

- Government bodies and representatives (four responses)
- Health bodies and associated groups (17 responses)
- Local authorities (seven responses)
- Parent bodies and representatives (three responses)
- Research organisations (five responses)
- Charities and not-for-profit organisations (eight responses)
- Other responses (one response).

13.7.1 Government bodies and Members of Parliament

National Institute for Health and Care Research

National Institute for Health and Care Research expressed no preference for where the service should be located.

⁵⁰ Full responses can be found in a separate annex to the main report.



Member of Parliament for Richmond Park

The MP for Richmond Park declared their view that the new Principal Treatment Centre should be located at St George's Hospital, as it would be cheaper for the public, pose a reduced risk to patients, and would be operationally simpler to achieve. The response also reflects on St George's Hospital experience and expertise in relation to treating children's cancer care.

Member of Parliament for Twickenham

The MP for Twickenham expressed their view that the new Principal Treatment Centre should be located at St George's Hospital, given its 25 years' experience in delivering the current Principal Treatment Centre in partnership with The Royal Marsden.

Member of Parliament for Wimbledon

The MP for Wimbledon stated their view, and the view of their constituents, that the new Principal Treatment Centre should be located at St George's Hospital, given the expertise and experience of the team and service already there.

13.7.2 Health bodies and associated groups

British Association of Paediatric Surgeons (BAPS)

The response from BAPS indicated that it fully supports the need to change cancer services in South London and is pleased to see a recognition that experts in Oncology, Radiotherapy and pathology in relation to cancer care will be needed under both proposals. While BAPS felt it would be wrong to comment on which centre the new site should be relocated to, it offered a number of factors which should be taken into consideration. These included:

- St George's Hospital has surgeons experienced in solid tumour resections. While Evelina London are aware of this and stated their willingness to support colleagues with their experience, a system must be developed where no child comes to harm if the services are relocated.
- While the surgeon is important and can potentially be relocated the wider extended surgical team is also important and must be taken into consideration if the services are relocated.
- There have been previous instances of relocation to paediatric surgery where physical and psychological support has been lacking resulting in staff leaving the relocated unit.

BAPS also asked to be consulted on any future proposals regarding changes to paediatric surgery in London or anywhere else in the UK.



Children's Hospital Alliance

This is a national network of 12 dedicated, specialist children's hospitals across England that works together to improve quality, access, and experience of hospital care for children and families. The response stated their support for the case for change and that very specialist children's cancer services must be co-located with a children's intensive care unit. Whilst noting that this does not diminish the excellent care that the team at The Royal Marsden provide; they underline the opportunity to further enhance the joined-up care, research and patient experience that will be provided once this important change is delivered.

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

The response stated the team's support for the consultation process and give equal support to the proposals. The response calls for the necessity to deliver age-appropriate care (highlighting the different needs of patients aged 13-16 and 16-25 for example). The response also stated the team want clarity on late effects services for children and young people, including resourcing.

Epsom and St Helier University Hospitals NHS Trust

Epsom and St Helier provides a Paediatric Oncology Shared Care Unit and works closely with both the Royal Marsden and St George's in the delivery of children's cancer care. The response states the Trust's commitment to working with the future Principal Treatment Centre, wherever it is located. Key points raised included:

- For Epsom and St Helier children's cancer shared care unit patients, accessing services at the Evelina will be more difficult than accessing services at St George's. St George's is closer to home and avoids the need to travel into central London. There is concern about how this will impact less well-off families in deprived areas of the catchment area.
- The consultation documentation outlines a potential negative impact on other paediatric services at St George's if the Principal Treatment Centre moves to Evelina London. Epsom and St Helier works closely with St George's paediatric services: paediatric surgeons from St George's operate on patients at the Trust's hospital sites, and paediatric pathologists at St George's also provide support (for instance, in perinatal pathology). There is concern that moving the Principal Treatment Centre to Evelina London would have a negative knock-on impact for other patients beyond children's cancer – and note that the risk would not arise if the Principal Treatment Centre remained at St George's.
- The consultation documentation describes the likelihood of stranded costs at St George's if the Principal Treatment Centre is moved to Evelina London. A financial problem at St George's becomes a financial problem for South West London, and therefore for Epsom and St Helier.



Given the scale of the financial challenge we face in South West London this is a significant potential further pressure that could be avoided by retaining the Principal Treatment Centre at St George's.

Great Ormond Street Hospital for Children

The response from Great Ormond Street Hospital confirmed its support for the case for change, stating that the outcome of the consultation must result in the co-location of paediatric intensive care services. The responses stated that the immediate adjacency of appropriately skilled staff and facilities to care for any child who may become critically unwell during their hospital treatment is essential for their safety, particularly for those who are under 13 years old. The response stressed that viewpoints of the expert staff groups who currently deliver these highly specialised services must be fully considered. The response also set out their commitment to working closely with any successful service provider in the best interests of patients, families, and staff.

Guy's and St Thomas' NHS Foundation Trust

The Trust's response stated its support for the case for change and that very specialist children's cancer services must be co-located with a children's intensive care unit. The Trust supported the proposal for the service to be located at Evelina London. Key points included:

- Evelina London is the only dedicated, purpose-built specialist children's hospital in South London and South East region and was the first children's hospital in the country to be rated 'Outstanding' by the Care Quality Commission. It has a scale and depth of expertise; 30 specialists in children's cardiology; and more than 50 surgeons working across 10 complex surgical specialties with 10 operating theatres; the region's only nephrology service for children with complex conditions including kidney failure; a critical care unit that has 30 beds.
- A new Children's Day Treatment Centre has been recently opened at Evelina London
- Evelina London would provide families with travel and accommodation support including bookable parking spaces, a dedicated door-to-door car shuttle service, reimbursement of travel costs, and access to family accommodation
- Evelina London has the ability to share electronic patient records across the main NHS Trusts, to improve patient safety and provide continuity of care
- Evelina London is located close to the radiotherapy hub at University College Hospital
- Track record of Evelina London in delivering research and clinical trials for children; the children's research team is already working on more than 180 children's research studies with academic and industry partners worldwide
- Staff give positive feedback scores about working at Evelina London



- Evelina London is supported by one of the largest healthcare charities in the UK, Guy's & St Thomas' Foundation, which has established a dedicated children's charity, Evelina London Children's Charity, that has raised almost £20m over the last five years to support projects at Evelina London

Healthwatch Richmond upon Thames and Healthwatch Merton

Healthwatch Richmond upon Thames and Healthwatch Merton considered the consultation to be insufficient and highlighted that it failed to meet from their perspective, the Gunning Principles of Consultations. They felt that insufficient information was provided for people to give an 'intelligent consideration' to the consultation. In particular, they suggested that there was an insufficient level of information provided on the rationale underpinning the need for change, which is evidenced by the presence of numerous opposition groups and statements. Moreover, Healthwatch raised concerns surrounding the ability to influence the pre-consultation phase, considering the consultation as 'fait accompli'. Further concerns were highlighted surrounding travel time and the impact it has on individuals' abilities to meet essential commitments, such as work and family commitments.

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

The organisation felt that the consultation questions did not collect information that would be required to influence decision making, such as:

- Reflecting on the scoring criteria
- Ability to express a preference between the two options
- Ability to describe the relative strengths and weaknesses of the two options

Kent and Medway Cancer Alliance

This response provided feedback based upon community engagement. They expressed support for all radiotherapy services to be delivered at University College Hospital and acknowledged that some children's cancer shared care units had preference towards Evelina London. They noted that the future Principal Treatment Centre should offer personalised care within a purpose-built environment, and provide access to education, space and facilities for families, and age-appropriate play. They also raised



concerns surrounding the accessibility of both options, suggesting that support with travel and travel costs would be necessary, whilst also recognising the impact this has on appointment times.

King's College Hospital NHS Foundation Trust

The Trust noted its ability and willingness to work in partnership with the future Principal Treatment Centre, either St George's Hospital or Evelina London. The Trust supports the proposals relating to the move of conventional radiotherapy to University College Hospital. It notes that St George's Hospital already has expertise in cancer care; however, the Trust expressed concerns about the nature of the campaign that has been run by St George's Hospital and related others, most notably by implying that all cancer care will be provided at St George's Hospital if that option is chosen. In the future, children will continue to be treated at King's and other specialist providers where needed.

NHS South East London Integrated Care Board

The response expressed support for the future location of the service at Evelina London, given that it is a dedicated children's hospital and is able to deliver high quality, coordinated care for children. NHS South East London Integrated Care Board also noted that Evelina London's international impact as a children's health research leader, as well as the Guy's and St Thomas' Hospital facilities and expertise in adult cancer research, will provide a strong basis for delivering the future service. South East London Integrated Care Board also expressed its commitment to working with the Guy's, St. Thomas', St George's, The Royal Marsden, other Integrated Care Boards, NHS England, patients and families, and others to ensure the service move is a success if Evelina London is the chosen option.

The response expressed support for the future location of the service at Evelina London, given that it is a dedicated children's hospital and is able to deliver high quality, coordinated care for children. South East London Integrated Care Board also noted that Evelina London's international impact as a children's health research leader, as well as the Guy's and St Thomas' Hospital facilities and expertise in adult cancer research, will provide a strong basis for delivering the future service. South East London Integrated Care Board also expressed its commitment to working with Guy's and St Thomas' Hospital, St George's, The Royal Marsden, other integrated care boards, NHS England, patients and families, and others to ensure the service move is a success.

Royal College of Paediatrics and Child Health

The response from the Royal College of Paediatrics and Child Health stated its support for the case for change. However, it raised concerns in relation to accessibility and affordability of travel for families in relation to both proposals. By way of mitigation, it suggests that this is a national issue and the children's cancer shared care units, network should be strengthened.



St George's Hospital

St George's Hospital stated its position that the Principal Treatment Centre should be consolidated on to the St George's Hospital site. Key points included:

- St George's Hospital has 25 years' experience of delivering paediatric cancer care. The expertise built up over these years, and the professional relationships built up between different clinical specialists as they collaborate to treat children with cancer, cannot be easily or quickly replicated overnight
- The services that matter most for children with cancer are available on site at St George's Hospital:
 - o 15% of children with cancer will have a neuroblastoma, renal tumour, or germ cell tumour, and these children will often require major surgery performed by a children's cancer care surgeon to remove or reduce their tumour. This expertise is rare: there are 20 such surgeons in the country, three of whom are at St George's Hospital
 - o 25% of children with cancer have a brain or spinal tumour, many of whom will need neurosurgery. Some other children with cancer will also need neurosurgery as a result of their treatment. Along with King's, St George's Hospital provides neuro-oncology surgery and acute neurosurgery; Evelina London does not have this
 - o St George's Hospital has a bone marrow transplant programme for adults and is accredited to provide CAR-T for adults, and so is well placed to extend the offer to children. Guys and St Thomas's does not have a bone marrow transplant programme, and is not accredited to deliver CAR-T. These highly regulated and complex clinical and laboratory services are difficult to set up without past experience
 - o The response states that for some 80% of children with cancer, St George's Hospital can offer or is poised to offer key treatments that Evelina London will not, or will have to develop
- St George's Hospital is located outside of central London, with good parking provision, meeting the needs of many parents who have said they want to travel by car
- Consolidating the children's cancer centre at St George's Hospital will be easier and less costly for the NHS to deliver; it will also be less disruptive for staff
- If the service moves from St George's Hospital, this will have a detrimental impact on other children's services at St George's Hospital. For example, surgeons at St George's Hospital who operate on children with cancer also operate on other children from across South West London and Surrey. This would present a budgetary challenge (the income associated with the



Principal Treatment Centre would be lost), as well as the risk of losing these expert staff if they move with the service and leave St George's Hospital

- Research at St George's Hospital is strong; St George's Hospital already supports more children into clinical trials than any other provider in South London
- The Government has given its support to build a new hospital in Sutton. This would see the St George's Hospital, Epsom and St Helier Group co-located with the Institute of Cancer Research.

South Thames Paediatric Network

The response from the South Thames Paediatric Network stated its support for the case for change, and recognised the strengths in providing the service at a hospital which offers both intensive care for children, and other specialist services. Although, they confer no preference for the future location of the Principal Treatment Centre and felt that both options provide exciting opportunities.

The Royal Marsden NHS Foundation Trust

The Royal Marsden highlighted its concern that other than achieving co-location with children's intensive care unit, there will be fragmentation of the service, the number of transfers for patients will be higher, research will be affected and the experience and outcomes for patient and families will not be improved overall. Key points about the current Principal Treatment Centre at The Royal Marsden included:

- Safe and high-quality children's cancer services delivered in a research active environment
- State of the art diagnostic techniques, specialist drug treatments and onsite radiotherapy
- Modern purpose-built, children's cancer centre, the Oak Centre for Children and Young People, opened in 2011
- Ease of access for patients, families, and staff
- The Royal Marsden and the Institute of Cancer Research are ranked in the top 5 centres globally for the impact of their research
- Substantial investment of £100 million in children's cancer by The Royal Marsden over the last decade.

The response also provided reflections on the proposal to move the service, which noted:

- The relocation will not provide a single site solution and the proposed model will increase the number of transfers that children experience (specifically for patients requiring photon radiotherapy)



- A more fragmented oncology service for children, specifically for patients requiring radiotherapy
- A lack of future resilience with only a single site for radiotherapy in London and the South East for children with cancer
- Impact on clinical research; maintaining research activity at the current level is unlikely to continue and access to world-leading clinical trials which is a national priority, will be at risk
- Families need assurance that there is a fully funded delivery plan which enables all of the benefits of the current service and the capacity to be made available in a new location
- Retention of a very specialist and expert workforce is not guaranteed
- Impact on the Teenage and Young Adult (TYA) services, which relies on the close integration of facilities and staff, led by consultants in the paediatric team.

University College London Hospitals NHS Foundation Trust

The Trust expressed its equal support for both options. It also expressed its support of the proposed changes to consolidate paediatric radiotherapy into one specialist pan-London service. The response states that the team has a strong track record of providing radiotherapy as part of the Principal Treatment Centre team in other organisations. The team is familiar with supporting patients travelling long distances for their care and look forward to working directly with the Principal Treatment Centre team to ensure that the pathways put in place fully support patients and families during this period of their treatment, and that care is seamlessly provided at University College London Hospital as part of their Principal Treatment Centre care. The response also highlighted the need to recognise the increased complexity and requirement for extensive age-appropriate support for children and families and its associated resource requirement. As such, the Trust asks for the development of a financial case which recognises capacity and resourcing requirements, including capital and revenue cost implications, and that this be included in the decision-making business case and risk register for the programme.

University Hospital Southampton NHS Foundation Trust

The Trust response outlines that they are supportive of the aims of the consultation to co-locate paediatric cancer services onto a site with children's intensive care in place. The response states that there are no plans within the options outlined to move any referral pathways to Southampton Children's Hospital and that there is no anticipated increase in the number of families choosing to transfer care to Southampton a result of the proposed changes. The Trust acknowledges that NHS England is open to reviewing the impact of this move if activity at Southampton did increase as a result of these changes.



13.8 Local authorities

London Borough of Bexley

London Borough of Bexley expressed its support for the service to be based at Evelina London, with conventional radiotherapy services located at University College Hospital. The response noted that Evelina London is a dedicated children's hospital, with care rated by Care Quality Commission as outstanding, and is part of the Guys and St Thomas' NHS Foundation Trust which has experience and expertise in cancer care and research. The response stated that Evelina London would be the most accessible option for families living in the Borough. However, emphasis was placed on providing support with transport for families, including ambulance transport, sufficient free parking, and reimbursement of the cost of travel (including Ultra Low Emission Zone and congestion charges).

Lewisham Council

Lewisham Council expressed their support for service to be located at Evelina London, highlighting:

- Evelina London provides outstanding care as demonstrated by its 'Outstanding' rating from the Care Quality Commission.
- A commitment to continuity of care, support for families and shared care
- The hospital's commitment to providing interdependent, specialist services.
- Evelina London's research track record and collaboration with King's College London.

London Borough of Merton

London Borough of Merton expressed its support for the service to be based at St George's Hospital.

Key points included:

- St George's Hospital has been delivering excellent specialist cancer care for over 25 years
- Given that around 25% of paediatric cancers are neurological and every other cancer centre (except for Leicester) is co-located with neurosurgery, it is essential to have access to skilled and experienced neurosurgeons who can deliver these services with easy access. Transferring the service to Evelina London would mean transporting very sick children to Kings College Hospital
- St George's Hospital can offer dedicated parking spaces for the families of children with cancer; parents have made it clear that it is easier, more comfortable, and safer to travel to hospital by car rather than public transport
- The evaluation of the bids placed St George's Hospital ahead of Evelina London on patient and carer experience, which should carry greater weighting in the evaluation process



- The capital cost of redeveloping St George's Hospital is an estimated £31 million; whereas it would cost an estimated £44 million to redevelop Evelina London; cost should be considered as part of the evaluation process
- Moving the service away from St George's Hospital could create a £2 million funding shortfall for the hospital

London Borough of Sutton

London Borough of Sutton stated its preference for the Principal Treatment Centre to be located at St George's Hospital. The reasons for this included:

- St George's Hospital is already part of the Epsom and St Helier Hospitals Trust offering consistency of care for patients and their families
- St George's Hospital has been part of the current Principal Treatment Centre, alongside The Royal Marsden NHS Foundation Trust, for more than 25 years and their children's services are rated Outstanding by the CQC. The benefits of this established relationship means that staff already work closely alongside one another and so the impact of the relocation of services on children and their families would be significantly reduced
- St George's Hospital is the only site in South London already delivering children's cancer care
- St George's Hospital is far more accessible for Sutton residents (patients, their families and staff).

Medway Council

Medway Council responded to state they had no formal response to make on the proposals.

Southwark Council

The response from Southwark Council stated its support for the service to be located at Evelina London, which would offer a more integrated and localised cancer service. The response also highlighted the disproportionate disadvantage that falls on families living in deprived areas when their child is diagnosed with cancer. Southwark Council states the specific needs of these families should be addressed in the planning and delivery of the future service.

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

The Committee's response was prefaced with a request for NHS England (London and South East Regions) to fully consider the voices of parents, their families, clinicians, and the wider community when deciding where and whether to move the service. They stated that:



'Patients and families will need 'cast-iron' assurances that the services on offer at either Evelina's or St George's are equal to if not better than the fantastic service already provided at the Royal Marsden. This will include, but is not limited to, significant retention of staff already working at the Royal Marsden, state of the art facilities, convenient access via private vehicle/ambulance, plentiful on-site parking provision, quick and easy travel/expense reimbursement for both parents, facilities for families to stay on-site (separate to other families/patients), access to trial therapies, and access to the general suite of paediatric care facilities under one roof' (South West London and Surrey Joint-Health Overview and Scrutiny Sub-Committee, formal response)

Reflecting on the options, the Committee expressed their preference towards St George's Hospital, given that it has 25 years of experience in working successfully alongside The Royal Marsden, and services in place already. They stated that the transfer of location to St George's Hospital would help with staff retention, and it is the cheaper option at a time when NHS budgets are tight. They highlighted that Evelina London would be much more difficult to access for families living in Kent and Medway, due to its central London location. Evelina London would also be more difficult to access for families living in Surrey, especially those from rural areas. The response stated that Evelina London option would seriously discriminate against low to middle income families especially those living in the more rural areas due to the economic and other impacts on them such as loss of working time and separation of families. The accommodation at Evelina London was also considered to be inadequate, as it is a ten-minute walk away from the hospital, adding stress to the experiences of families. In terms of the proposal to move radiotherapy services to University College Hospital, it was noted that this would cause uncertainty to current and future patients and families. It was also acknowledged that children may still be required to be transported to a different site in some cases, regardless of which site is chosen, dependent on the specialist care that individuals may require.

Wandsworth Council

Wandsworth Council expressed its support for the service to be based at St George's Hospital. This reflects feedback received from local residents. Key points included:

- St George's Hospital already delivers part of the current Principal Treatment Centre, with 25 years of experience and expertise in delivering children's cancer care.
 - o The existing service at St George's Hospital offers ground-breaking and innovative treatment, such as new immunotherapy treatment. St George's Hospital already has an adult bone marrow transplant programme, which is about to start delivering CAR-T therapy
 - o St George's Hospital is the paediatric centre in South London where pathologists regularly undertake cancer pathology



- St George’s Hospital can deliver neurosurgery on site; one in four children with cancer have neuro-oncological cancer
- Moving the service away from St George’s Hospital would impact its existing service delivery (Evelina London would not lose any of its existing provision if it was not chosen to lead the service). For example, moving the service could impact other specialities delivered at St George’s Hospital (and wider impact on other services across South West London), particularly paediatric pathology and paediatric surgery. It is not clear that this has been adequately considered by the evaluation of options to date
 - If the service moves, St George’s Hospital could face a significant financial gap of around £2.5 million in the first year of the change
- Travel time analysis did not consider the impact of the complexity of journey, reliability of transport services, and costs associated with this. It also did not acknowledge that some families are already travelling to the Principal Treatment Centre at St George’s Hospital
- Parents of children with cancer have made it clear that travelling by car is the preferred option. More than 60% of children having inpatient care at the current Principal Treatment Centre are from outside London. St George’s Hospital proposal offers dedicated parking directly outside the Principal Treatment Centre, as well as accommodation. There are concerns over travel and access if the service moved to Evelina London in central London (parking availability, traffic and journey times, and financial implications)
- Care at the Principal Treatment Centre is mainly provided on an in-patient basis, meaning that ease of access in terms of transport and availability of suitable accommodation for families is significant
- Evelina does not have experience in delivering cancer care for children; it does not currently have children’s cancer care surgeons. If the service moved to Evelina London, it would need specialists to move from St George’s Hospital or develop a new multi-disciplinary team which could take years
- St George’s Hospital is the most cost-effective option
- Choosing St George’s Hospital would minimise disruption for staff, patients, and families

This response also noted the strength of feeling from local families with lived experience of cancer in children who feel that their voice has not been heard by NHS England (London and South East) during the pre-consultation process.

West Sussex Health and Adult Social Care Scrutiny Committee

The Committee responded to say they were giving no formal response to the consultation.



13.8.1 Parent bodies and representatives

Greenwich Parent Carer Forum

The Greenwich Parent Carer Forum expressed its preference for Evelina London given the clinical expertise at Evelina London and its central location for travel and access for patients and families.

Young Lives vs Cancer

Young Lives vs Cancer expressed no preference towards either option and highlighted the importance of NHS England (London and South East Regions) to consider the voices of children, families and organisations in the development of the future Principal Treatment Centre. Although, they voiced their thoughts about what the future Principal Treatment Centre should include:

- The Principal Treatment Centre should provide access to a wide range of services and support, such as mental health services, dedicated play specialists, and dietician services
- Provide facilities which are appropriate for all children using the services, such as waiting areas and wards, and promote a positive environment which provides a sense of comfort for children
- A good level of clinical expertise in children's care, including specialist cancer care
- Support with travel costs incurred, such as reimbursements and hospital transport provision.

#HearTheMarsdenKids Campaign

The campaign group of parents stated their strong opposition to the case for change (national service specification) and stated that paediatric specialist children's cancer services should remain at The Royal Marsden. They wanted the national service specification to reconsider for the specific case of The Royal Marsden. Key feedback included:

- There is no guarantee that the new service would exceed, or indeed even meet, the current world-leading treatment programmes in place at The Royal Marsden
 - o Evelina London is not a cancer specialist hospital
- The number of patients affected by children's intensive care unit transfer is low. Many future treatments in development will minimise the need for children's intensive care unit. In 2022, only 3 children required children's intensive care unit transfers from The Royal Marsden to St George's Hospital; this is less than 1% of patients
- No proposal would provide a single site where all related care could be accessed. Those requiring radiotherapy would also be moved and have to travel elsewhere. Neurosurgery would not be provided at Evelina London. The number of patients who require radiotherapy



- is far greater than those requiring children's intensive care unit yet these are not being considered in terms of the huge impact this decision will have on them
- Travel times for the vast majority of patients and their families will be negatively impacted – around 63.6% of patients do not live in South East or South West London
 - o Both hospitals being proposed have limited parking available
 - o Evelina London is located within the Congestion Charge zone
 - o NHS London would only provide reimbursements for one member of the family
 - The estimated cost is £40 million, at a time when the NHS is underfunded
 - The Institute of Cancer Research, one of the world's most influential cancer research organisations, is based on the same site as The Royal Marsden Hospitals in Chelsea and Sutton
 - o Moving the service away from this centre of research could make it difficult for patients to access trials
 - o The change would also result in moving the service away from the Oak Children & Young People's Drug Development Unit which is the largest and most active drug development programme for children and young people in the UK.

The campaign calls for the reconsideration of an alternative proposal involving a risk-adapted model whereby patients deemed likely to require children's intensive care unit services would be cared for at St George's Hospital to minimise the need for transfers. All other patients would continue to receive care at The Royal Marsden.

13.8.2 Research organisations

City, University of London

The response from the City, University of London stated its support for St George's Hospital proposal. City, University of London is in the final stages of agreeing a merger with St George's Hospital, University of London, which will create a strong research and health education capability there, with ambitious plans to invest in the St George's Hospital campus, to develop further impact and entrepreneurship facilities, and to support multidisciplinary research contributing to health.

Institute of Cancer Research

The response from the Institute of Cancer Research highlighted the importance for clinical care and research to be co-located. Their concern is that the relocation of the Principal Treatment Centre poses significant risk to the delivery of a highly successful paediatric research programme led by the Institute of Cancer Research and, The Royal Marsden. Distance between the new Principal Treatment Centre



and the research laboratory would create real challenges in maintaining synergy between researchers and clinicians and impact laboratory research for clinicians. Key areas of concern included:

- Maintaining the relationships built up over many years; co-location is key to this
- Uncertainties around relocation have affected retention of key staff and the ability to recruit
- Potential to lose the excellent track-record and recognition as an Innovative Therapies for Children with Cancer Centre, Experimental Cancer Medicine Centre Partner, and developer of early phase clinical trials
- Loss of co-location with teenage and young adults cancer service and Adult Drug Development and Disease Specialist Teams
- Uncertainty around the clinical service is a risk to grant applications and charity funding
- Biomedical Research Centre and Experimental Cancer Medicine Centre infrastructure funding supports the research programme, this would be lost in the future models.

The Institute of Cancer Research calls for clear plans for the future that provide dedicated space for the Institute of Cancer Research staff in the new Principal Treatment Centre; potential use of The Royal Marsden brand at least in the short-term; build on current excellence in laboratory and clinical research the Institute of Cancer Research and The Royal Marsden; support for clinicians to facilitate research across organisations; and financial commitment to laboratory research and continued collaborations.

King's College London

As the academic research partner for Evelina London, King's College London expressed their support for the future service to be located at Evelina London, enabling them to create an outstanding programme of research for children's cancer care. This would include the immediate start of new children's cancer clinical research studies and offer the latest immune therapies like CAR-T. King's College London has a strong network of university, health partner and industry collaborations to offer children's cancer care researchers, providing a comprehensive research environment, if Evelina London is chosen as the future location of the Principal Treatment Centre. Key partnerships include:

- CRUK City of London Major Centre
- CRUK RadNet City of London Radiation Research Unit
- GSK- King's College London Translational Oncology Research Hub
- King's College London Institute of Cancer Policy
- King's College London School of Biomedical Engineering and Imaging Sciences
- Pears Maudsley Centre for Children and Young People within the King's College London Institute of Psychiatry, Psychology & Neuroscience



King's College London would also extend its clinical academic training environment to children's cancer care researchers joining Evelina London.

King's Health Partners

Evelina London is part of the King's Health Partners through Guy's and St Thomas's NHS Foundation Trust and expressed its support for the future service to be located at Evelina London.

National Institute for Health and Care Research (as referenced above)

NIHR expressed no preference for where the service should be located.

13.8.3 Charities and not-for-profit organisations

Action for XP

A charity supporting people with xeroderma pigmentosum, Action for XP stated their preference for the future service to be located at Evelina London. The response refers to the multiple specialities of Evelina London, which would benefit patients, as well as the academic track record of Evelina London and calibre of healthcare professionals it attracts.

Christopher's Smile

A charity that funds paediatric cancer research, Christopher's Smile stated their objection to the case for change. The charity expressed its view that the service should not move to St George's Hospital or Evelina London; the service should remain at The Royal Marsden.

An alternative approach is proposed by the charity, which involves three stages:

1. Patients at risk of children's intensive care unit transfer are treated at St George's Hospital
2. A trial of an 'eICU' (intensive care unit) solution for paediatrics aimed at providing more PCC Level 2 and 3 coverage across the country and enabling those hospitals such as The Royal Marsden who do not have PCC Level 2 or 3 facilities to have patients linked to intensive care specialists at a hub location
3. Building of a new children's specialised services hospital at a South Thames location (enabling ease of access for families compared to St George's Hospital or Evelina London). Two suggested locations for this are the current site of The Royal Marsden and Kenley, Surrey.

Further comments on the two proposals included:

- Neither proposals can provide a single-site solution



- Both hospitals have suffered a lack of capacity for beds (winter 2022)
- No clarity on the cost-effectiveness of the proposals, and if this change constitutes the best way to spend public money given other challenges the NHS is facing
- The implementation of CAR-T cell treatment has been stated as the reason why Principal Treatment Centres must be co-located with a children's intensive care unit, as the treatment would carry a higher risk of needing intensive care admittance. The charity notes that there have been no estimates of future CAR-T cell patient numbers, or any data showing PCC Level 3 occupancy rates, and no allowance included in the costs for any increase in children's intensive care unit capacity at either of the proposed sites
- No consideration given to the impact on Southampton Hospital Principal Treatment Centre if families decide to go there for care instead of central London

Specific feedback relating to Evelina London:

- Much longer travel times for families to get to Evelina London than The Royal Marsden
- No assurances that family accommodation will be available at Ronald McDonald House
- Charitable support from the Foundation is problematic, if helping the Trust to attract the service
- No specific research experience in children's cancer care

Specific feedback relating to St George's Hospital:

- No assurances that family accommodation will be available at Ronald McDonald House
- Car parking is limited
- Access is better than Evelina London for families, but journey times are longer than for The Royal Marsden
- If the service moves from St George's Hospital, it would negatively impact St George's Hospital budget (with an estimated £2-£3 million deficit)

Children's Cancer and Leukaemia Group

The Children's Cancer and Leukaemia Group expressed its support for the case for change; however, a number of concerns were raised, which included:

- Specialist staff may not be able to transfer to a role in central London or Tooting for family or economic reasons. There is also a risk that the new Principal Treatment Centre may not be able to attract the best talent in terms of future clinical academics or future leaders if the attractiveness of the strong links with a world-leading research institution are not maintained. There is a wider crisis in the NHS cancer workforce



- Consideration needs to be given to capacity and funding requirements of University College London Hospitals NHS Foundation Trust to take on new patients as part of the Principal Treatment Centre service, particularly in relation to future resilience
- Patients requiring total body radiation (TBI) as part of conditioning for bone marrow transplantation will need to be transferred between the future Principal Treatment Centre and University College Hospital when they are particularly vulnerable; this patient journey needs further consideration
- Consideration needs to be given to molecular radiotherapy (such as MIBG treatment); The Royal Marsden is a national referral centre and there might be an increasingly important role for this treatment in future
- Neurosurgery was considered out of scope for the consultation, which contributes to the fragmentation of services at the new Principal Treatment Centre, whether this is located at Evelina London or St George's Hospital (given its capacity). There is evidence that suggests that Principal Treatment Centres for childhood cancers should be co-located with neurosurgery. This would be the only Principal Treatment Centre in the UK where neurosurgery is not carried out on site; this would give rise to inequality of access and care
- Evelina London does not currently provide cancer surgery; this cannot be resolved quickly. The Children's Cancer and Leukaemia Group would want to know more about the weight given to St George's Hospital as it currently runs the service in partnership with The Royal Marsden
- There is a risk to grant funding for research if there is a loss of confidence in the ability of the new Principal Treatment Centre to deliver the volume and quality of paediatric cancer research, especially by an unproven provider in that field
- There is a risk that the transfer of clinical trials will result in trials not being opened during the transition, which would disadvantage patients
- The new Principal Treatment Centre would need to demonstrate that they can comply with the O'Shaughnessy recommendations in a timely manner
- Families have a lot of questions about travel to the future Principal Treatment Centre. The Children's Cancer and Leukaemia Group want this issue to be explored at a national level, to ensure accessibility for all patients across the country
- The Children's Cancer and Leukaemia Group highlighted that the majority of Principal Treatment Centres are based in specialist children's hospitals, which provide ready access to other children's services which are required for children with cancer and recognised that Evelina London scored higher overall.

The Children's Cancer and Leukaemia Group advises on the implementation of The 'Royal Marsden @' model to help mitigate some of the risks they have outlined.



Guy's and St Thomas' Foundation

The Foundation expressed its support for the service to be located at Evelina London. It has committed to support the Principal Treatment Centre at Evelina London, through Evelina London Children's Charity. This includes underwritten support, in the form of a substantial anchor donation confirmed by the Trustees (for a minimum of £10m) to support the build and development of the new cancer centre. It also states Evelina London's experience and expertise as a dedicated children's hospital, as well as its current experience treating children with cancer (including for heart and kidney complications and through the children's ambulance service). There is also support for the research expertise and facilities at the disposal of Evelina London, including the new MRC-funded Total Body PET imaging centre.

Rare Revolution Magazine

The response from Rare Revolution expressed its support for the future service to be located at Evelina London, within the context of rare disease and cancer. Rare Revolution states the benefits of Evelina London to include its geographical location and, as a dedicated children's hospital, the enhancement it can offer to the coordination of care and the overall patient experience. There was also reference made to the research track record of Evelina London, with strong connections with academic and industry partners.

Ronald McDonald House Charities UK

The response stated that both proposals stated that parental accommodation would be provided by Ronald McDonald House Charities UK at both Evelina London and St George's Hospital sites. However, the response makes it clear that the charity is unaware what is expected of them in terms of supporting the potential increase in demand for parental accommodation at both sites. The charity states its willingness to be an active partner and its intention to support the future Principal Treatment Centre at whichever site is chosen. However, both Ronald McDonald Houses at Evelina London and St George's Hospital run at capacity. The response states that Ronald McDonald House at St George's Hospital is already too small for the existing paediatric provision in the hospital (it has eight bedrooms).

The Royal Marsden Cancer Charity

The charity expressed its concern that the level of charitable support being provided for research and to the children's cancer care service will decline with the proposed move, given the timing of the proposed move and the fact that many donors pledge their support over multiple years. In addition, the case for change did not evidence where this additional, charitable funding will come from in the future.

St George's Hospital Charity



The charity expressed its support for the future service to be located at St George’s Hospital. Their response refers to the 25 years of experience that St George’s Hospital has in delivering paediatric cancer care, with a wealth of expertise and cultivated professional relationships among clinical specialists. The charity also states that St George’s Hospital can deliver services that matter most for children with cancer, including neurosurgery, and consolidating the service at St George’s Hospital would be easier and less costly. The charity highlights the impact on other children’s services at St George’s Hospital if the service was to move.

13.8.4 Other representatives

Merton Liberal Democrats councillors

The Merton Liberal Democrats councillors expressed their preference for the new Principal Treatment Centre to be located at St George’s Hospital. The response states that they do not believe that the evaluation process has not given enough weight to the services already being carried out at St George’s Hospital and the challenge of change (such as the risks associated with maintaining a specialist workforce when the service moves, and the travel and accessibility difficulties that would be experienced by families).





14 Geography: Integrated care boards

An integrated care board (ICB) is an NHS organisation responsible for developing a plan to meet the health needs of their local population based on agreed priorities; managing the NHS budget; and arranging for the provision of health services in the area. There are five ICBs in the catchment area for the Principal Treatment Centre under consultation. These ICBs are:

- NHS South West London ICB
- NHS South East London ICB
- NHS Surrey Heartlands ICB
- NHS Sussex ICB
- NHS Kent and Medway ICB

This section of the report deals with the key findings from these different areas and grouped them into ICB areas for the ease of NHS decision-makers. This includes key demographics from responses to the consultation and a spotlight on key themes in feedback where there are nuances between ICB areas. Specifically, this relates to travel and accessibility. Efforts were made to reach people from outside London, particularly through qualitative engagement.



14.1 Questionnaire responses by ICB area: maps

The maps below show:

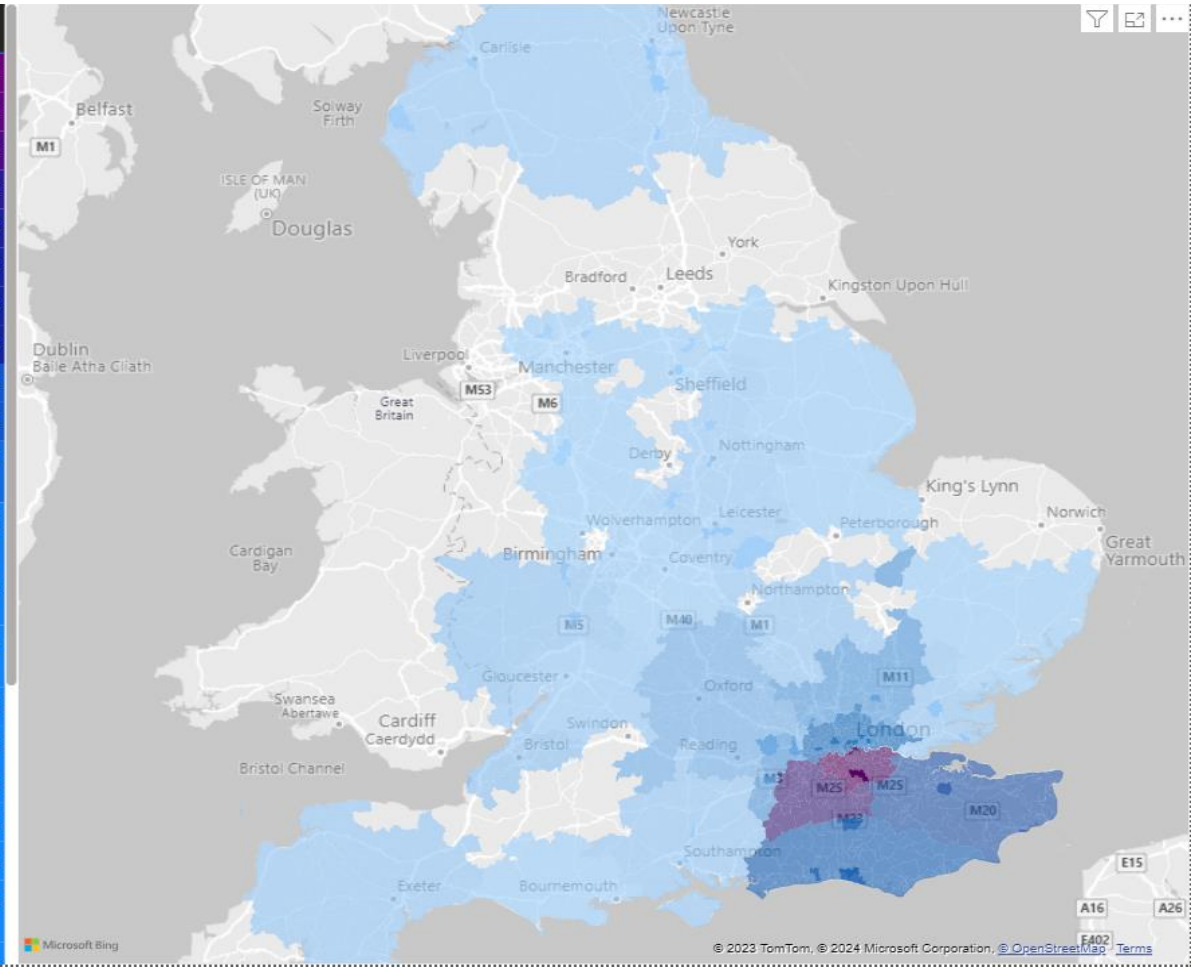
- Total questionnaire responses by ICB area
- Questionnaire responses by ICB in the catchment area⁵¹.

⁵¹ The graphs below do not include all questionnaire responses with 1,648 responses to the questionnaire having usable postcodes.

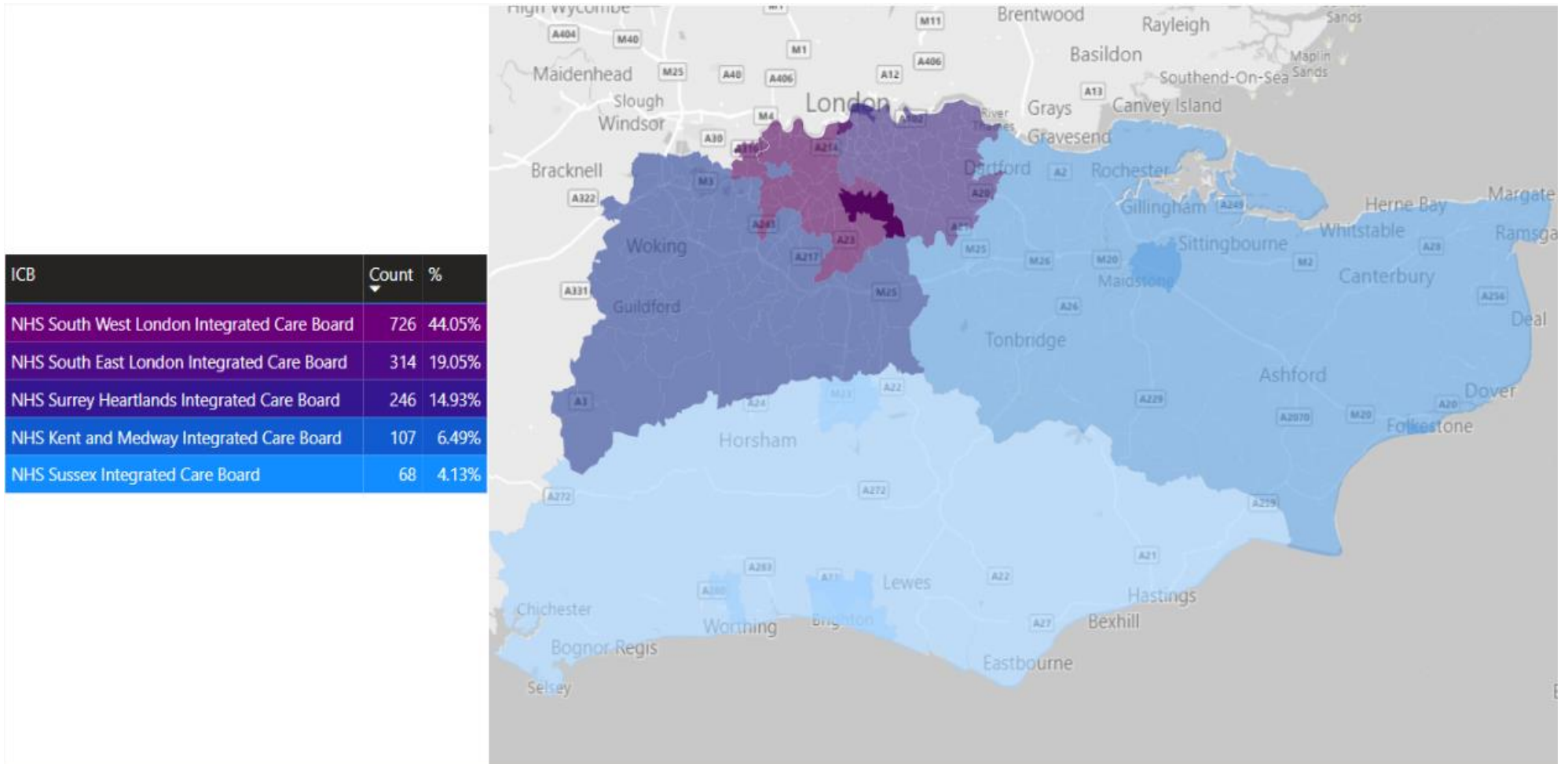


Map of questionnaire responses by ICB region across England

ICB	Count	%
NHS South West London Integrated Care Board	726	44.05%
NHS South East London Integrated Care Board	314	19.05%
NHS Surrey Heartlands Integrated Care Board	246	14.93%
NHS Kent and Medway Integrated Care Board	107	6.49%
NHS Sussex Integrated Care Board	68	4.13%
NHS North West London Integrated Care Board	43	2.61%
NHS North Central London Integrated Care Board	33	2.00%
NHS North East London Integrated Care Board	31	1.88%
NHS Frimley Integrated Care Board	16	0.97%
NHS Hertfordshire and West Essex Integrated Care Board	16	0.97%
NHS Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board	10	0.61%
NHS Bristol, North Somerset and South Gloucestershire Integrated Care Board	5	0.30%
NHS Herefordshire and Worcestershire Integrated Care Board	4	0.24%
NHS Bedfordshire, Luton and Milton Keynes Integrated Care Board	3	0.18%
NHS Devon Integrated Care Board	3	0.18%
NHS Hampshire and Isle of Wight Integrated Care Board	3	0.18%
NHS Mid and South Essex Integrated Care Board	3	0.18%
NHS Birmingham and Solihull Integrated Care Board	2	0.12%
NHS Gloucestershire Integrated Care Board	2	0.12%
NHS Leicester, Leicestershire and Rutland Integrated Care Board	2	0.12%
NHS North East and North Cumbria Integrated Care Board	2	0.12%



Map of questionnaire responses with NHS England (London and South East) catchment area



15 NHS South West London ICB

This chapter focuses on feedback from respondents living in the South West London ICB area. 45.84% of responses to the consultation were from people living in South West London. Of those respondents who provided their demographic details, 30.9% were from ethnic groups other than white, over two-thirds were female (68.4%), more than half were aged 41-65 (53.6%), 7.9% were disabled, almost 80% were from socio-economic groups ABC1 (77.4%) and 7.3% were receiving additional income support. More than a quarter of responses were from affected clinical and non-clinical staff (26.8%).

This chapter presents the most important factors regarding travel and making the move easier are presented for this region. It also compares qualitative responses to the two proposals and highlights any differences. Although feedback was mostly consistent against key overall findings, of more importance to those from the South West London ICB region included the positive aspect of St George’s Hospital providing neurosurgery.

For ease of viewing this section, graphs presenting data captured before the questionnaire was changed on 23 October 2023 have been provided in Appendix H.

15.1 Feedback on travel

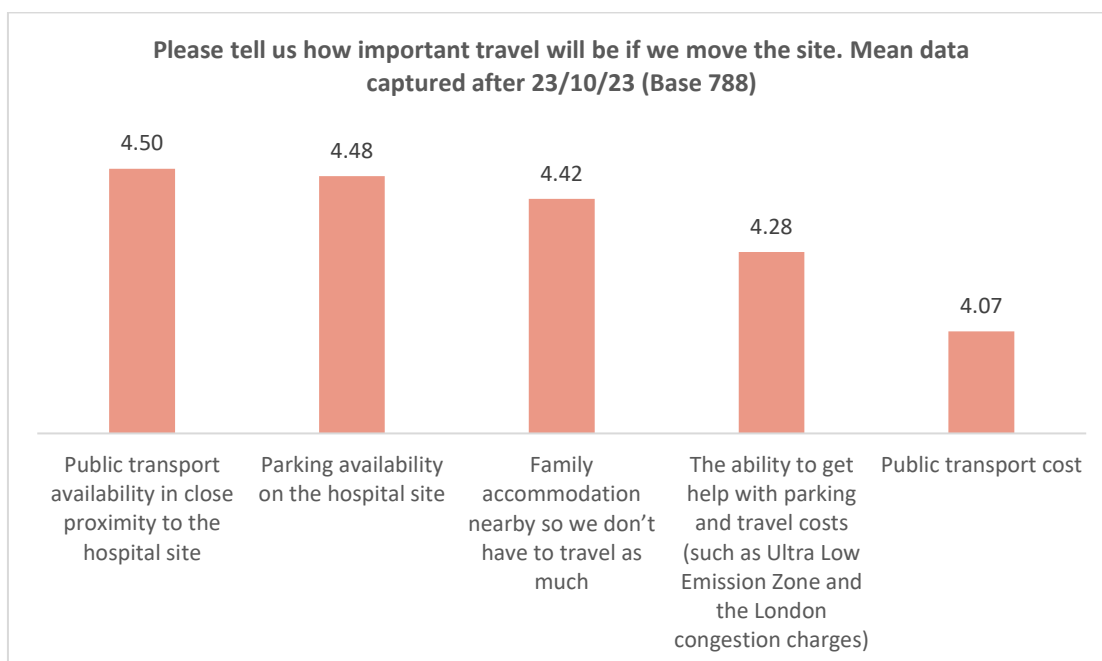


Figure 53 NHS South West London ICB, Importance of Travel, After 23/10/23



Respondents from the South West ICB region see having ‘public transport availability in close proximity to the hospital site’ (4.5) and ‘parking availability on the hospital site’ (4.48) as being the most important aspects of travel. Here, ‘public transport cost’ was seen as less of a priority receiving a mean score of 4.07 out of 5.

Responses captured before the 23 October 2023 for respondents within the South West London ICB region closely reflect these themes, with ‘parking availability on the hospital site’ being seen as one of the most important factors of travel with 64% seeing it as very important as well as ‘public transport availability in close proximity’ with 65% seeing it as very important.

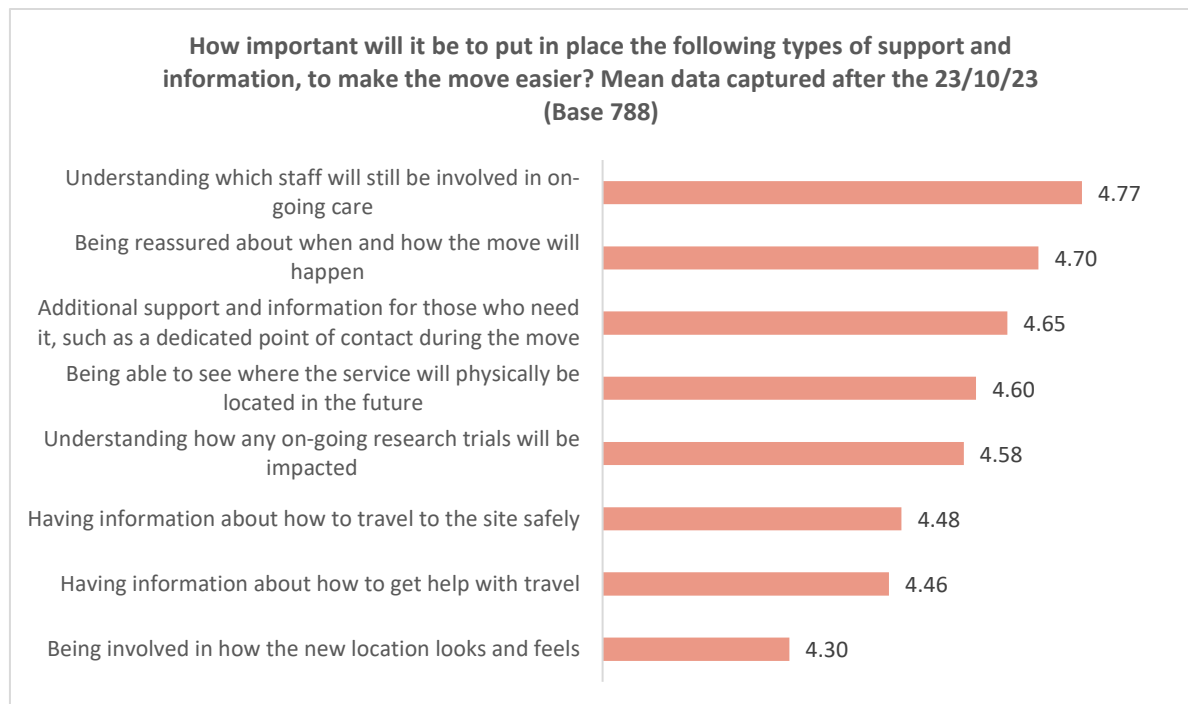


Figure 54 NHS South West London ICB, Support and Information, After 23/10/23

Here, ‘understanding which staff will be involved in the move’ (4.77) as well as being ‘reassured about when and how the move will happen’ (4.7) were seen as the most important factors for respondents from South West London in making the move easier. ‘Being involved in how the new location looks and feels’ while still of overall importance, was considered less of a priority for respondents from South West London in making the move easier for them.

The smaller number of responses captured before the 23 October 2023 differ to those captured after the questionnaire change, with having ‘information about how to get help with travel’ being seen as one of the least important factors in making the move easier with 61% stating it is very important. As well as this, ‘understanding which staff would be involved in on-going care’ was seen as one of the least important factors for respondents after the 23 October 2023, whereas respondents before the then



considered this to be a significant priority in making the move easier with 80% stating it is very important.

15.2 Proposal for Evelina London

15.2.1 Good points

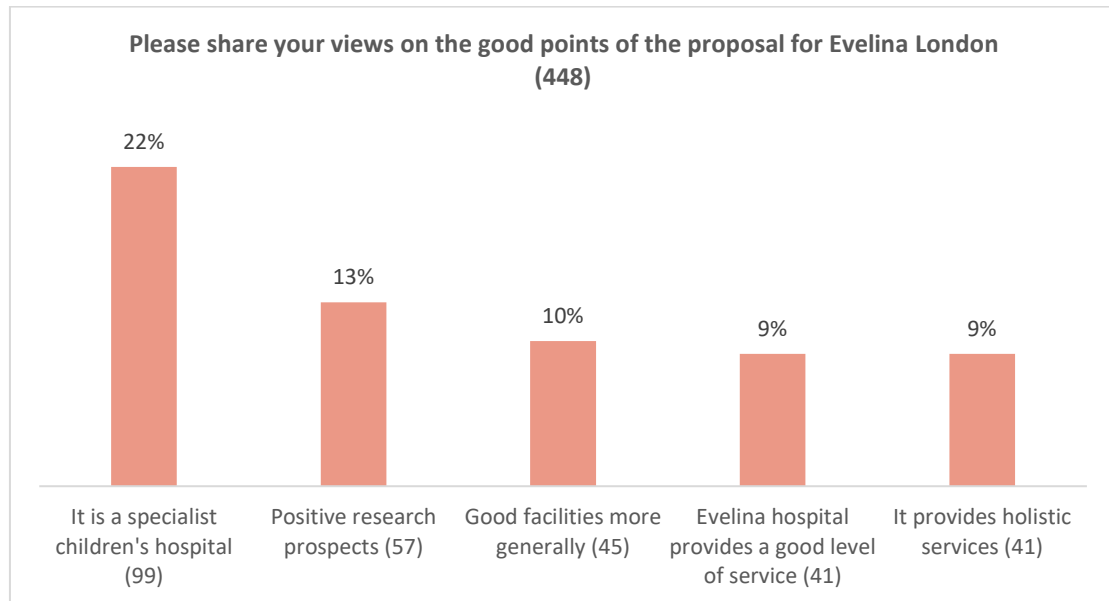


Figure 55 NHS South West London ICB, Good Points about Evelina London

Key themes left by respondents from the South West London ICB region regarding the strengths of Evelina London proposal reflect those found in the overall findings, with respondents here citing that Evelina London is already a specialist children's hospital (22%), which offers positive research prospects (13%).



15.2.2 Potential challenges

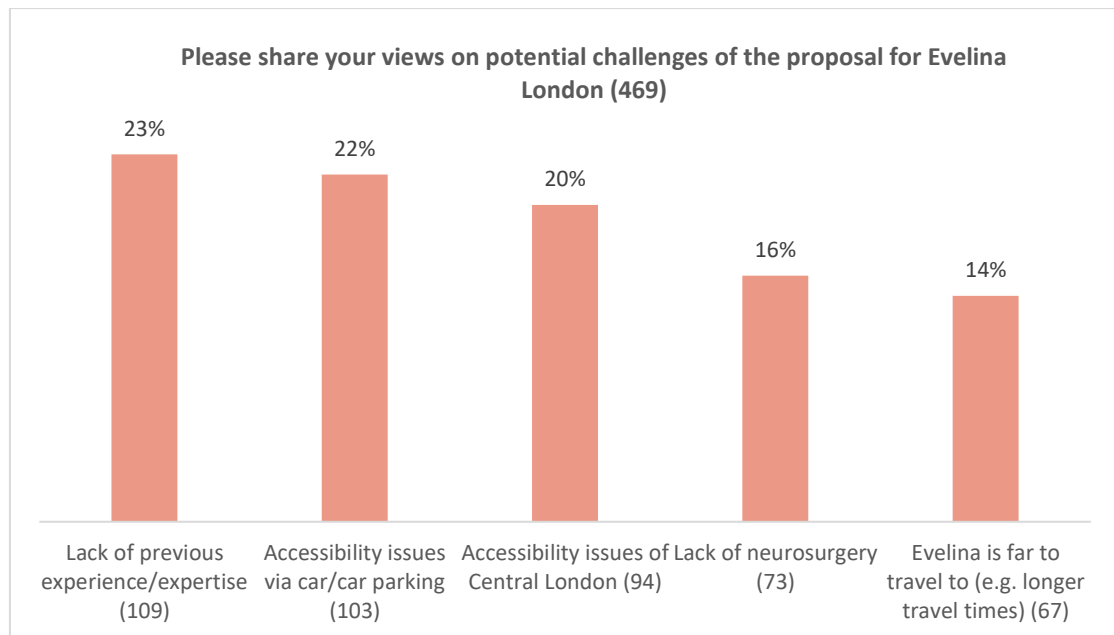


Figure 56 NHS South West London ICB, Potential Challenges about Evelina London

Again, responses from South West London respondents closely reflect the key overall findings regarding the potential challenges of Evelina London proposal, with most discussing its lack of previous expertise or experience in treating children with cancer (23%), as well as difficulties accessing the hospital via car (22%), with reference made to the difficulties of travelling into Central London as well as the limited parking available onsite.



15.2.3 Improvements

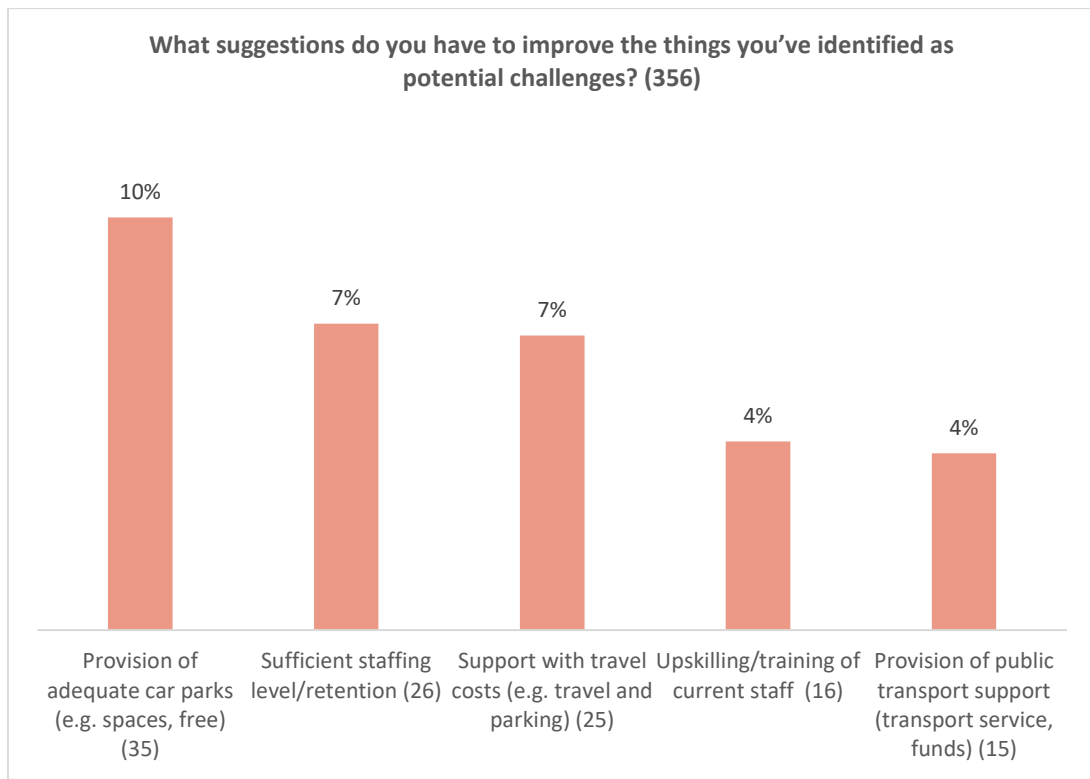


Figure 57 NHS South West London ICB, Improve Potential Challenges about Evelina London

Responses from South West London again stated that there needs to be adequate provision of car parking spaces or free spaces for families/staff (10%), as well as providing support with travel costs (7%). Yet, differing from the overall findings, training staff in caring or treating for children with cancer was seen as a key mitigation for respondents from the South West London ICB region (4%).



15.3 Proposal for St George's Hospital

15.3.1 Good points

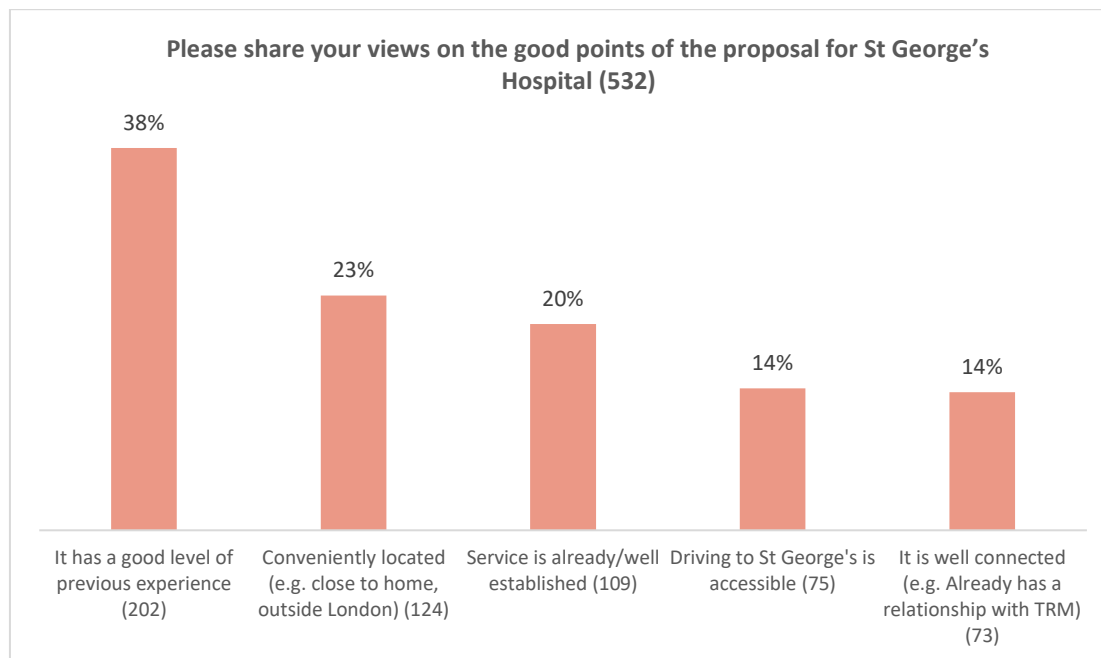


Figure 58 NHS South West London ICB, Good Points about St George's Hospital

Responses from those within the South West London ICB region regarding the strengths of the proposal for St George's Hospital again reflect overall findings, with most stating that it has a good level of previous experience in treating children with cancer (38%).



15.3.2 Potential challenges

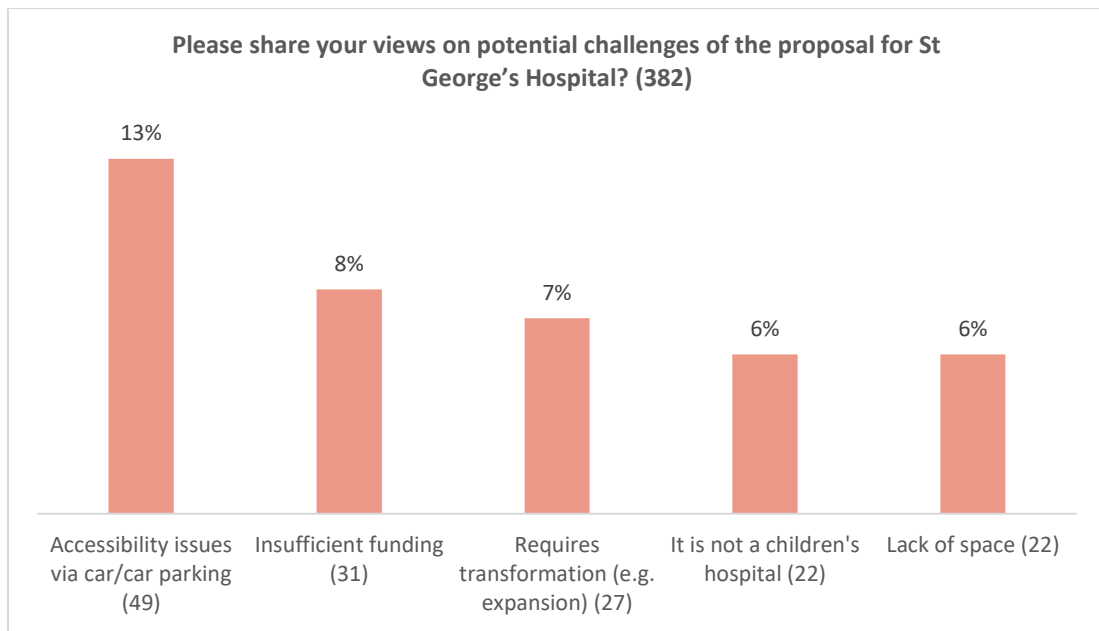


Figure 59 NHS South West London ICB, Potential Challenges about St George's Hospital

Here, responses closely reflect overall findings regarding the potential challenges of the St George's Hospital proposal.



15.3.3 Improvements

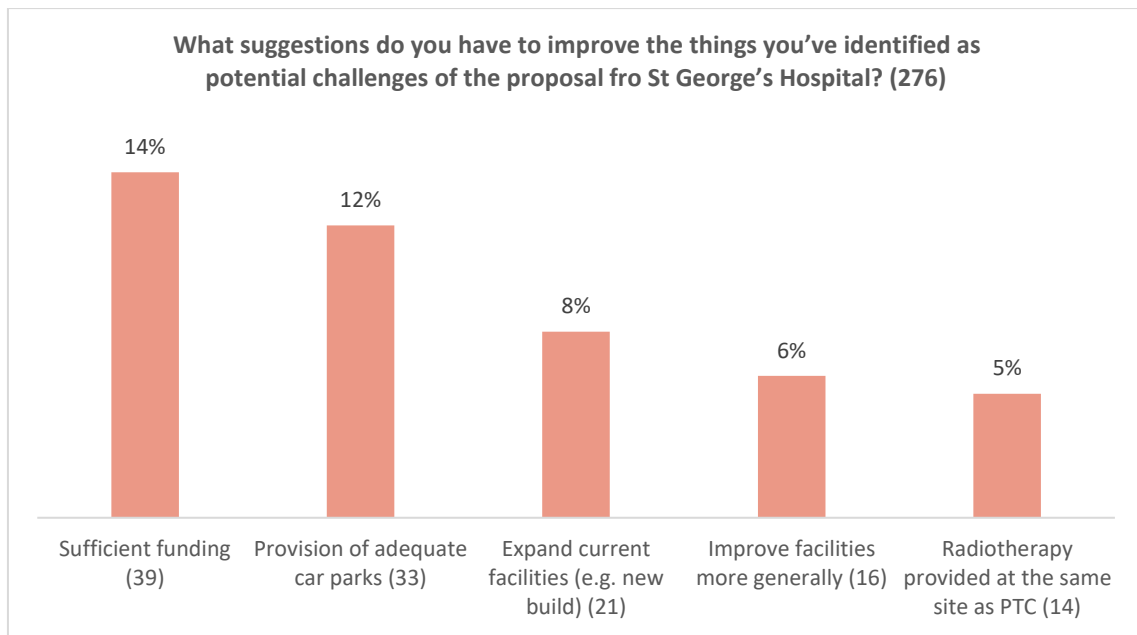


Figure 60 NHS South West London ICB, Improve Potential Challenges about St George's Hospital

Again, the key themes from respondents from the South West London ICB region reflect the overall findings for suggestions to improve the St. George's Hospital proposal.



15.4 Views on the delivery of radiotherapy services at University College Hospital

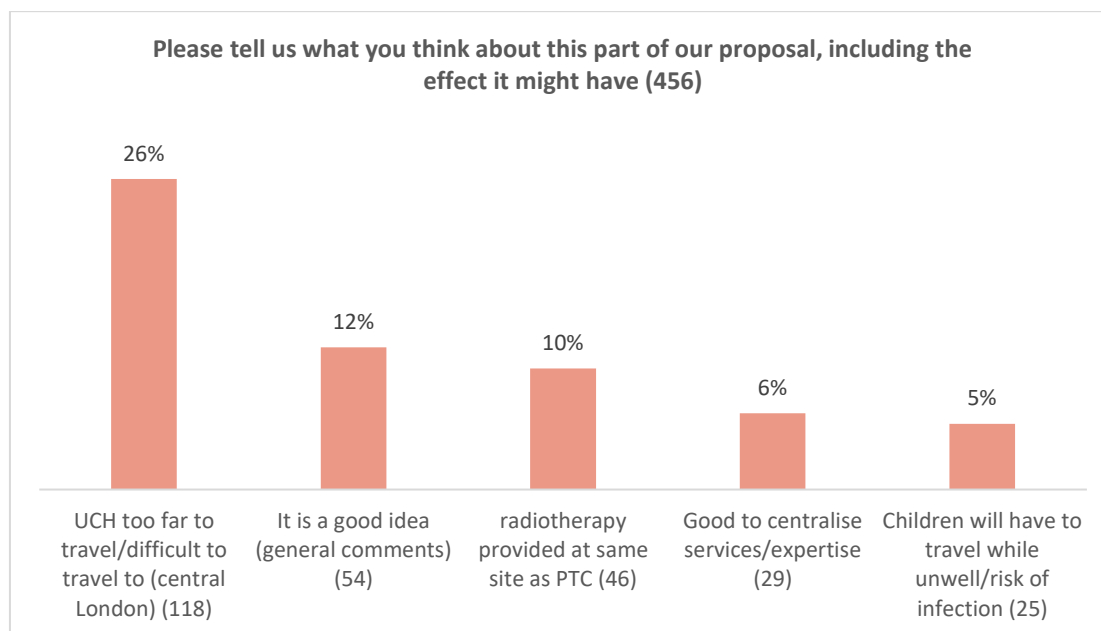


Figure 61 NHS South West London ICB, Radiotherapy Services at University College Hospital, effect proposal might have

Here, feedback from responses was mixed, with most respondents from South West London ICB area arguing that University College Hospital is too far and difficult to travel to (26%), while some left more general comments about the positives of moving radiotherapy to University College Hospital (12%).



16 NHS South East London ICB

This chapter focuses on feedback from respondents living in the South East London ICB area. 15.47% of responses to the consultation were from residents of South East London, with 30.8% of them from affected clinical and non-clinical staff. Of those respondents who provided their demographic details, more than a quarter (26.7%) were from ethnic groups other than white, almost two-thirds were female (65.0%), 4.9% were disabled, more than four-fifths were people in socio-economic groups ABC1 (81.2%) and 3.9% were receiving additional income support. A higher proportion of respondents living in South East London were aged 26-40 than other areas (36.5%) although the highest number of responses by age were from people aged 41-65 (47.4%).

This chapter depicts the most and least important factors regarding travel and making the move easier for patients and families. It also compares qualitative responses to the key overall findings and highlights any differences although feedback was largely consistent against overall findings.

16.1 Feedback on travel

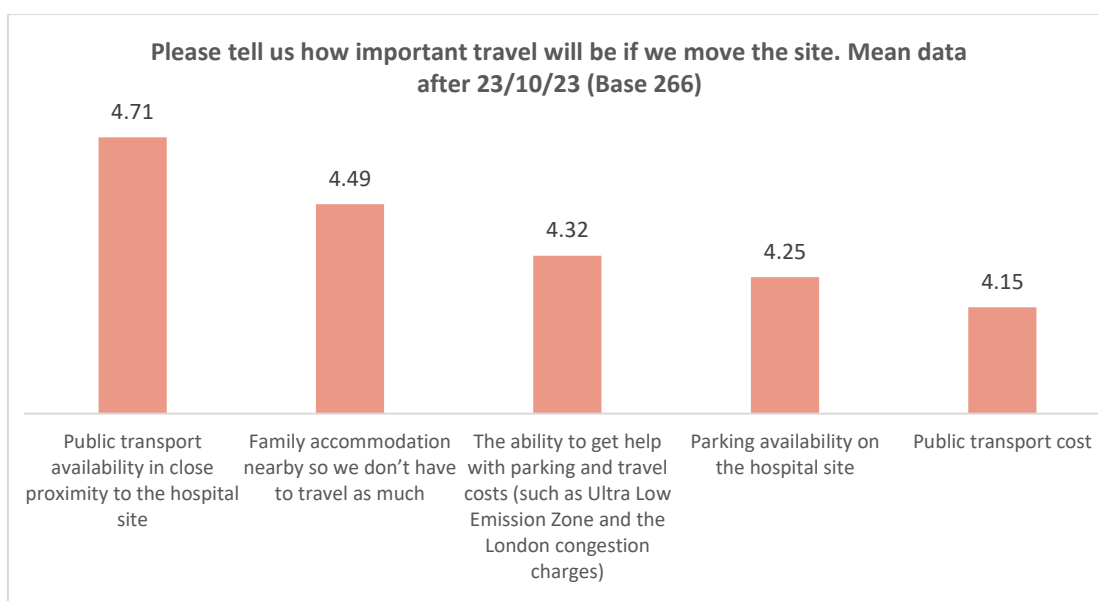


Figure 62 NHS South East London ICB, Importance of Travel, After 23/10/23

For respondents from the South East ICB region, 'public transport availability in close proximity' was seen as the most important aspect of travel, with a mean score of 4.71 out of 5. While still of overall importance to respondents from South East London, 'public transport cost' was considered less of a priority receiving a mean score of 4.15 out of 5.



For data captured before 23 October 2023, 'family accommodation nearby' was considered to be the most important factor with 63% stating it is a very important aspect of travel. Similarly to data captured after 23 October 2023, 'public transport cost' was seen as the least important factor regarding travel with only 37% stating it is very important.

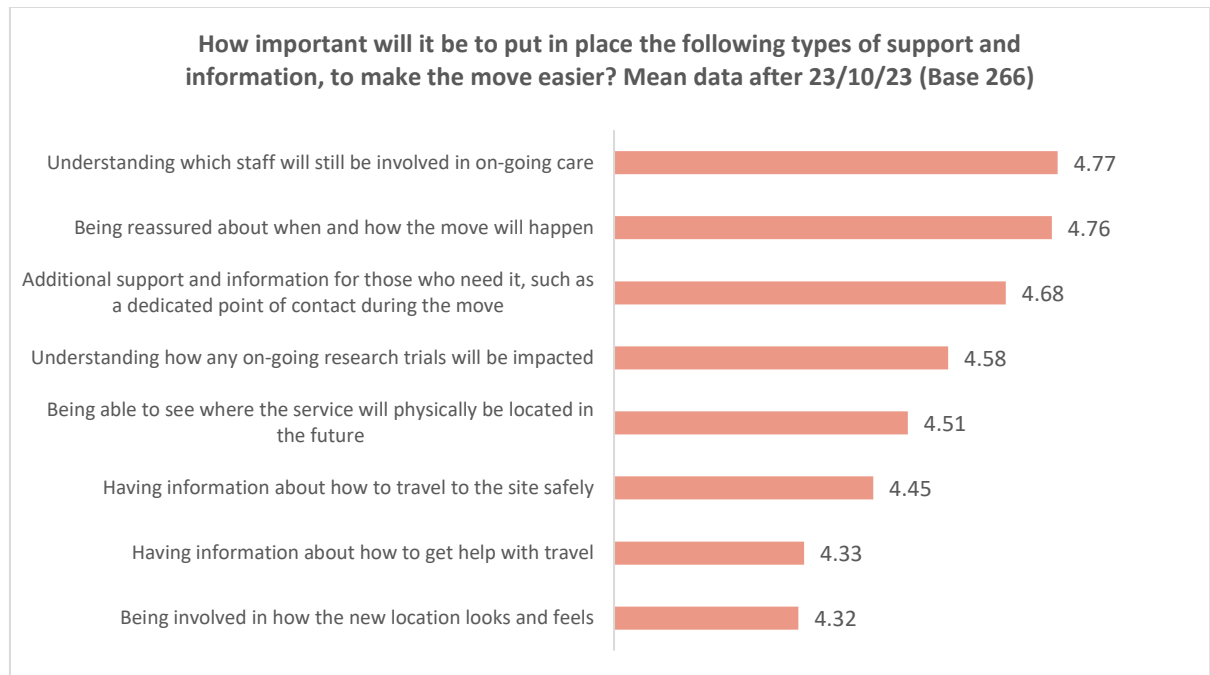


Figure 63 NHS South East London ICB, Support and Information, After 23/10/23

Here, respondents from South East London would find understanding 'which staff will be involved in on-going care' (4.77) as well as being 'reassured about when and how the move will happen' (4.76) as being the most important factors to make the move easier for them. Being 'involved in how the new location looks and feels' (4.32) and 'having information about how to get help with travel' (4.33) while still of importance to respondents from South East London were considered as less of a priority in making the move easier for them.

For data captured before 23 October 2023 from those within South East London, being 'involved in how the new location looks and feels' as well as understanding 'which staff will be involved in on-going care' were seen as the most important factors in making the move easier with 57% seeing both these two factors as very important.



16.2 Proposal for Evelina London

16.2.1 Good points

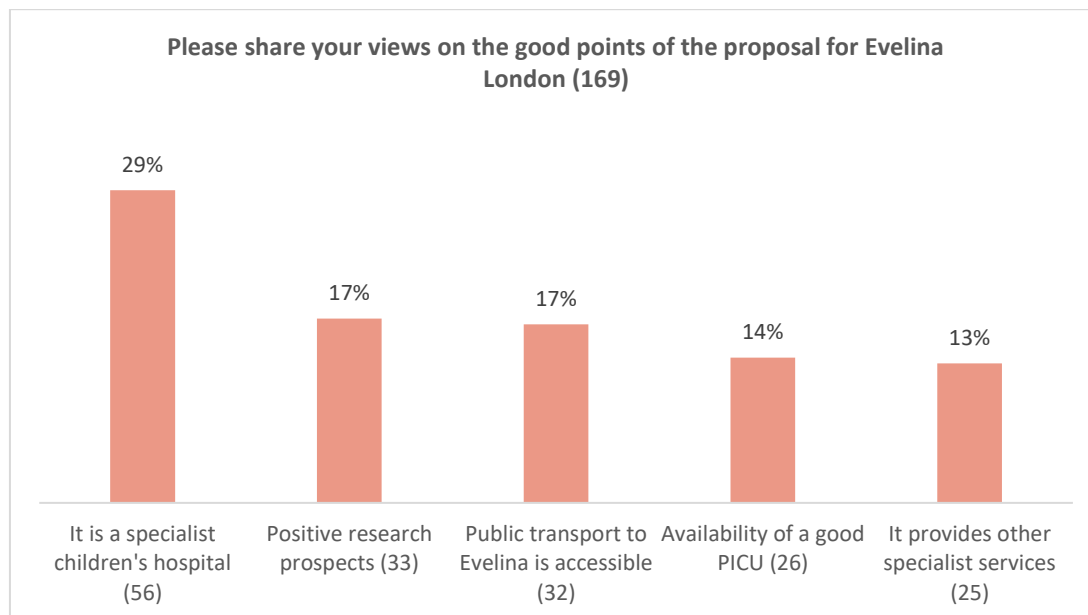


Figure 64 NHS South East London ICB, Good Points about Evelina London

Here, responses remain consistent to overall findings regarding the key strengths of the proposal for Evelina London with respondents from South East London also commonly referencing Evelina London being a specialist children's hospital (29%), as well as it also offering strong prospects for future research (17%).



16.2.2 Potential challenges

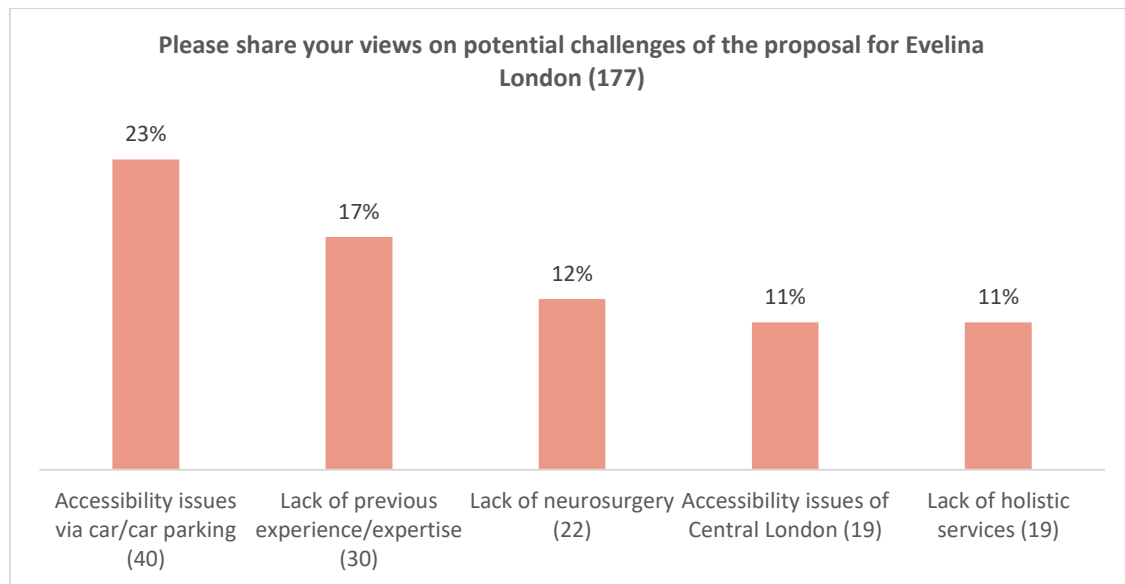


Figure 65 NHS South East London ICB, Potential Challenges about Evelina London

Again, responses from those within the South East London ICB region reflect overall findings regarding the potential challenges of the proposal for Evelina London, with issues of accessing the site via car (23%) as well as its lack of previous experience of treating children with cancer being strongly mentioned (17%), including its lack of neurosurgery on site (12%).



16.2.3 Improvements



Figure 66 NHS South East London ICB, Improve Potential Challenges about Evelina London

Here, responses remain consistent to overall findings for suggested improvements to the proposal for Evelina London with respondents seeing a key mitigation being the provision of adequate or free car parking spaces for families/staff (11%) as well as training existing staff (10%).



16.3 Proposal for St George's Hospital

16.3.1 Good points

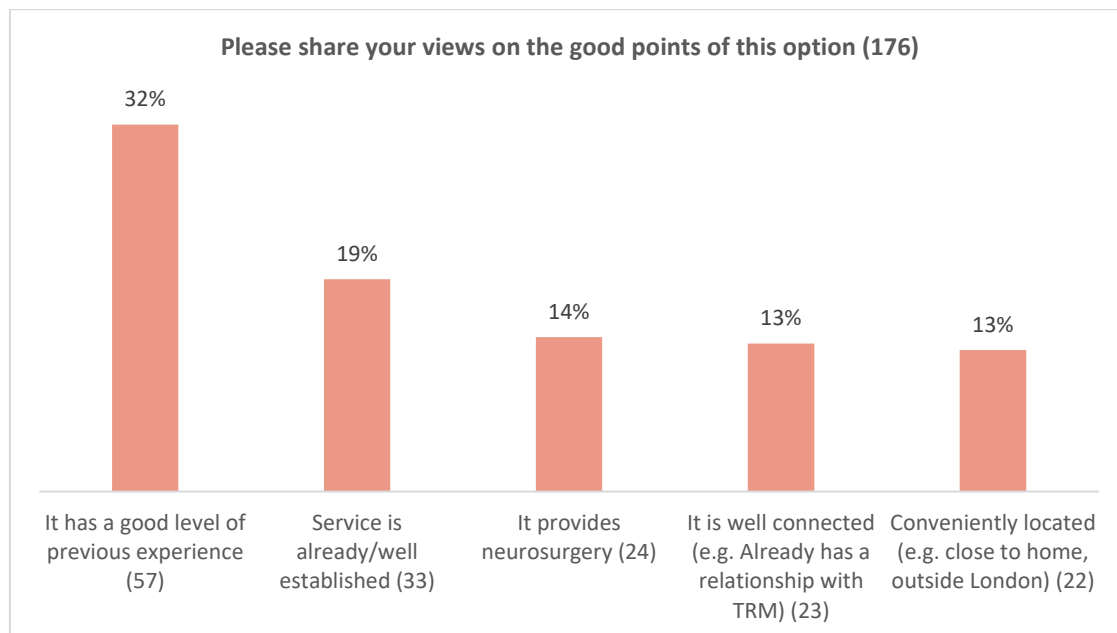


Figure 67 NHS South East London ICB, Good Points about St George's Hospital

Here, the most common themes from respondents within the South East London ICB region remain consistent to overall findings.



16.3.2 Potential challenges

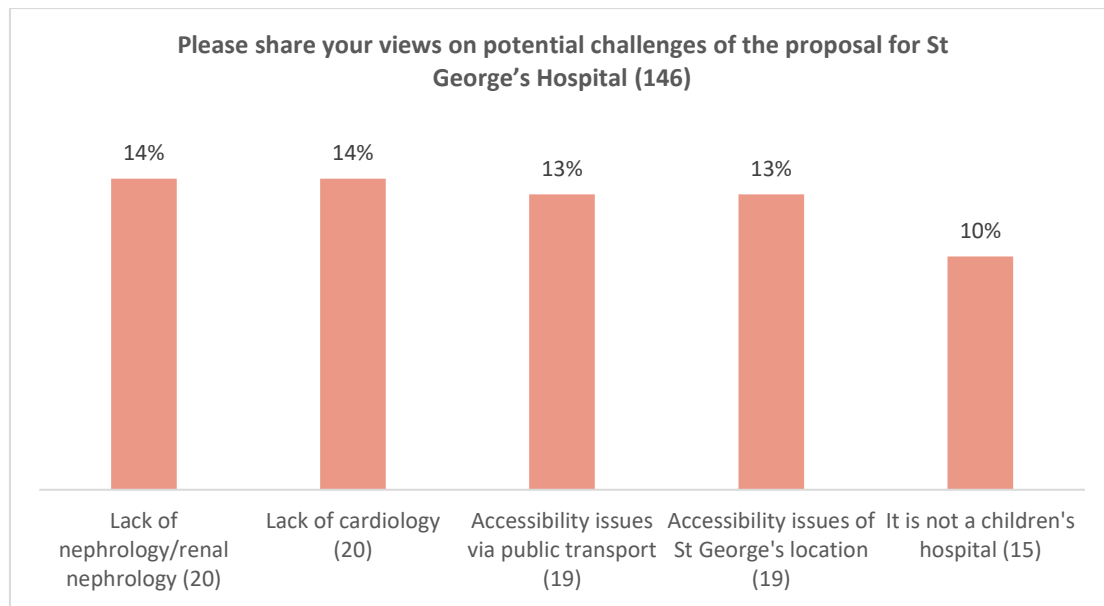


Figure 68 NHS South East London ICB, Potential Challenges about St George's Hospital

In contrast to overall findings, respondents from the South East London ICB region were more likely to consider the lack of nephrology/renal nephrology (14%) and cardiology (14%) as key challenges of the proposal for St George's Hospital.



16.3.3 Improvements

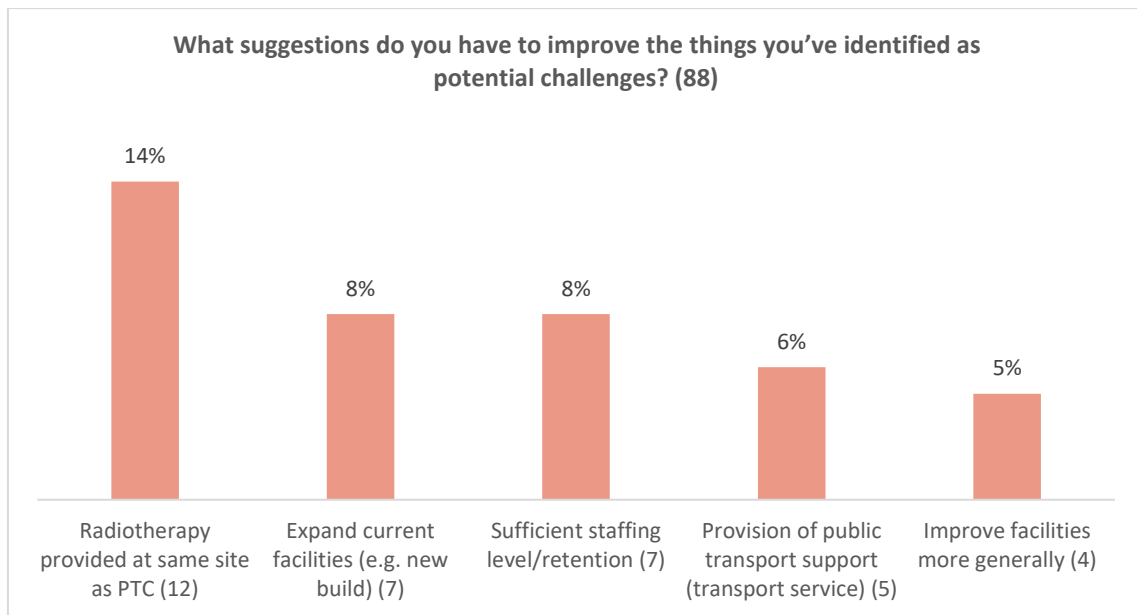


Figure 69 NHS South East London ICB, Improve Potential Challenges about St George's Hospital

While key themes here generally remain consistent to overall findings, it is clear that respondents from South East London are more likely to identify the need to expand current facilities at St George's Hospital as a key improvement to the proposal (8%).



16.4 Views on the delivery of radiotherapy services at University College Hospital

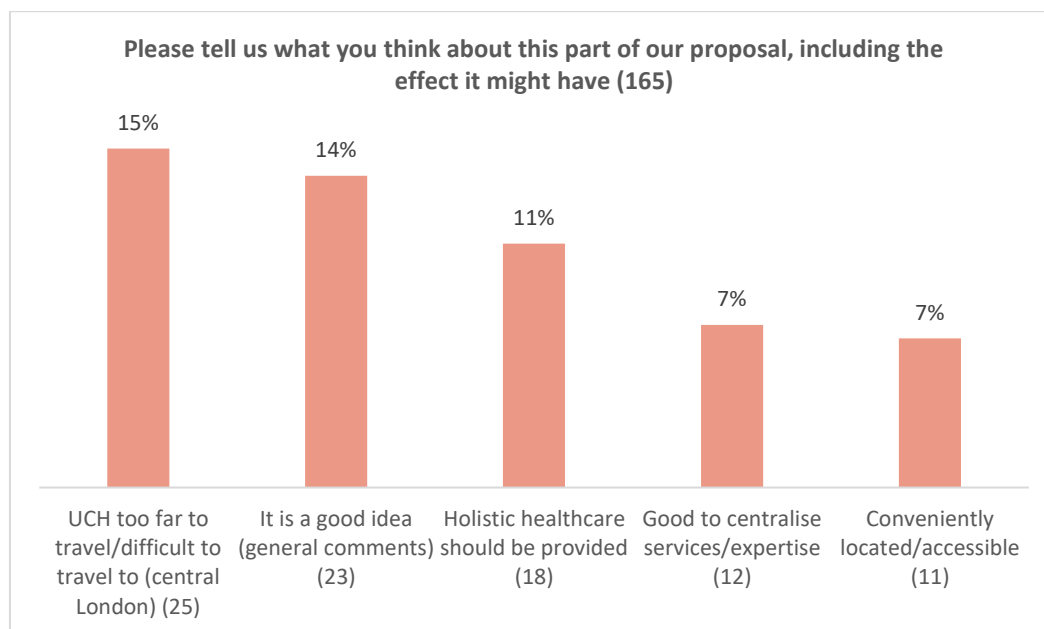


Figure 70 NHS South East London ICB, Radiotherapy Services at University College Hospital, effect proposal might have

Again, responses from those located in the South East London ICB area remain consistent to overall findings, with these respondents commenting on the extra distance for patients/families to travel to (15%), as well as leaving more general positive comments to providing radiotherapy at University College Hospital (14%).



17 NHS Surrey Heartlands ICB

This chapter focuses on feedback from respondents living in the Surrey Heartlands ICB area. 15.13% of responses to the consultation were from people living in Surrey Heartlands. Of those respondents who provided their demographic details, 13.5% were from ethnic groups other than white, over two-thirds were female (73%), more than half were aged 41-65 (56.2%), 6.5% were disabled, almost 80% were from socio-economic groups ABC1 (78.1%) and 4.3% were receiving additional income support. More than a quarter of responses were from affected clinical and non-clinical staff (29.6%).

This chapter depicts the most and least important factors regarding travel and making the move easier for patients and families. It also compares qualitative responses to the key overall findings and highlights any differences, although feedback was largely consistent against overall findings.

17.1 Feedback on travel

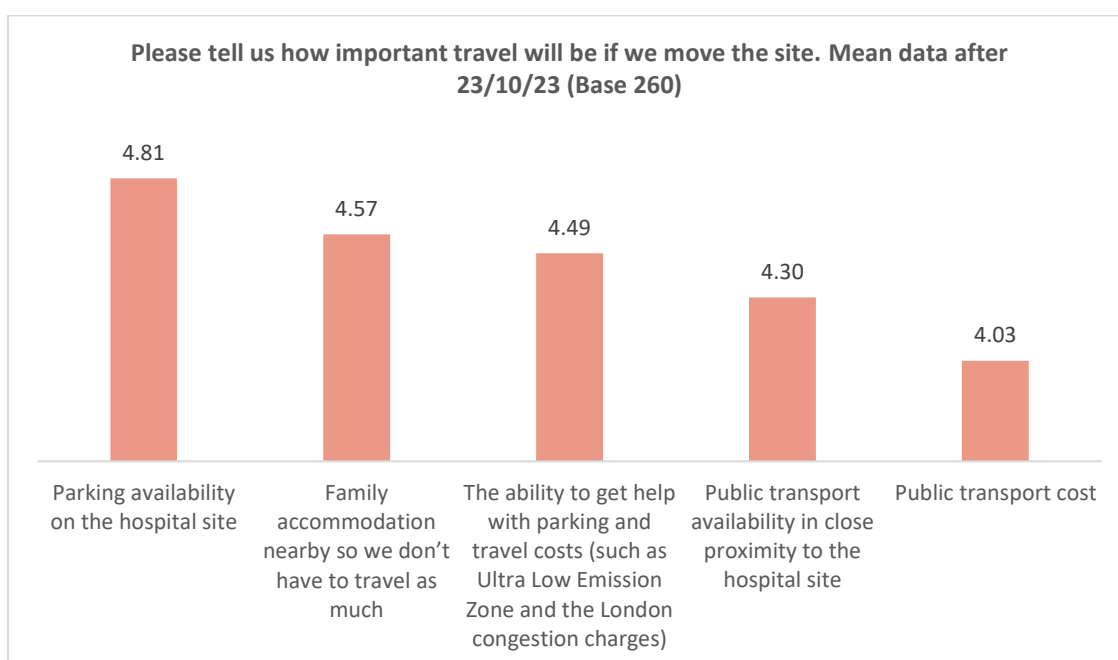


Figure 71 NHS Surrey Heartlands ICB, Importance of Travel, After 23/10/23

For respondents from the Surrey Heartlands ICB region, having 'parking availability on the hospital site' was seen as the most important aspect of travel with a mean score of 4.81 out of 5, while 'public transport cost' was considered of less importance with a mean score of 4.03 out of 5.



Responses from the Surrey Heartlands before 23 October 2023 found, ‘parking availability on the hospital site’ was seen as the most important aspect of travel with 86% finding it very important, while ‘public transport costs’ was seen as the least important issue of travel if the Principal Treatment Centre was to move with 61% finding it very important.

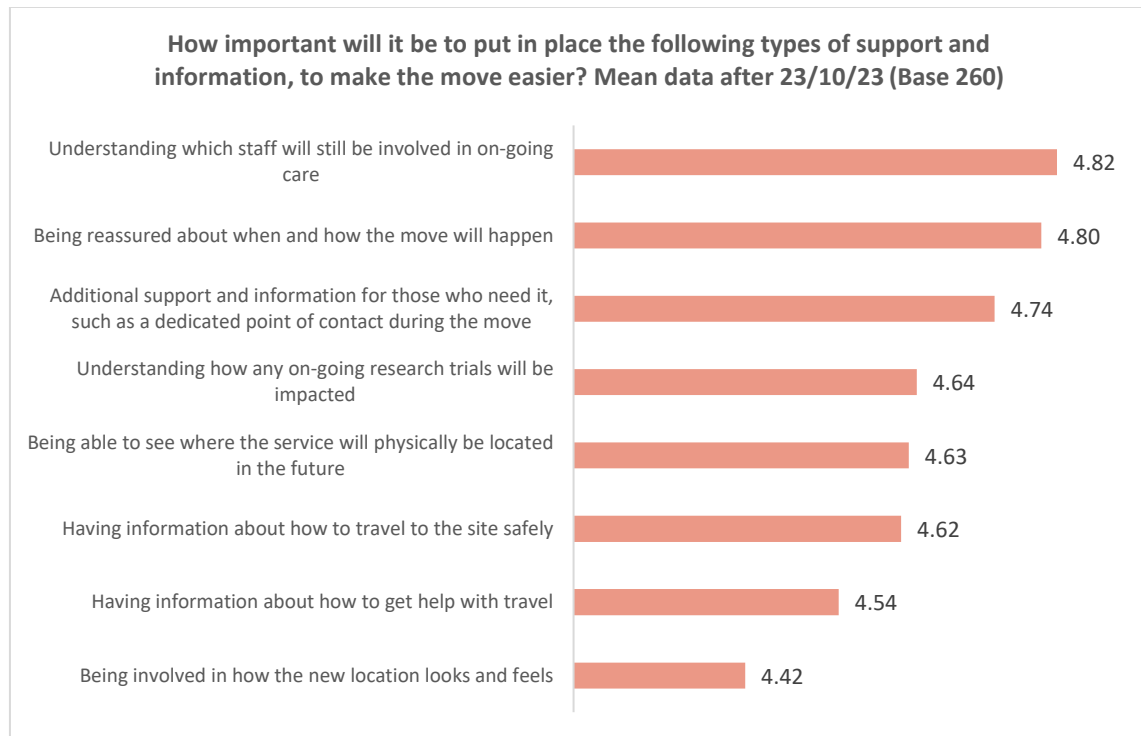


Figure 72 NHS Surrey Heartlands ICB, Support and Information, After 23/10/23

Here, the move could be made easier for respondents from the Surrey Heartlands ICB region if they understand ‘which staff will still be involved in on-going care’ (4.82) as well as being ‘reassured about when and how the move will happen’ (4.8). Being ‘Involved in how the new location looks and feels’ while of importance to respondents from the Surrey Heartlands was seen as less of a priority is making the move easier for them.

Responses captured before 23 October 2023 for the Surrey Heartlands ICB region differ to those captured after changes to the questionnaire were made, with ‘being involved in how the new location looks and feels’ considered as the least important factor for making the move easier with 43% stating it is very important. As well as this, ‘understanding which staff will be involved in ongoing care’ was seen as less of a priority for data captured after 23 October 2023, yet 79% of respondents before 23 October 2023 stated it was very important.



17.2 Proposal for Evelina London

17.2.1 Good points

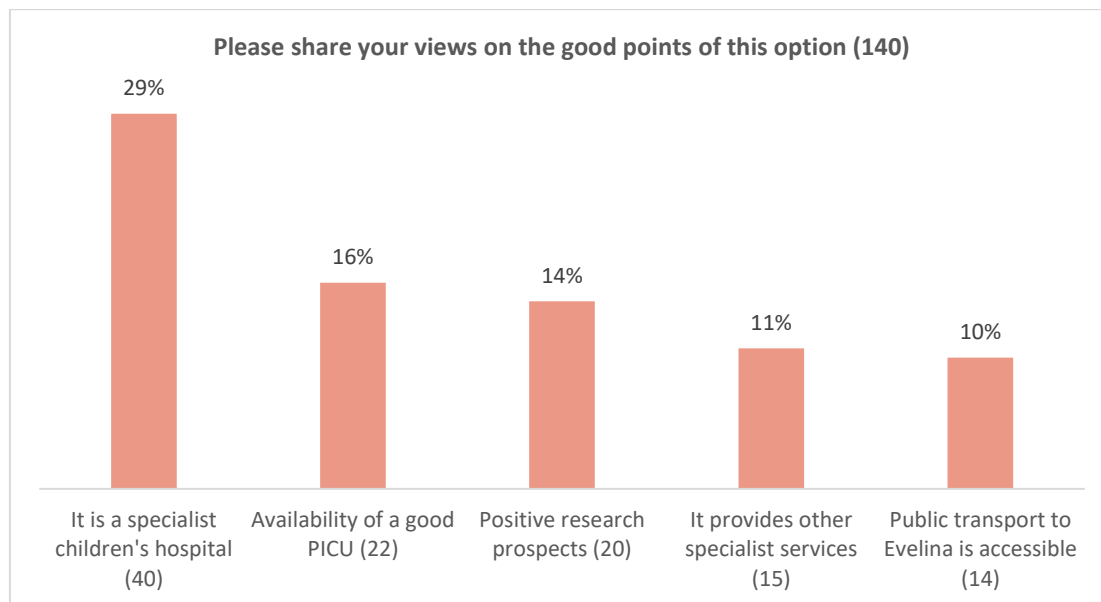


Figure 73 NHS Surrey Heartlands ICB, Good Points about Evelina London

Here, responses from those within the Surrey Heartlands ICB region remain consistent with overall findings on the strengths of the proposal for Evelina London.



17.2.2 Potential challenges

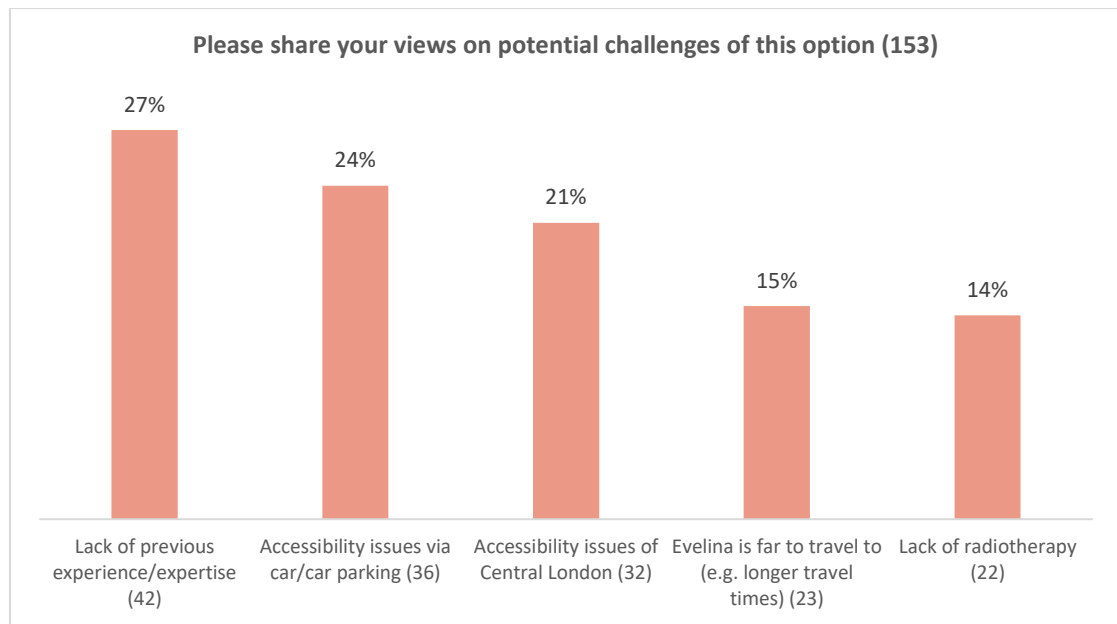


Figure 74 NHS Surrey Heartlands ICB, Potential Challenges about Evelina London

Again, key themes emerging from respondents within the Surrey Heartlands ICB region remain consistent with overall findings on the potential challenges of the proposal for Evelina London with most commenting around the lack of previous experience of caring/treating children with cancer (27%) as well as accessibility issues of Evelina London via car (24%).



17.2.3 Improvements

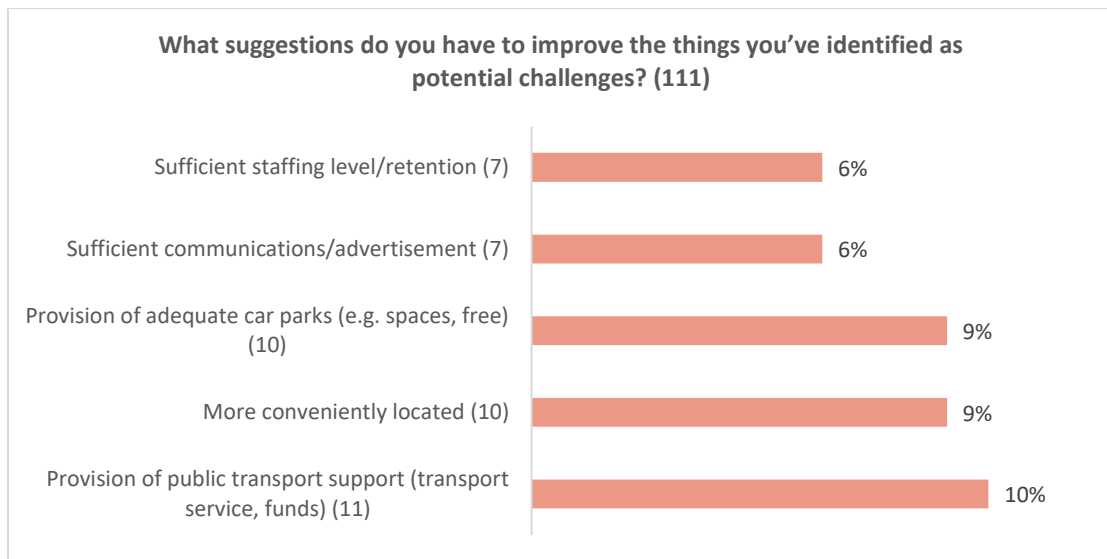


Figure 75 NHS Surrey Heartlands ICB, Improve Potential Challenges about Evelina London

Here, suggested improvements on the proposal for Evelina London from those within the Surrey Heartlands ICB region remain largely consistent with overall findings.



17.3 Proposal for St George's Hospital

17.3.1 Good points

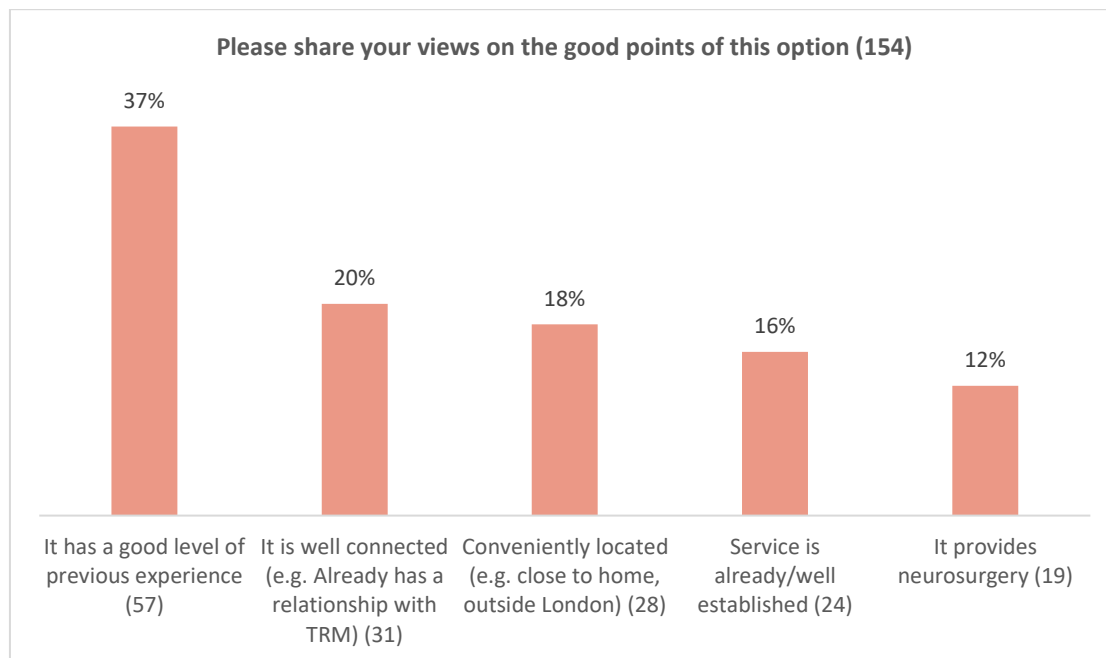


Figure 76 NHS Surrey Heartlands ICB, Good Points about St George's Hospital

Here, key themes raised by respondents from the Surrey Heartlands ICB region remain consistent with overall findings on the key strengths of the proposal for St George's Hospital.



17.3.2 Potential challenges

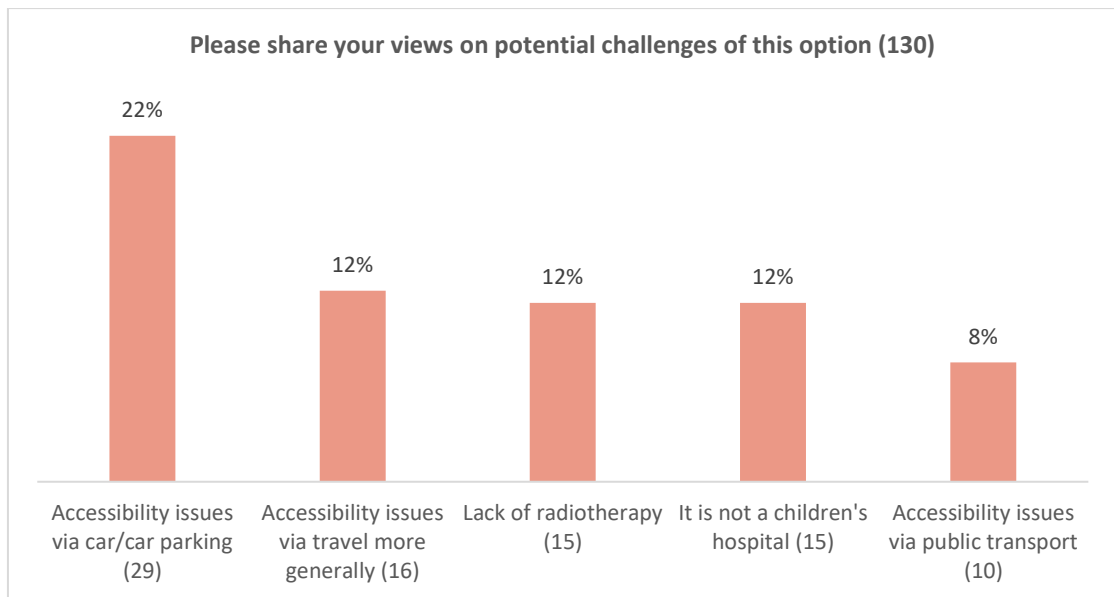


Figure 77 NHS Surrey Heartlands ICB, Potential Challenges about St George's Hospital

Here, responses from those within the Surrey Heartlands ICB area remain consistent with overall findings, with these respondents again mentioning key themes of accessibility via car (22%).



17.3.3 Improvements

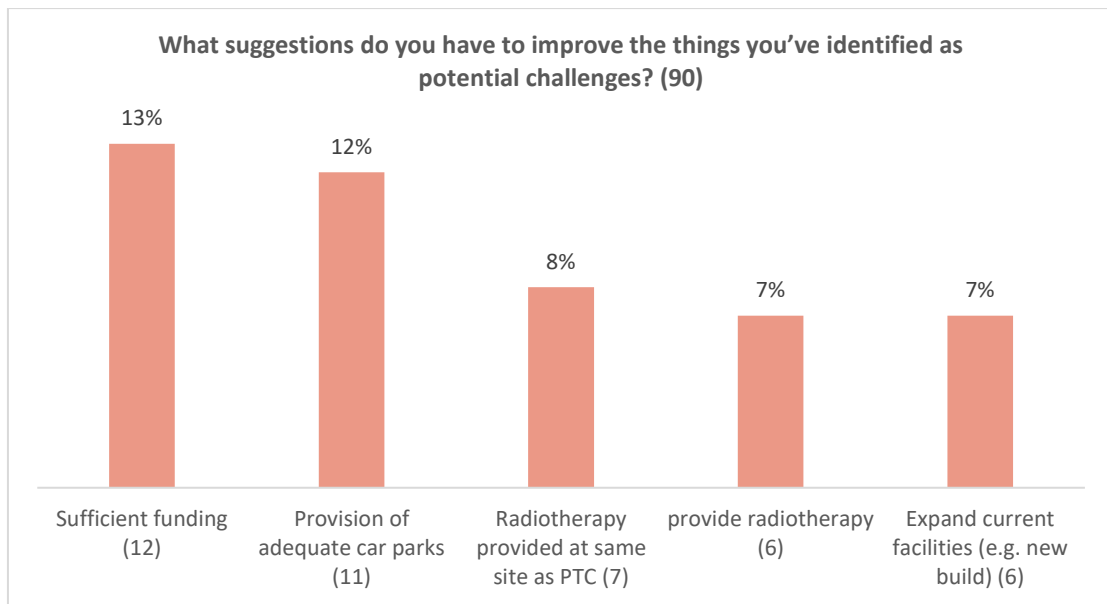


Figure 78 NHS Surrey Heartlands ICB, Improve Potential Challenges about St George's Hospital

Again, key themes coming out of responses made by those within the Surrey Heartlands ICB remain consistent with overall findings on suggestions to improve the proposal for St George's Hospital.



17.4 Views on the delivery of radiotherapy services at University College Hospital

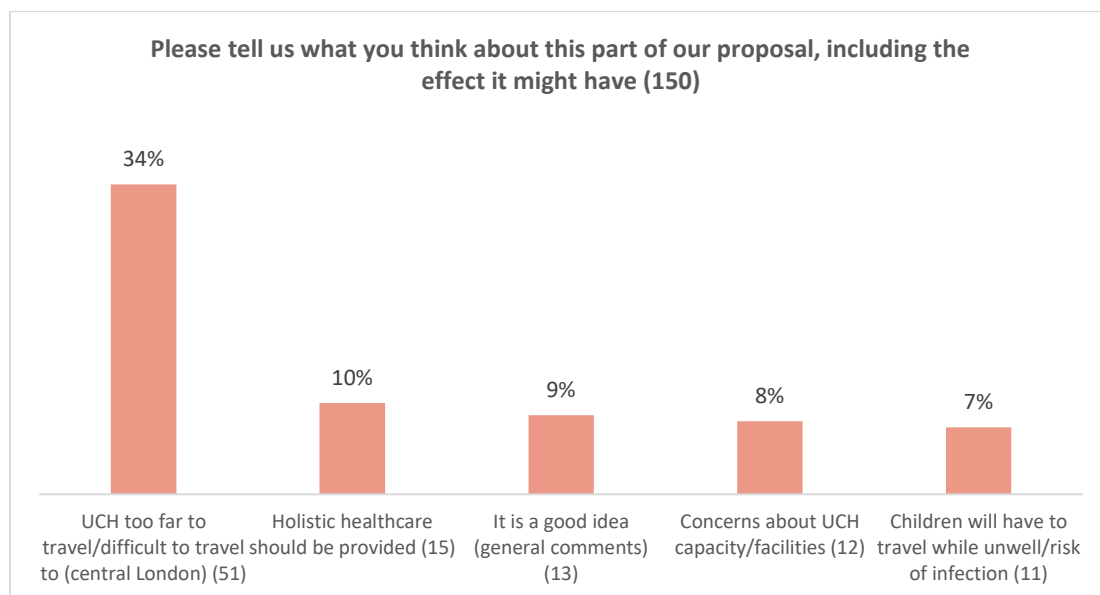


Figure 79 NHS Surrey Heartlands ICB, Radiotherapy Services at University College Hospital, effect proposal might have

When asked to share their feedback on radiotherapy being provided at University College Hospital under both proposals, key themes made by those within The Surrey Heartlands ICB region remain largely consistent with overall findings. Yet the issue of children traveling while unwell, bringing the potential risk of infection was seen as of a greater concern to these respondents (7%).



18 NHS Sussex ICB

This chapter focuses on feedback from respondents living in the Sussex ICB area. 4% of responses to the consultation were from residents of Sussex. Over a third of these responses (31.9%) were from family members of children with cancer. Of those respondents who provided their demographic details, 10.2% were from ethnic groups other than white, more than 70% were female, (72.5%), more than half were aged 41-65 (55.1%), 11.6% were disabled (more than the other areas), 8.6% were receiving additional income support and 15.9% were from socio-economic groups C2DE - more than the other areas.

This chapter depicts the most and least important factors regarding travel and making the move easier for patients and families. It also compares qualitative responses to the key overall findings and highlights any differences. Although feedback was largely consistent against overall findings, those within this ICB area were more likely to see the cost of travel into central London as being key challenges across both proposals.

18.1 Feedback on travel

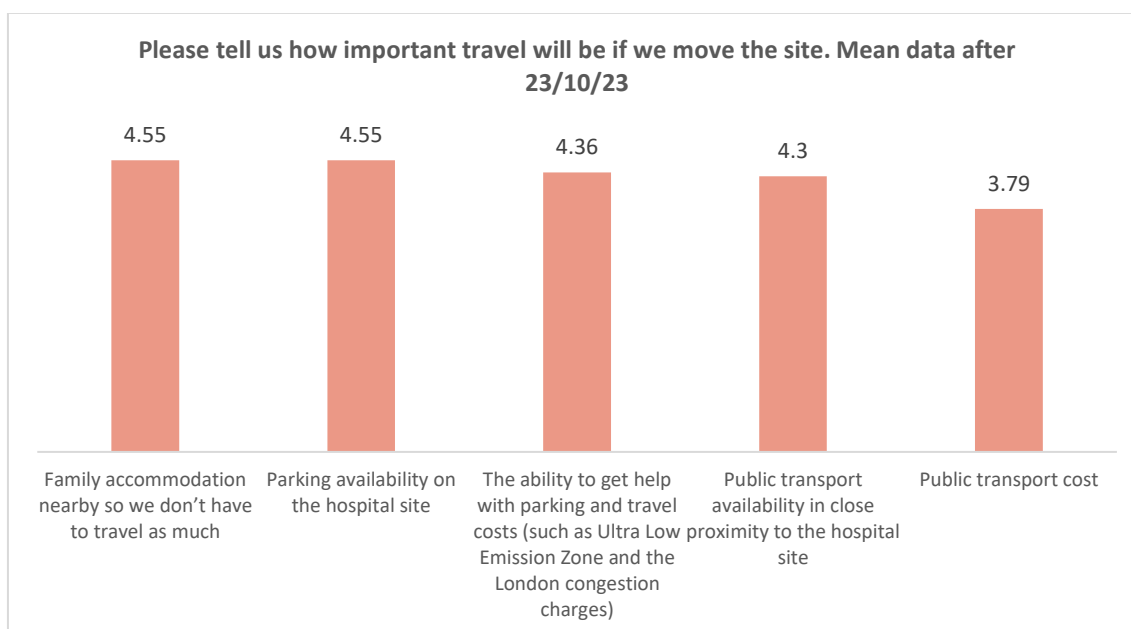


Figure 80 NHS Sussex ICB, Importance of Travel, After 23/10/23

The two most important aspects of travel for respondents from the Sussex ICB region include having 'family accommodation on site' as well as 'parking availability on the hospital site', with both receiving a mean score of 4.55 out of 5.





Figure 81 NHS Sussex ICB, Support and Information

Respondents from Sussex would find ‘understanding which staff will be involved in ongoing care’ (4.87) and ‘being reassured about when and how the move will happen’ (4.82) as the most important factors to make the change easier. While still of importance, ‘being involved in how the new location looks and feels’ was the least important factor (4.30) for making the move easier for respondents from the Sussex ICB region.

Data for respondents within the Sussex ICB region captured before 23 October 2023 has not been presented here for questions seven and eight due to only having a base size of ten.



18.2 Proposal for Evelina London

18.2.1 Good points

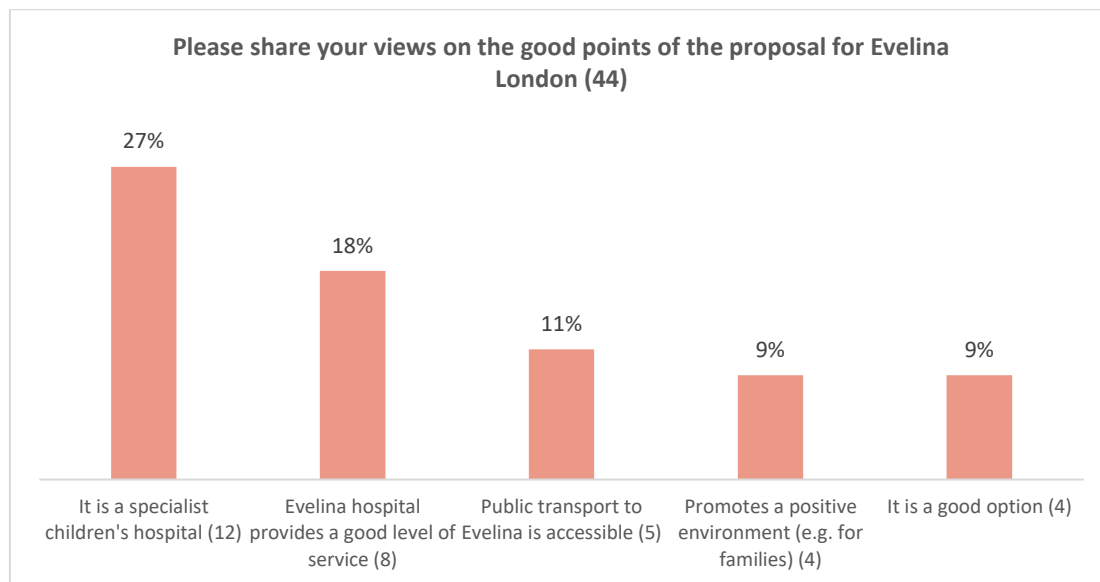


Figure 82 NHS Sussex ICB, Good Points about Evelina London

When asked to state the positive of the proposal for Evelina London, key themes made by respondents from Sussex ICB area remain consistent with overall findings, with again most raising the point of Evelina London already being a specialist children's hospital (27%).



18.2.2 Potential challenges

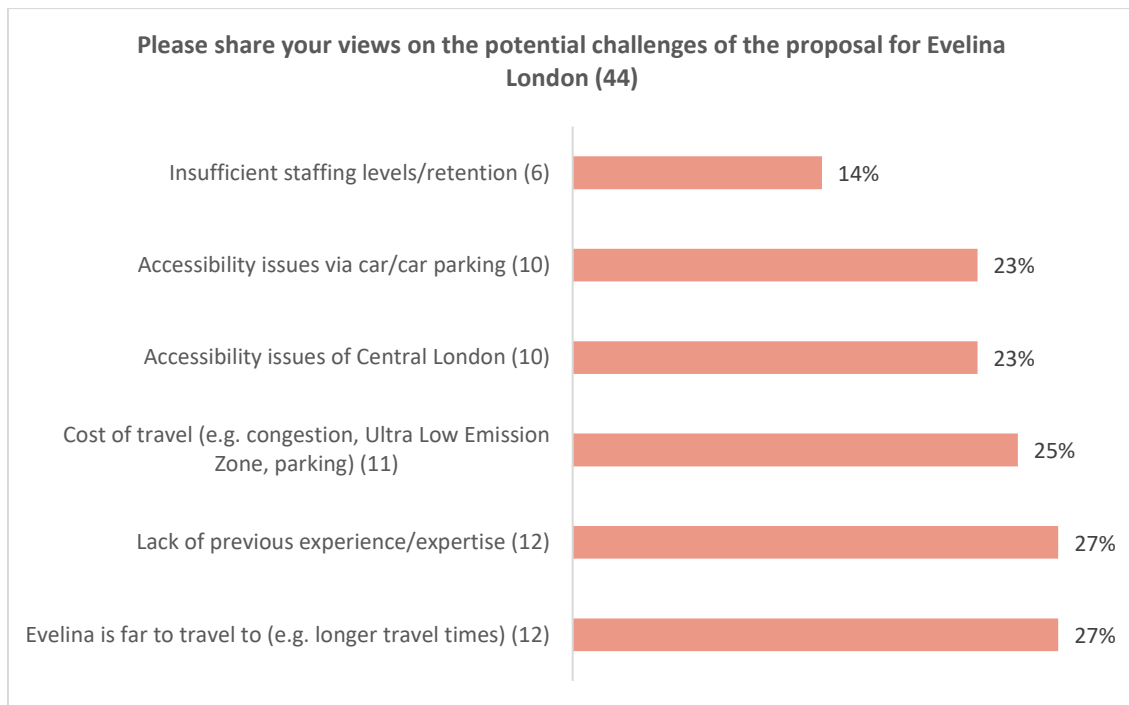


Figure 83 NHS Sussex ICB, Potential Challenges about Evelina London

Responses made by respondents from the Sussex ICB region remain largely consistent to overall findings with issues surround the accessibility being raised as central themes.



18.2.3 Improvements

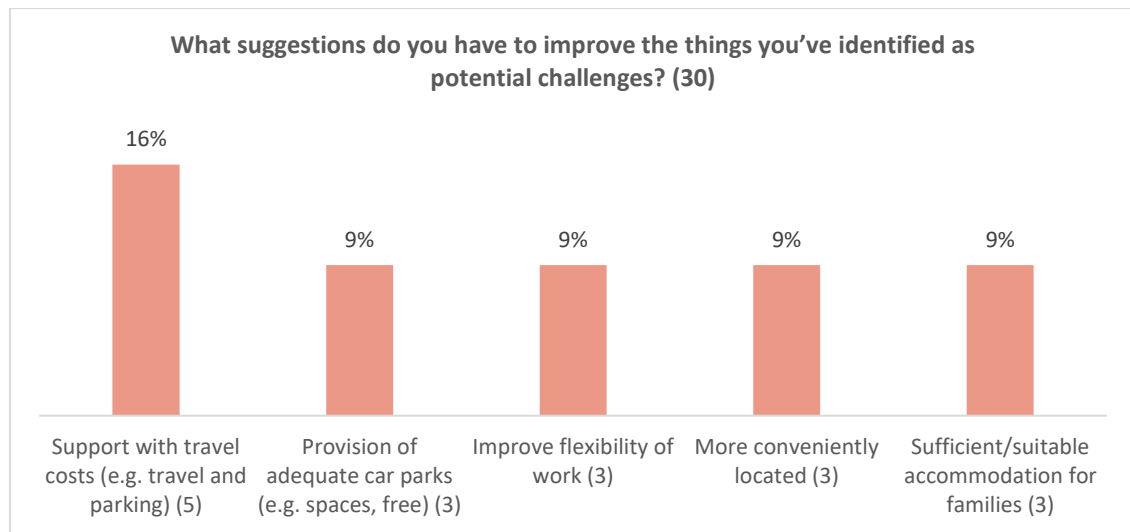


Figure 84 NHS Sussex ICB, Improve Potential Challenges about Evelina London

Only 30 respondents from the Sussex ICB region answered this question on the improvements needed to address the challenges with the proposal for Evelina London, with the greatest number of comments centring on ensuring patients are supported with increased costs of travelling longer distances or on public transport to access the Evelina London.



18.3 Proposal for St George's Hospital

18.3.1 Good points

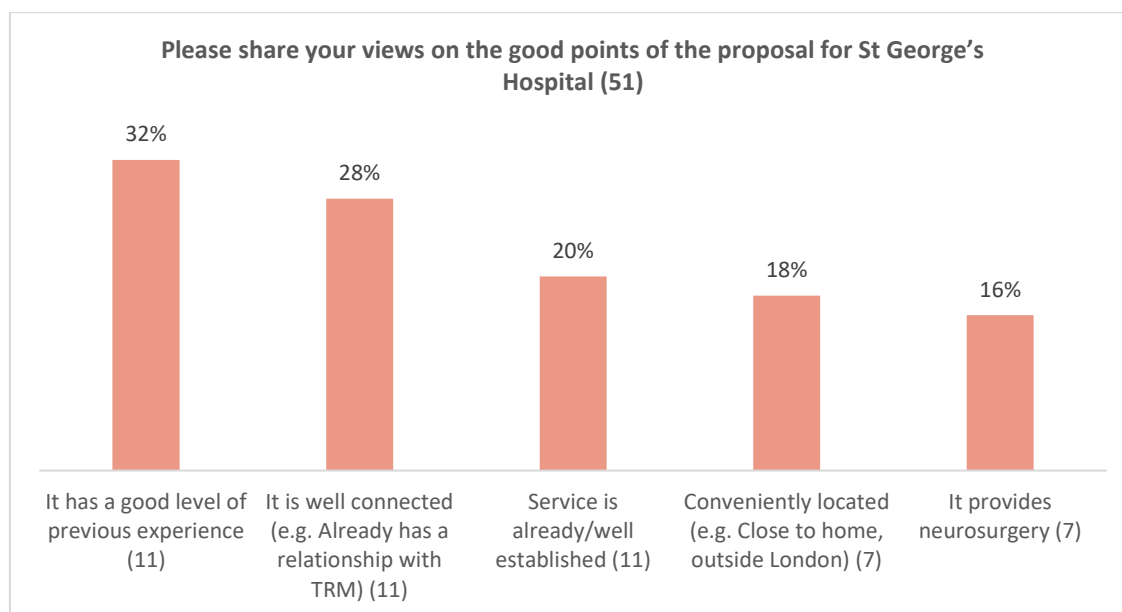


Figure 85 NHS Sussex ICB, Good Points about St George's Hospital

When asked to share what they consider the strengths of the proposal for St George's Hospital to be, key themes raised by respondents from the Sussex ICB region remain consistent to overall findings, with again, respondents here mentioning how St George's Hospital has a good level of experience in treating children with cancer (32%) due to its current relationship with The Royal Marsden (28%).



18.3.2 Potential challenges

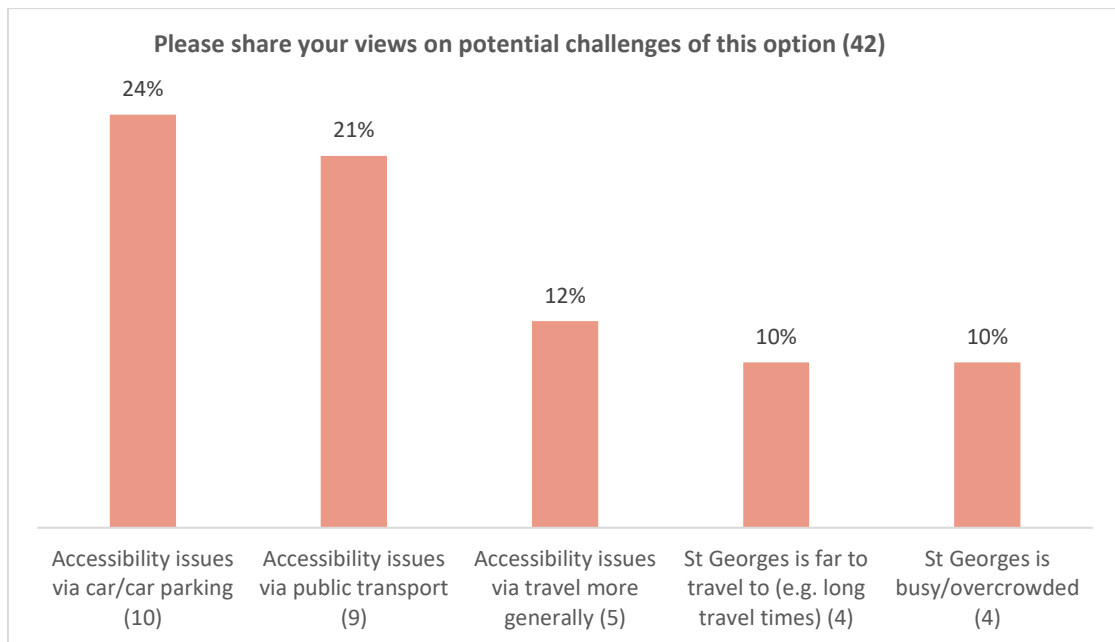


Figure 86 NHS Sussex ICB, Potential Challenges about St George's Hospital

Here, key themes from those within the Sussex ICB region remain consistent to overall findings on the potential challenges of the proposal for St George's Hospital, with key challenges centring on accessibility.



18.3.3 Improvements

Due to a low base size of 30 and small individual base sizes for each theme a table has not been displayed here. Key improvements again closely reflected overall findings, with the most common theme centring on ensuring the provision of adequate car parking spaces (23% of questionnaire responses).

18.4 Views on the delivery of radiotherapy services at University College Hospital

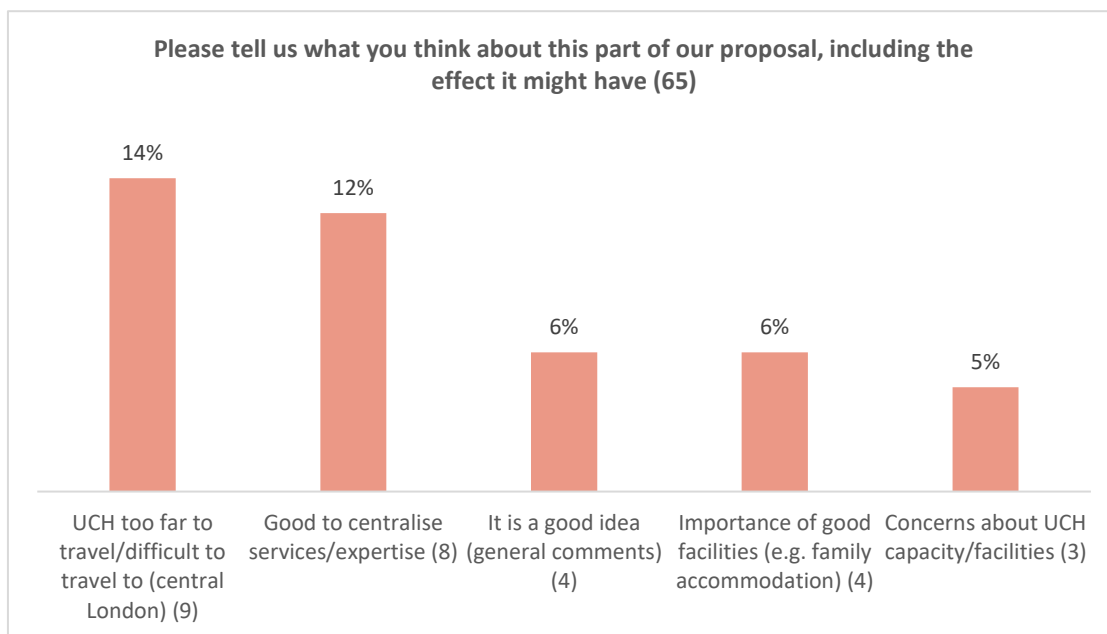


Figure 87 NHS Sussex ICB, Improve Potential Challenges about St George's Hospital

Despite individual base sizes for each theme being low, key themes made by respondents from the Sussex ICB area on radiotherapy being provided at University College Hospital under both proposals remain consistent to overall findings.



19 NHS Kent and Medway ICB

This chapter focuses on feedback from respondents living in the Kent and Medway ICB area. 6.4% of responses to the consultation were from residents of Kent and Medway. Almost a third of these responses (32.7%) were from family members of children with cancer - a higher proportion than any other area. Of those respondents who provided their demographic details, more than a fifth were from ethnic groups other than white (21.8%), almost two-thirds were female (65.5%), more than half were aged 41-65 (59.1%), 10% were disabled, almost 70% were from socio-economic groups ABC1 (69.1%) and 13.2% were receiving additional income support - more than the other areas.

This chapter depicts the most and least important factors regarding travel and making the move easier for patients and families. It also compares qualitative responses to the key overall findings and highlights any differences. Although feedback was largely consistent again overall findings, those within this ICB area were more likely to consider Evelina London being co-located with St. Thomas' as a key strength of the proposal for Evelina London.

19.1 Feedback on travel

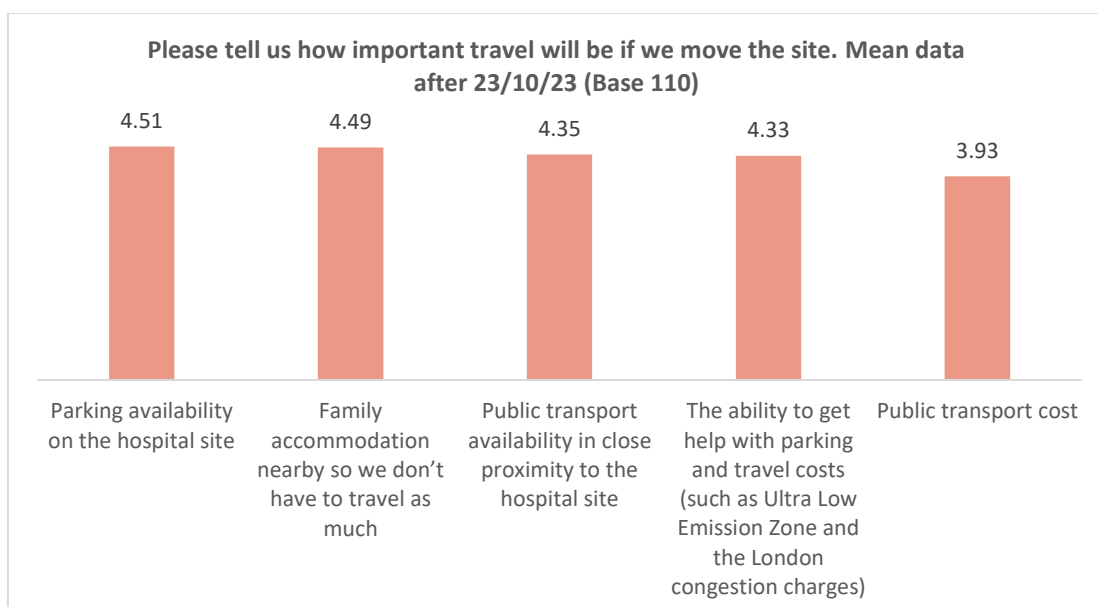


Figure 88 NHS Kent and Medway ICB, Importance of Travel, After 23/10/23

For respondents from Kent and Medway ICB, 'parking availability on the hospital site' was seen as the most important aspect of travel along with 'family accommodation nearby'. The least important area



of travel for respondents from Kent and Medway ICB is 'public transport cost' receiving a mean score of 3.93 out of 5.

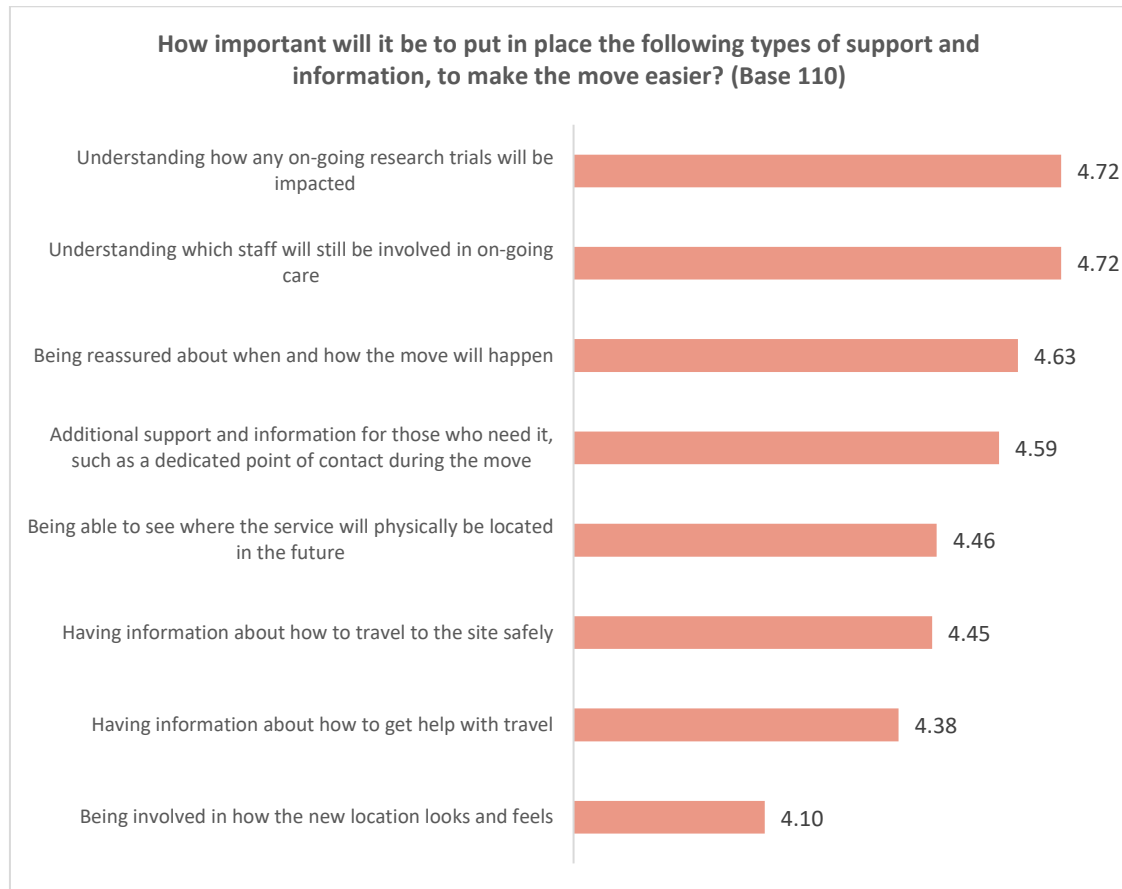


Figure 89 NHS Kent and Medway ICB, Support and Information

For respondents from Kent and Medway ICB, understanding 'how any on-going research will be impacted' will be the greatest factor in making the move easier, with this receiving a mean score of 4.72 out of 5. In contrast, the least important factor for making the move easier for respondents from Kent and Medway is 'being involved in how the new location looks and feels'.⁵²

Again, due to low base sizes for both these questions of around 5 respondents from Kent and Medway responding to this question, data captured before the 23rd of October has not been reflected here.

⁵² Again, data for respondents within the Kent and Medway ICB region captured before the 23 October 2023 has not been presented here due to its base size being too small to be reported on with only 5 respondents having taken part in the online questionnaire at this stage.



19.2 Proposal for Evelina London

19.2.1 Good points

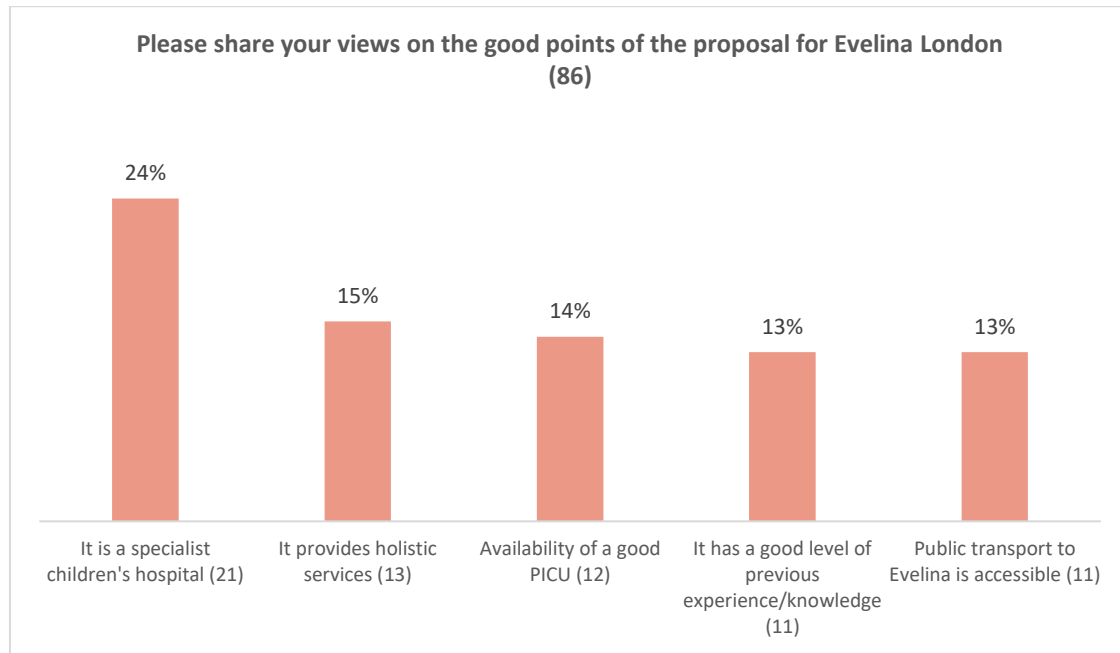


Figure 90 NHS Kent and Medway ICB, Good Points about Evelina London

Here, responses from those within the Kent and Medway ICB region remain largely consistent with overall findings, with respondents here mentioning how it is already a specialist children's hospital.



19.2.2 Potential challenges

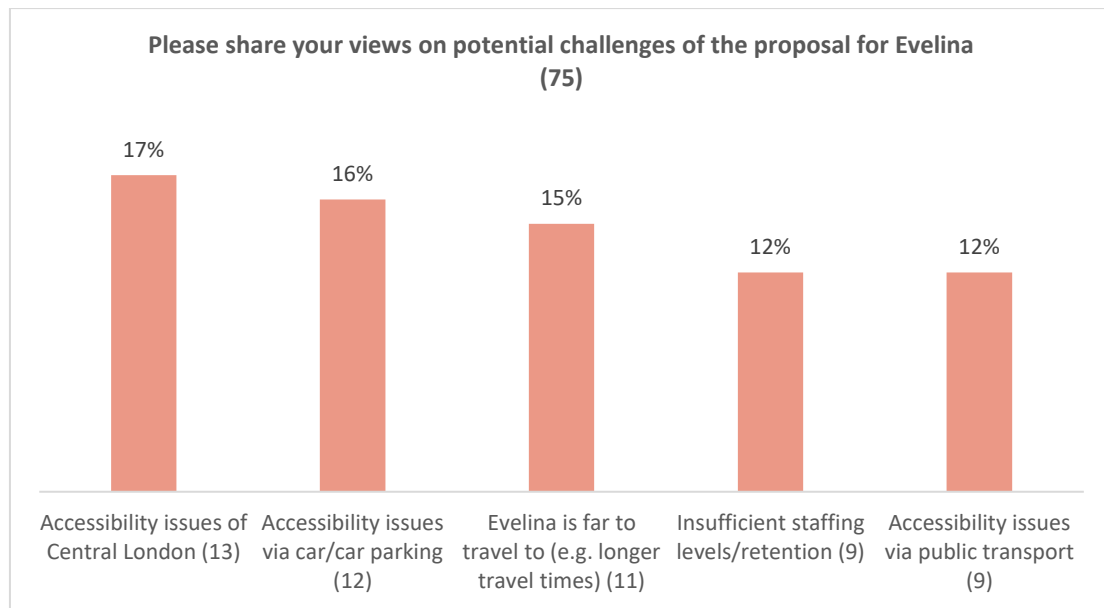


Figure 91 NHS Kent and Medway ICB, Potential Challenges about Evelina London

While key findings from those within the Kent and Medway ICB region remain largely consistent with overall findings here, it is clear that these respondents were more likely to focus on accessibility issues of Evelina London. As well as this, the theme of Evelina London lacking the experience of caring for children with cancer did not come through as strongly for respondents within Kent and Medway ICB as it did for responses in other ICB areas.

19.2.3 Improvements



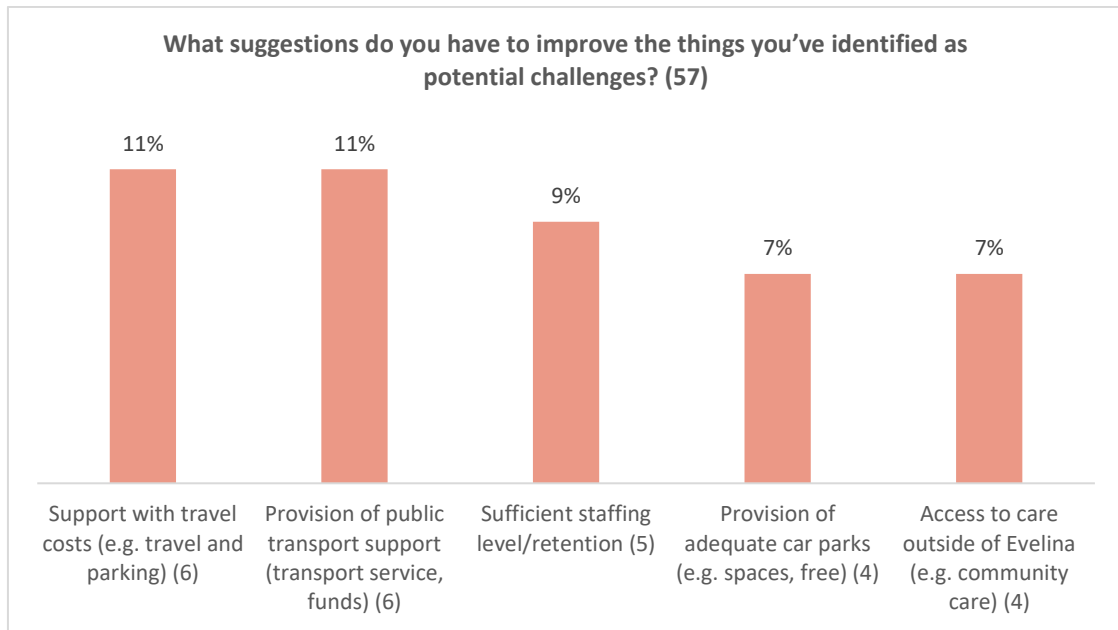


Figure 92 NHS Kent and Medway ICB, Improve Potential Challenges about Evelina London

Again, responses made by those within the Kent and Medway ICB region remain largely consistent with overall findings on the suggestions to improve the proposal for Evelina London, with most comments centering around the greater distance to travel to the site and added costs incurred because of this.



19.3 Proposal for St George's Hospital

19.3.1 Good points

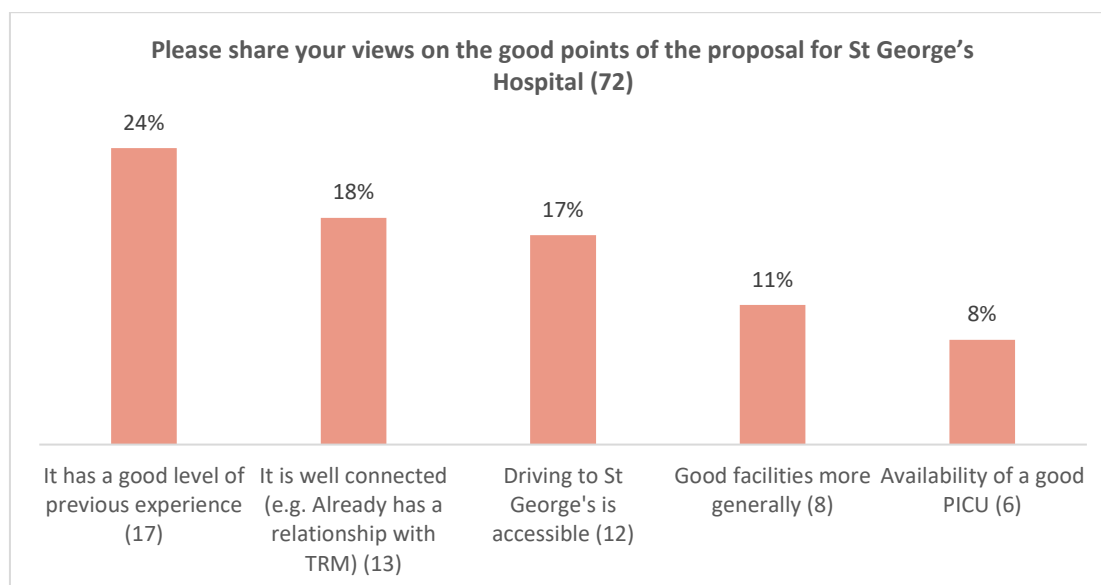


Figure 93 NHS Kent and Medway ICB, Good Points about St George's Hospital

When asked to share the positive aspects of the proposal for St George's Hospital, key themes left by those within the Kent and Medway ICB region remain consistent with overall findings.



19.3.2 Potential challenges

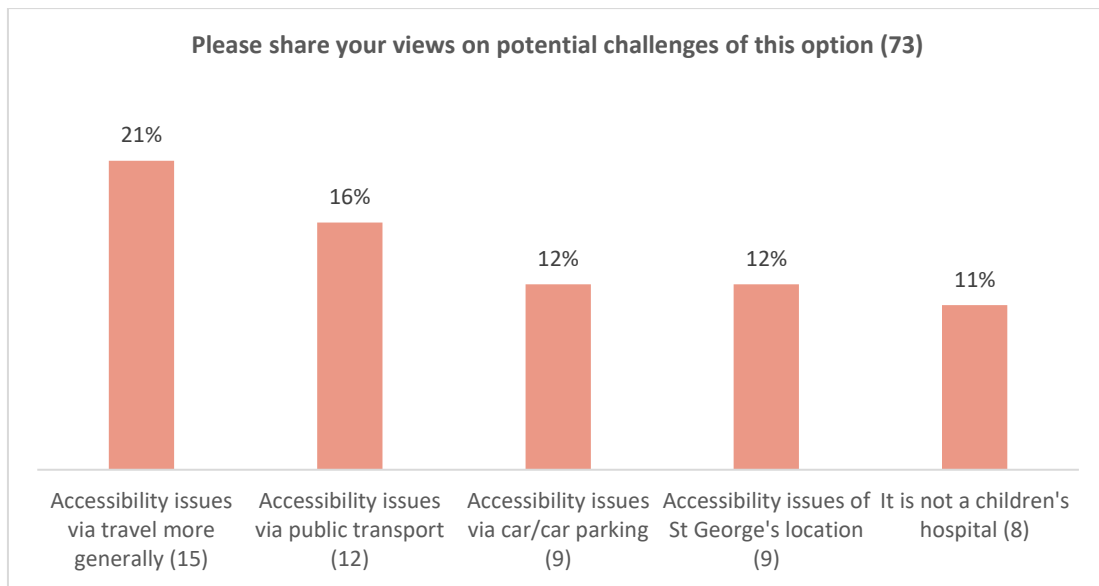


Figure 94 NHS Kent and Medway ICB, Potential Challenges about St George's Hospital

Key themes coming through from respondents within the Kent and Medway ICB region on the potential challenges of the proposal for St George's Hospital, findings remain consistent to overall findings. Here, key themes left by respondents within this region centred strongly on the accessibility of St George's Hospital.

19.3.3 Improvements

Here, a graph has not been displayed for responses for Kent and Medway responses due to only 37 respondents commenting on this question as well as small individual base sizes for each theme.

For respondents within the Kent and Medway ICB region key improvements of the proposal for St George's Hospital include providing public transport support such as shuttle services (13%), as well as expanding or improving the provision of car parking availability on site (13%).



19.4 Views on the delivery of radiotherapy services at University College Hospital

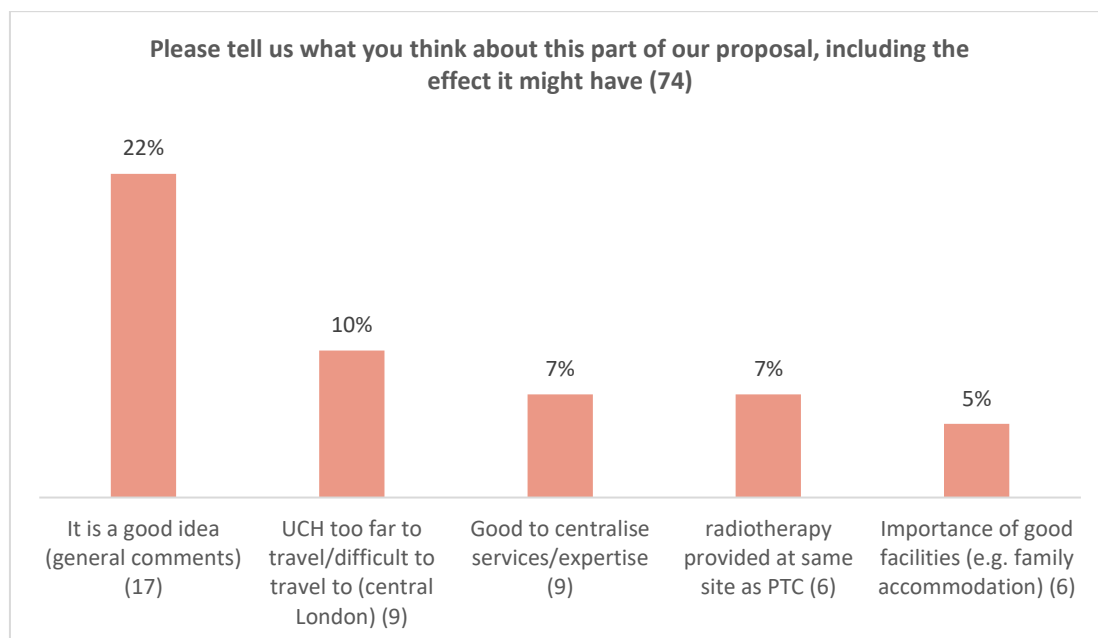


Figure 95 NHS Kent and Medway ICB, Improve Potential Challenges about St George's Hospital

Here, key themes coming through from respondents in the Kent and Medway ICB region differ slightly to overall findings on the question of radiotherapy being moved to University College Hospital, under both options with respondents being more likely to state that it is a good idea (22%). While some recognised that this would mean patients and families would be travelling across London to receive care, they also understood that this would be necessary since University College Hospital offers dedicated/specialist radiotherapy services (7%).





Conclusions

A summary review of the feedback received.

20 Conclusions

This report presented 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 successfully engaged stakeholders resulting in a total of 2,669 responses submitted. This included 1,763 questionnaire responses and 831 people reached through face-to-face activities across 115 engagement sessions. Promotion of the consultation reached over 600,000 individuals, inviting them to share their views.

In terms of key demographic strengths, responses from children and young people to the consultation were broadly representative of the wider patient cohort in terms of ICB region and socio-economic group/deprivation levels. Ethnicity was broadly reflective of the population across ICB regions, with 70% being from white ethnicities and 23% from ethnic minority communities (excluding white minorities). The consultation heard from 81% of The Royal Marsden Staff and 52% of St George's Hospital staff currently working at the Principal Treatment Centre.

In terms of key demographic gaps, most respondents were aged 41-65 (51%), compared to 32% of members of the public across ICB regions. Around 90% of total respondents were from socio-economic groups ABC1 compared to around 66% from across ICB regions. This means these respondents are likely to hold professional or managerial job roles; it may also indicate that they have a higher education qualification. 70% of overall responses were from females compared to only 52% of the population across ICB regions.

Overall, the feedback received on the proposals was mixed. There were strong views on the benefits and challenges of both options, as well as 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 Hospital). 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.

Across all stakeholder groups, feedback identified challenges common to both options. These challenges related to the absence of a 'single-site solution' for children's cancer care (referring to neurosurgery, radiotherapy, and other key specialist services like heart and kidney care) and the



potential loss of the personalised care and expertise of The Royal Marsden. It is important to note that there were no key differences in findings when feedback was analysed by region as findings were consistent.

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 with direct experience of children's cancer care.

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.

20.1 Improvements: common to both proposals

Across all engagement activities, respondents were asked to suggest improvements that could be implemented which would minimise the effects of any perceived challenges. Respondents were asked to respond to mitigations already being considered by NHS England (London and South East regions) as well as being invited to suggest new ones, based on their own experiences and personal circumstances. These suggestions will be used to help inform implementation planning by NHS England (London and South East regions).

20.1.1 Access to healthcare

Improvement of children's cancer care closer to home

It was suggested that the proposals involve plans for the future Principal Treatment Centre to work together with the team responsible for managing children's cancer shared care units, to help deliver more effective treatments closer to the homes of families. If actioned, this would mitigate the need for some travel for families. It is acknowledged that this would require investment, training, and support for children's cancer shared care units.

20.1.2 Travel

Provision of hospital transport



A consideration should be given to improving the provision of effective and free hospital transport, such as a shuttle service or private hire vehicles, particularly in terms of expanding eligibility criteria for the scheme. This would help to mitigate issues relating to:

- Increased journey times
- Increased financial cost of travel for families
- Minimisation or avoidance of public transport use when a child is very sick or undergoing treatment that renders them immunocompromised.

Financial support with travel costs for the family network

Some feedback emphasised the need to recognise that caring for a child with cancer often involves a wider support network than just a single parent or carer. Individuals who make up this wider support network may incur additional costs to travel as a result of the move. It is not just a case of reimbursing one parent or carer; it is about reimbursing all visitors who go to hospital to visit the child.

Financial support with travel costs in advance of travel

Some feedback highlighted the need to acknowledge that some families will struggle to meet any increased financial cost to travel to the new Principal Treatment Centre. Paying upfront to cover these costs, and the wait for reimbursement, could significantly affect household finances for families already under financial pressure resulting from having a very sick child. This could be exacerbated further by the cost-of-living crisis. An alternative model whereby families are supported with travel costs in advance of a journey, such as the use of transport vouchers, should be considered.

Support with appointment times

Some feedback suggested that the provision of flexible appointment times would be appropriate, in recognition of the distance families need to travel to reach hospital alongside family and/or work commitments – as well as preferences of families to avoid travelling at peak times. As well as considering the timing of appointments - for those furthest away offering later appointment time and for those with disabilities or additional support needs offering longer appointments. Coordination of appointments across a day or week should also be considered. Overnight accommodation could be provided for families travelling the longest distances or experiencing the longest travel times.

20.1.3 Facilities

Outdoor spaces dedicated to children cancer patients



Some feedback suggested that the proposals should develop clear plans for dedicated outdoor spaces for use by patients, families, and specialist staff (such as physiotherapists, to inspire and encourage children to move by being outdoors). These outdoor spaces should be contained or near to the unit as possible.

Guaranteed parental accommodation on or very close to the Principal Treatment Centre

Some feedback suggested that the proposals should specify capacity and funding plans to deal with the increased number of families requiring parental accommodation on-site or close to the Principal Treatment Centre.

Separate entrance

A dedicated, separate entrance for the Principal Treatment Centre was suggested by some respondents, in order to minimise interaction between patients and others at both hospitals.

20.1.4 Research

Using The Royal Marsden @ model for continuity in research

It is suggested that use of The Royal Marsden @ model is considered to maintain a connection between The Royal Marsden site and the new Principal Treatment Centre, as research capability and services transfer. It is also considered valuable from a continuity perspective with funders, to provide a level of assurance and security that the reputation of The Royal Marsden would be upheld.

20.1.5 Staffing

Using The Royal Marsden @ model to support staff retention and recruitment

It is suggested that use of The Royal Marsden @ model is considered to foster a sense of belonging and continuity between The Royal Marsden/St George's Hospital and the new Principal Treatment Centre to assist with staff retention and recruitment.

Staff retention and recruitment

Some thought was given to ensuring current experienced staff at The Royal Marsden are retained at the new site, with suggestions including the provision of a detailed staff retention plan, as well as the implementation of necessary training and/or upskilling of current staff at Evelina London or St George's Hospital to reduce the pressures on recruitment.



Implementing a staff retention package for staff who move to the new Principal Treatment Centre

Some feedback related to the need for the proposals to consider a package to incentivise staff to move to the new Principal Treatment Centre. This could assist with costs associated with the transfer and longer-term cost implications such as increased travel costs.

Flexible working contracts offered to staff who move to the new Principal Treatment Centre

In recognition of the extended journey times some staff may face, and the impact on work-life balance, it was suggested that flexible working is considered as a mitigation.

Assurances to staff that their role is safeguarded

Staff want assurances that they will be working solely with oncology patients to retain that specialist knowledge and expertise. This would also extend to protections over study leave and research time for staff who request it.

20.1.6 Equality groups

Some of the suggested mitigations reported so far tied into feedback from members of equality groups. Below is a summary of mitigations specific to groups that typically experience disproportionate burden of effects of change:





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



20.2 Suggestions to address challenges: Evelina London

Support on travel

With some respondents explaining they would have to travel further into central London if the future Principal Treatment Centre was as Evelina London there is concern from some respondents over the exposure sick children could have while on public transport. Due to this, steps should be taken to ensure adequate provision of transport support such as hospital provided transport for those who are concerned about using public transport when travelling to Evelina London.

Leading on from this, to recognise the greater distances families/patients would have to travel to Evelina London, financial support to cover increased travel costs should be provided. This includes increased costs if travelling on public transport or Ultra Low Emissions Zone charges.

Travelling via car as well as parking on the hospital site was a key concern from respondents. To accommodate the increased number of patients, visitors and staff accessing the hospital site, feedback suggested that there should be an increase in the scale of onsite parking as well as dedicated or discounted parking for families and staff.

20.3 Suggestions to address challenges: St George's Hospital

Estates and facilities upgrade

It was suggested that further steps are needed to ensure that sufficient funding is given to St George's Hospital to upgrade the estate and facilities. This will give respondents confidence in the proposal.

Implications for St George's Hospital if the Principal Treatment Centre moves

A thorough plan and finance for St George's Hospital if the service moves here were suggested to mitigate concerns about the future of all other services at St George's Hospital.

Support with travel

Travelling via car as well as parking on the hospital site was a key concern from respondents. To accommodate the increased number of patients, visitors and staff accessing the hospital site, feedback suggested that there is an increase in the scale of onsite parking as well as dedicated or discounted parking for families and staff.



20.4 Other needs

Across all feedback types, there was a clear interest from respondents in receiving further information on the consultation. This included:

- Detailed financial plans for both proposals, for the short and long-term
- Realistic timelines
- Detailed explanation of what The Royal Marsden's role will be in the future
- Physical capacity and financial resourcing plans for University College Hospital.





Appendices

Supporting documentation can be found in this section.



21 Appendices

21.1 Appendix A – Glossary of acronyms

AML - Acute myeloid leukaemia

BMT - Bone marrow transplant

CICU - Cardiac intensive care unit

CQC – Care Quality Commission

CYP – Children and young people

EL or ELCH – Evelina London

GA – General Aesthetic

GOSH – Great Ormond Street Hospital

GSTT – Guy’s and St Thomas’ NHS Foundation Trust

ICB – Integrated Care Board

ICU – Intensive Care Unit

JHOSCs - Joint Health Overview and Scrutiny Committees

MDT – Multidisciplinary teams

MIBG – Metaiodobenzylguanidine

PCBC - Pre-Consultation Business Case

PICU – Paediatric Intensive Care Unit (children’s intensive care unit)

POSCU - Paediatric oncology shared care unit (children’s cancer shared care units)

PTC – Principal Treatment Centre

SIHMDS - specialist integrated haematology malignancy diagnostic service

STRS – South Thames Retrieval Service

TBI – Total body irradiation



RMH -The Royal Marsden

TYA – Teenagers and young adults

UCH – University College Hospital

21.2 Appendix B – Engagement log

A log of qualitative engagement activities, organised by date.

Date	Activity/forum	Audience	No. of people in attendance
October 2023			
04/10/2023	South West London Integrated Care Partnership	South west London ICB leads, South west London Local Authority Leads, Patients	38
11/10/2023	Ronald McDonald House Charities	Ronald McDonald House Charities	2
16/10/2023	South East Cancer Programme Wider Leadership Group	NHS colleagues working within the south east region on cancer programmes	24
16/10/2023	Play specialist session - The Royal Marsden	Children and young people currently receiving Principal Treatment Centre treatment	3
17/10/2023	Children and young people Network - Wandsworth Care Alliance	Voluntary and Community organisations within Wandsworth, supporting children and young people	17
17/10/2023	Play specialist session - The Royal Marsden	Children and young people currently receiving Principal Treatment Centre treatment	4
19/10/2023	Operational Delivery Network	Operational Delivery Network leads	46
20/10/2023	Play specialist session - The Royal Marsden	Children and young people currently receiving Principal Treatment Centre treatment	3
22/10/2023	Briefing/Q&A session - South West London and Surrey Joint Overview and Scrutiny sub-committee - formal meeting to consider mid-point review report	Councillors, Trusts, patient reps, ICB and Healthwatch representation	9
23/10/2023	Play specialist session - The Royal Marsden	Children and young people currently receiving Principal Treatment Centre treatment	3
25/10/2023	Community focus group - South West London (in person)	Children and young people and families	9
27/10/2023	Play specialist session - The Royal Marsden	Children and young people currently receiving Principal Treatment Centre treatment	2
30/10/2023	Play specialist session - The Royal Marsden	Children and young people currently receiving Principal Treatment Centre treatment	3
November 2023			
01/11/2023	Meeting with East Kent Paediatric Oncology Shared Care Unit	POSCU clinicians	3
01/11/2023	Briefing/Q&A session - Meeting with Councillors from Sutton Health Scrutiny Committee	Councillors/Democratic Officer	4
01/11/2023	Meeting with North Thames Paediatric Network	Clinicians who are part of the paediatric network	36

01/11/2023	Community focus group - Sussex (online)	Children and young people and families	10
02/11/2023	Public Listening Event 1	General public	8
02/11/2023	Briefing/Q&A session - Meeting with Councillors from Sutton	Councillors	3
06/11/2023	North Thames Paediatric Network	Cancer Team / NHS staff	4
08/11/2023	Epsom and St. Helier Maternity Voice Partnership	New and expecting mothers	14 (6 service users)
08/11/2023	MP Roundtable	MPs	10 MPs
10/11/2023	Community focus groups 1 - Brighton and Hove (in person)	Children and young people and families from protected characteristic groups without direct experience of cancer services	7
10/11/2023	Community focus groups 2 - Brighton and Hove (in person)	Children and young people and families from protected characteristic groups without direct experience of cancer services	7
13/11/2023	Briefing/Q&A session - ICB comms and engagement mid-point review meeting	ICB comms and engagement leads	4
13/11/2023	Play specialist session- St George's Hospitals	Children and young people currently receiving Principal Treatment Centre treatment	1
14/11/2023	Site Visit to Evelina Hospital for Councillors from South West London and Surrey JHOSC sub-committee	JHOSC	4
15/11/2023	Principal Treatment Centre Stakeholder Group meeting	Parents of children with direct experience of the current service and children's cancer charities	6
15/11/2023	Briefing/Q&A session - MP briefing	MPs (South East London)	2
15/11/2023	Community focus group: Surrey (online)	Children and young people and families from protected characteristic groups without direct experience of cancer services	9
16/11/2023	South & North Thames Paediatric Network Session (session 1 of 2)	Wider NHS paediatric clinicians	3
16/11/2023	Site Visit: South west London/Surrey JHOSC sub-committee to St George's Hospital	JHOSC	4
16/11/2023	Traveller Movement Conference	Gypsy, Roma and Traveller Communities	7
16/11/2023	Community focus group: south east London (in person)	Children and young people and families from protected characteristic groups without direct experience of cancer services	8
17/11/2023	Bromley Parent Voice coffee morning	Parents/carers of children with special education needs and disabilities (SEND)	7
17/11/2023	1:1 Parent interview	Parents of children currently accessing Principal Treatment Centre services	1
20/11/2023	Public Listening Event 2	General public	14
20/11/2023	Site Visit to St. George's Hospital for Councillors from South West	Councillors	2

	London and Surrey JHOSC sub-committee		
21/11/2023	Briefing/ Q&A session - South east London JHOSC - informal meeting to consider mid-point review report	Councillors	10
22/11/2023	East Kent POSCU session	POSCU staff	6
22/11/2023	Parent focus group	Families experiencing specialist children's cancer services	5
22/11/2023	Community focus group: Kent	Children and young people and families from protected characteristic groups without direct experience of cancer services	8
23/11/2023	Surrey POSCU session	Surrey POSCU lead	1
23/11/2023	St. George's Patient Partnership and Experience Group (PPEG)	Patients, Healthwatch	14
23/11/2023	Parent focus group	Families experiencing specialist children's cancer services	1
23/11/2023	Site visit: Councillors (London) to St George's Hospital	Councillors	2
24/11/2023	Community focus group: South London	Children and young people and families from protected characteristic groups without direct experience of cancer services	12
25/11/2023	Hastings Market session 1 (in-person)	Children and young people and families from protected characteristic groups without direct experience of cancer services	18
25/11/2023	Hastings Market session 2 (in-person)	Children and young people and families from protected characteristic groups without direct experience of cancer services	18
27/11/2023	Service user and charity focus group	POSCU parents and charities with experience of the current PTC service	4
27/11/2023	Parent focus group	Families experiencing specialist children's cancer services	7
28/11/2023	Staff session: Evelina London	Staff at Evelina London	29
28/11/2023	South & North Thames Paediatric Network Session (session 2 of 2)	Wider NHS paediatric colleagues	19
28/11/2023	Parent focus group	Families experiencing specialist children's cancer services	5
28/11/2023	Community focus group: South London	Children and young people and families from protected characteristic groups without direct experience of cancer services	8
29/11/2023	Refugee and Migrant Women's Network Group	Refugee and Migrant Communities	16
29/11/2023	North Thames Paediatric Network Cancer Board Meeting	Clinicians who are part of the North Thames Cancer Board	34
29/11/2023	Community focus group: Sussex	Children and young people and families from protected characteristic groups without direct experience of cancer services	6
30/11/2023	The Royal Marsden TYA Forum	Teenagers and Young Adults who've used the paediatric cancer services	2

30/11/2023	Meeting with Great Ormond Street Hospital representative	Research colleagues	1
December 2023			
01/12/2023	Staff session: The Royal Marsden	Staff at The Royal Marsden working in the current Principal Treatment Centre	6
04/12/2023	South Thames Operational Delivery Network	Operational Delivery Network colleagues	18
04/12/2023	Public Listening Event 3	General public	9
04/12/2023	The Royal Marsden site visit: engagement with families	Children and young people/families with direct experience of the current service	<i>Respondents completed the questionnaire with support from the team</i>
04/12/2023	Play specialist session: St George's Hospital	Children and young people currently receiving Principal Treatment Centre treatment	1
05/12/2023	The Royal Marsden site visit: engagement with families	Children and young people/families with direct experience of the current service	8
05/12/2023	East Kent POSCU visit	Children and young people/families with direct experience of the current service	2
06/12/2023	Staff session: The Royal Marsden	Staff at The Royal Marsden	3
06/12/2023	1:1 interview with Great Ormond Street Hospital Consultation	Great Ormond Street Hospital Paediatric Consultant	1
06/12/2023	The Royal Marsden site visit: engagement with families	Children and young people/families with direct experience of the current service	8
06/12/2023	Ashford and St. Peter's POSCU	Children and young people/families with direct experience of the current POSCU service	7
07/12/2023	Staff session: The Royal Marsden	Staff at The Royal Marsden	7
07/12/2023	Staff session: St George's University Hospitals	St George's University Hospitals staff members	18
07/12/2023	Briefing/Q&A - Healthwatch meeting with representatives from Kent, Medway and Surrey	Healthwatch organisations	3
07/12/2023	The Royal Marsden site visit: engagement with families	Children and young people/families with direct experience of the current service	13
08/12/2023	1:1 interviews: The Royal Marsden staff	The Royal Marsden staff currently working in the PTC	2
08/12/2023	The Royal Marsden site visit: engagement with families	Children and young people/families with direct experience of the current service	5
08/12/2023	Play specialist session: The Royal Marsden	Children and young people currently receiving Principal Treatment Centre treatment	5
08/12/2023	Medway POSCU	Children and young people currently receiving Principal Treatment Centre treatment	6

11/12/2023	1:1 Parent interview	Children and young people/families with direct experience of the current service	1
11/12/2023	The Royal Marsden site visit: engagement with families	Children and young people/families with direct experience of the current service	6
11/12/2023	Online play session for Children and young people	Children and young people currently receiving Principal Treatment Centre treatment	1
11/12/2023	Play specialist session: The Royal Marsden	Children and young people currently receiving Principal Treatment Centre treatment	3
11/12/2023	East Kent POSCU visit: Margate	Children and young people currently receiving Principal Treatment Centre / POSCU treatment	5
12/12/2023	1:1 interviews: The Royal Marsden staff	The Royal Marsden staff currently working in the PTC	2
12/12/2023	Additional Parent Focus Group	Parents of children currently/ recently having had treatment	2
12/12/2023	Mental Health Forum - Voluntary Action South West Surrey	Mental health service users	19
12/12/2023	The Royal Marsden site visit: engagement with families	Children and young people/families with direct experience of the current service	16
13/12/2023	1:1 interviews: The Royal Marsden staff	The Royal Marsden staff currently working in the PTC	3
13/12/2023	Briefing/ Q&A - South west London Healthwatch session	Healthwatch	3
13/12/2023	Briefing/ Q&A - London Borough of Sutton Scrutiny Committee Meeting	Committee members	10
13/12/2023	Operational Delivery Network	Children's cancer Operational Delivery Network Leads (staff with knowledge of cancer services)	5
13/12/2023	The Royal Marsden site visit: engagement with families	Children and young people/families with direct experience of the current service	3
13/12/2023	Belvedere Asian Women's Group	Asian women	24
14/12/2023	Great Ormond Street Hospital focus group	Staff with experience of cancer services/children's services	24
14/12/2023	1:1 interviews: The Royal Marsden staff	The Royal Marsden staff currently working in the PTC	8
14/12/2023	The Royal Marsden site visit: engagement with families	Children and young people/families with direct experience of the current service	8
14/12/2023	Young Lives vs Cancer focus group	Children and young people or their parents who are currently / have previously received Principal Treatment Centre treatment	5
15/12/2023	Be Seen Be Heard: Learning disability advocacy group	Young people and people with a learning disability	9
15/12/2023	1:1 interviews: The Royal Marsden staff	The Royal Marsden staff currently working in the PTC	1
15/12/2023	The Royal Marsden site visit: engagement with families	Children and young people/families with direct experience of the current service	4

15/12/2023	Community focus group: Surrey	Children and young people and families from protected characteristic groups without direct experience of cancer services - specifically children and young people in care	4
16/12/2023	Community focus group: Kent	Children and young people and families from protected characteristic groups without direct experience of cancer services - specifically people experiencing homelessness	11
17/12/2023	Community focus group: Medway	Children and young people and families from protected characteristic groups without direct experience of cancer services - specifically people experiencing homelessness	<i>Combined with number above</i>
18/12/2023	1:1 interviews: The Royal Marsden staff	The Royal Marsden staff currently working in the PTC	1
18/12/2023	1:1 Parent interview	Children and young people/families with direct experience of the current service	1

21.3 Appendix C: Questionnaire and easy read questionnaire

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

We are holding a public consultation about these changes. It launched on 26 September 2023 and will run for 12 weeks until 18 December 2023.

Have your say – fill in this questionnaire.

Please return your completed questionnaire in an envelope addressed to FREEPOST CHILDRENS CANCER CENTRE.

There is no need to buy a stamp – the postage is free.

NHS England (London and South East regions)

For more information, please visit our website:

<https://www.transformationpartnersinhealthandcare.nhs.uk/childrenscancercentre/>

You can also call our consultation phoneline (this is free to call) on 0800 135 7971 or email england.childrenscancercentre@nhs.net with questions.

If you or someone you know needs this consultation document in a different language, please contact us at england.childrenscancercentre@nhs.net

Dacă dumneavoastră sau cineva pe care îl cunoașteți aveți nevoie de acest document de consultare într-un alt format sau limbă, vă rugăm să ne contactați la england.childrenscancercentre@nhs.net

Si usted o alguien que conoce necesita este documento de consulta en un formato o idioma distinto, contáctenos en england.childrenscancercentre@nhs.net

Se você ou alguém que você conhece precisa deste documento de consulta num formato ou idioma diferente, entre em contato conosco através do england.childrenscancercentre@nhs.net

Jeśli Ty lub ktoś, kogo znasz, potrzebuje tego dokumentu konsultacyjnego w innym formacie lub języku, skontaktuj się z nami pod numerem england.childrenscancercentre@nhs.net

如果閣下或者任何人士需要另一種方式或者語言閱讀此諮詢文件，請電郵至
england.childrenscancercentre@nhs.net

यदि तपाईं वा तपाईंले चिन्ने व्यक्तिलाई यो परामर्श कागजात फरक ढाँचा वा भाषामा चाहिन्छ भने, कृपया हामीलाई [फोन नम्बर] वा england.childrenscancercentre@nhs.net मा सम्पर्क गर्नुहोस्।

உங்களுக்கோ அல்லது உங்களுக்குத் தெரிந்தவருக்கோ இந்த ஆலோசனை ஆவணம் வேறு வடிவத்தில் அல்லது மொழியில் தேவைப்பட்டால், எங்களை [தொலைபேசி எண்] அல்லது england.childrenscancercentre@nhs.net இல் தொடர்பு கொள்ளவும்.

Siz veya tanıdığınız birinin bu danışma belgesinin farklı bir formatta veya dilde olması gerekiyorsa, lütfen england.childrenscancercentre@nhs.net adresinden bizimle iletişime geçin.

As NHS England (London and South East regions), we are working with NHS and other partners on proposed changes to very specialist cancer treatment services for children who live in south London and much of south east England. These services are provided as part of the Principal Treatment Centre for children's cancer for Brighton and Hove, East Sussex, Kent, Medway, south London and most of Surrey.

[The change we are consulting on](#)

The current children's cancer centre is provided in partnership between The Royal Marsden NHS Foundation Trust and St George's University Hospitals NHS Foundation Trust. The service the Principal Treatment Centre provides is safe and high quality. The teams on the two sites work very hard to make sure children with cancer get safe, joined-up care.

But very specialist cancer treatment services for children, like those at The Royal Marsden, are now required to be on the same site as a children's intensive care unit that can give life support to the most unwell children. This is because children being treated for cancer are sometimes at risk of needing urgent intensive care. With future, cutting-edge treatments being developed for children with cancer, intensive care and other specialist children's services will increasingly be required to be on the same site.

As a specialist cancer hospital, The Royal Marsden does not have a children's intensive care unit. They 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.

Specialist cancer services for children currently provided at The Royal Marsden therefore need to move to a hospital which has a children's intensive care unit and other specialist children's services on site. It is a national clinical requirement.

- This consultation will help to answer the question: "Where should the proposed future children's cancer centre be?"
-

The options

We are consulting on two options for the future Principal Treatment Centre. Both already have a children's intensive care unit and other specialist children's services, which are rated outstanding. Under both options, all conventional 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.

The options we are consulting on are that the future centre is either:

- at Evelina London Children's Hospital, which is part of Guy's and St Thomas' NHS Foundation Trust, and is in Lambeth, south London, with conventional radiotherapy services at University College Hospital
or
- at St George's Hospital, which is part of St George's University Hospitals NHS Foundation Trust, and is in Tooting, south London, with conventional radiotherapy services at University College Hospital.

Under both options, children's cancer services would relocate from The Royal Marsden to the chosen site. Depending on the decision, some specialist children's cancer services currently provided by St George's Hospital might move too.

There will be no sudden changes to how children and young people receive care. The future children's cancer centre would not be ready until at least 2026. The move would be carefully planned with the full involvement of current teams and clear information for parents and families.

Our consultation

We are holding a public consultation about these changes. It launched on 26 September 2023 and will run for 12 weeks until 18 December 2023. Our website has lots of information about our proposals. This includes our consultation document and summary. There is also information aimed at children and young people.

To hear more, ask questions and share feedback, anyone can join one of our events on the following dates:

- Thursday 2 November
- Monday 20 November
- Monday 4 December



For consultation information, including to register for one of our events, please visit our website using the address below or scanning our QR code to the left.

www.transformationpartnersinhealthandcare.nhs.uk/childrencancercentre

You can also call our consultation phoneline (this is free to call) on **0800 135 7971** or email england.childrencancercentre@nhs.net

Have your say

Please tell us what you think about our proposals. We really want to know your thoughts about the good points and drawbacks of each option, as well as your ideas for making these proposed changes go smoothly. We also welcome your views, questions and any additional information you think we should know. A public consultation is not a vote or referendum. It is a chance to tell us what you think.

NHS England leaders who will take the decision will consider all the feedback and additional evidence that comes forward during the consultation, as well as other relevant information.

They will:

- decide which option is taken forward
- identify what, if any, improvements are needed to the proposed changes and/or find solutions for any concerns.

Please return your completed questionnaire in an envelope addressed to FREEPOST CHILDRENS CANCER CENTRE.

There is no need to buy a stamp – the postage is free.

We, NHS England (London and South East regions), want to make sure everyone has the chance to participate in this consultation. By completing the following section, you will help us to understand who we are reaching so that we can improve our engagement work.

Your answers will help us understand the impacts of our proposals to change the location of very specialist cancer treatment services for children who live in south London and much of south east England. These are part of the children’s cancer Principal Treatment Centre which is currently provided by The Royal Marsden NHS Foundation Trust and St George’s NHS University Hospitals NHS Foundation Trust. Although we would be grateful if you completed all of the questions, please skip any questions that make you feel uncomfortable, or that you feel don’t apply.

Please tick one option for each question. All responses will remain anonymous.

<p>1. A) Please tell us about you and tick one box.</p> <p>I am a...</p>	<p>A) Child or young person</p> <ul style="list-style-type: none"> <input type="checkbox"/> who is currently having treatment for cancer <input type="checkbox"/> who has previously been treated for cancer <input type="checkbox"/> who has never had cancer <p>B) Parent, carer or advocate for a child or young person</p> <ul style="list-style-type: none"> <input type="checkbox"/> who is currently having treatment for cancer <input type="checkbox"/> who has previously been treated for cancer <input type="checkbox"/> who has never had cancer <p>C) Sibling/ other relative or a friend of a child or young person</p> <ul style="list-style-type: none"> <input type="checkbox"/> who is currently having treatment for cancer <input type="checkbox"/> who has previously been treated for cancer <input type="checkbox"/> who has never had cancer <p>D) <input type="checkbox"/> Children’s cancer charity</p> <p>E) <input type="checkbox"/> Member of the public</p> <p>F) <input type="checkbox"/> Voluntary organisation</p> <p>G) Member of NHS staff</p> <ul style="list-style-type: none"> <input type="checkbox"/> who currently works for the Principal Treatment Centre at The Royal Marsden Hospital <input type="checkbox"/> who currently works for the Principal Treatment Centre at St. George’s Hospital <input type="checkbox"/> who currently works for Evelina London <input type="checkbox"/> who works for a Paediatric Oncology Shared Care Unit in London or the south east <input type="checkbox"/> who works for the Paediatric Operational Delivery Network
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	<p><input type="checkbox"/> who works for another part of the NHS (for example, other NHS trust, primary, community or mental health provider, commissioner of services etc)</p> <p><input type="checkbox"/> Other members of staff supporting children's services</p> <p>H) <input type="checkbox"/> Member of research organisation such as The Institute of Cancer Research</p> <p>I) <input type="checkbox"/> Other public body/stakeholder/political representative (please state)</p> <p><input type="text"/></p> <p><input type="text"/></p> <p>J) <input type="checkbox"/> Other (please state)</p> <p>K) <input type="checkbox"/> Prefer not to say</p>
<p>1. B) If you are responding on behalf of an organisation, which organisation do you represent? <i>Please give us the name of the organisation and any specific group or department.</i></p>	
<p>2. A) Please tell us where you live</p>	<p><input type="checkbox"/> Brighton and Hove</p> <p>East Sussex</p> <p><input type="checkbox"/> Eastbourne</p> <p><input type="checkbox"/> Hastings</p> <p><input type="checkbox"/> Lewes</p> <p><input type="checkbox"/> Rother</p> <p><input type="checkbox"/> Wealden</p> <p>Kent</p> <p><input type="checkbox"/> Ashford</p> <p><input type="checkbox"/> Canterbury</p> <p><input type="checkbox"/> Dartford</p> <p><input type="checkbox"/> Dover</p> <p><input type="checkbox"/> Gravesham</p> <p><input type="checkbox"/> Maidstone</p> <p><input type="checkbox"/> Sevenoaks</p>

- Shepway
- Swale
- Thanet
- Tonbridge and Malling
- Tunbridge Wells

Medway

South east London

- Bexley
- Bromley
- Greenwich
- Lambeth
- Lewisham
- Southwark

South west London

- Croydon
- Kingston
- Merton
- Sutton
- Richmond
- Wandsworth

Surrey

- Elmbridge
- Epsom and Ewell
- Guildford
- Mole Valley
- Reigate and Banstead
- Runnymede
- Spelthorne
- Surrey Heath
- Tandridge
- Waverley
- Woking

West Sussex

- Adur
- Arun

	<input type="checkbox"/> Chichester <input type="checkbox"/> Crawley <input type="checkbox"/> Horsham <input type="checkbox"/> Mid Sussex <input type="checkbox"/> Worthing <input type="checkbox"/> Somewhere else (please state) <div style="border: 1px solid black; height: 40px; width: 100%; margin-top: 5px;"></div>
<p>2. B) Please tell us the first part of your postcode: This will help us see where, geographically, we are getting responses from. We won't use it to identify where you live.</p>	

<p>3. If you are a parent or carer, has your child ever had cancer? If you are a young person, have you ever had cancer?</p>	<p>a. <input type="checkbox"/> Yes b. <input type="checkbox"/> No (if no, please move to Section 2)</p>
<p>4. Was part or all of that care at the Principal Treatment Centre at The Royal Marsden or St George's Hospital?</p>	<p>a. <input type="checkbox"/> Yes b. <input type="checkbox"/> No (if no, please move to Section 2)</p>
<p>5. How long ago did you, or the child you are connected to, have cancer care?</p>	<p>a. <input type="checkbox"/> Currently having cancer care b. <input type="checkbox"/> Had cancer care 1-2 years ago c. <input type="checkbox"/> Have not had cancer care in the last 2 years d. <input type="checkbox"/> First had care more than 2 years ago but now require cancer care again e. <input type="checkbox"/> Other (please state): <div style="border: 1px solid black; height: 40px; width: 100%; margin-top: 5px;"></div> </p>

Section 2: Our proposals

If you haven't done so already, we recommend reading our consultation document before completing the following section. This will help you understand why this change is needed (see pages 12-13 of the full document, 8-9 of the summary) and what the two options are (see pages 41-47 of the full document, 19-23 of the summary).

Often, children go to 'Paediatric Oncology Shared Care Units' as part of their cancer journey. These are hospitals that provide some cancer care for children with cancer and are usually more local to home. They are different to the Principal Treatment Centre and are not a part of this consultation.

6. In a future Principal Treatment Centre, what would you value most?	
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This might include things about:

- *the service itself*
- *children, young people and family experience*
- *things that help the service to run well*
- *research*

We have heard, through feedback from parents and carers, that travelling with sick children on public transport can at times be difficult, and that travel by car also can be challenging but for different reasons. We want to understand more about travel and access challenges to help us consider what additional support might be needed. People entitled to hospital transport would continue to receive this under these proposals. You can read more on our website about getting to the different hospital sites and what support is on offer.

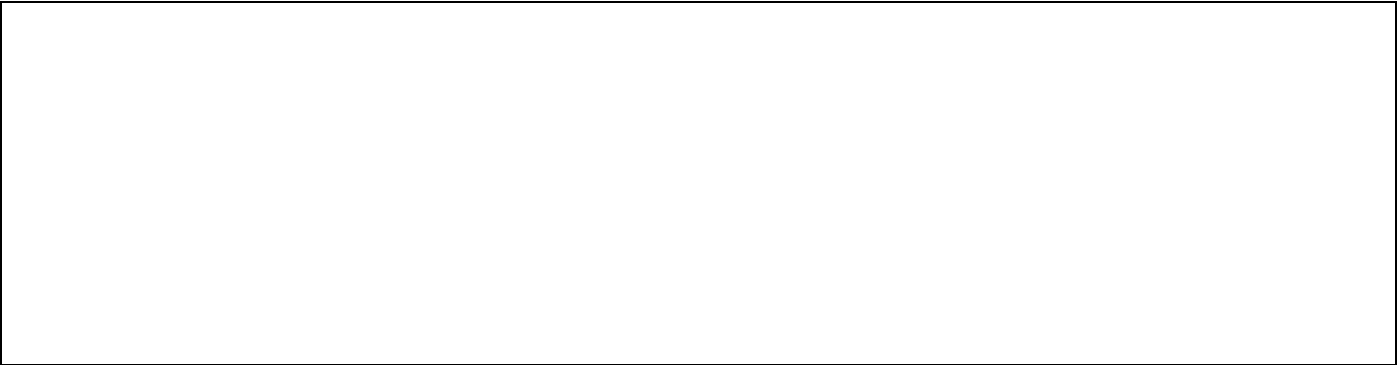
7. How important are the following aspects of your travel?

	Not at all important	Important	Very important
A. Parking availability on the hospital site			
B. Public transport availability in close proximity to the hospital site			
C. The ability to get help with parking and travel costs (such as Ultra Low Emission Zone and the London congestion charges)			
D. Public transport cost			
E. Family accommodation nearby so we don't have to travel as much			
F. Something else. Tell us more			

8. For staff or patients connected to the current Principal Treatment Centre service...

How important will it be to put in place the following types of support and information, to make the move easier?

	Not at all important	Important	Very important
A. Being reassured about when and how the move will happen.			
B. Additional support and information for those who need it, such as a dedicated point of contact during the move.			
C. Understanding which staff will still be involved in on-going care.			
D. Being able to see where the service will physically be located in the future.			
E. Having information about how to travel to the site safely.			
F. Having information about how to get help with travel.			
G. Understanding how any on-going research trials will be impacted.			
H. Being involved in how the new location looks and feels.			
I. Please tell us if other types of support or information might be needed, to make the change easier for staff and families.			



Thinking about Evelina London ...

<p>Having read about the option for the future children's cancer centre to be at Evelina London...</p> <p>9. Please share your views on the good points of this option (including anything we may have missed)</p>	
<p>10. Please share your views on potential challenges of this option (including those we may have missed)</p>	
<p>11. What suggestions do you have to improve the things you've identified as potential challenges?</p>	

Thinking about St George's Hospital...

<p>Having read about the option for the future children's cancer centre to be at St George's Hospital ...</p> <p>12. Please share your views on the good points of this option (including anything we may have missed)</p>	
<p>13. Please share your views on potential challenges of this option (including those we may have missed)</p>	
<p>14. What suggestions do you have to improve the things you've identified as potential challenges?</p>	

Other changes

<p>Under both options, conventional radiotherapy would move from The Royal Marsden to University College Hospital where it would be delivered as part of a larger service alongside proton beam and other radiotherapy services.</p>	
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15. Please tell us what you think about this part of our proposal, including the effect it might have

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

Section 3: Demographic information

If you are responding as an individual, please answer the questions below...

The NHS has a duty to promote equality in relation to age, gender, sexual orientation, disability, race, and religion and belief. We want to make sure that we include all parts of the community in our consultation, but these questions are optional. We will take all consultation responses fully into account when making decisions, regardless of whether you provide your personal details.

<p>17. How old are you?</p>	<p><input type="checkbox"/> Under 15 <input type="checkbox"/> 16-18 <input type="checkbox"/> 19-25 <input type="checkbox"/> 26-40 <input type="checkbox"/> 41-65 <input type="checkbox"/> 66-74 <input type="checkbox"/> 75 or over <input type="checkbox"/> Prefer not to say</p>
<p>18. What is your gender?</p>	<p><input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Transgender <input type="checkbox"/> Non-binary <input type="checkbox"/> Other <input type="checkbox"/> Prefer not to say</p>
<p>Is the gender you identify with the same as your sex registered at birth?</p> <p>Your gender identity is how you perceive yourself and how you refer to yourself. Your gender identity can be the same or different from the you sex registered at birth.</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Prefer not to say</p>
<p>19. Do you consider yourself to have a disability?</p> <p>The Equality Act 2010 defines disability as a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities.</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Prefer not to say</p> <p>If yes, please provide more information about your condition, if you wish to do so.</p> <div data-bbox="627 1525 1362 1827" style="border: 1px solid black; height: 135px; width: 100%;"></div>
<p>20. Which of the following best describes your sexual orientation?</p>	<p><input type="checkbox"/> Heterosexual <input type="checkbox"/> Straight <input type="checkbox"/> Gay <input type="checkbox"/> Lesbian <input type="checkbox"/> Bisexual <input type="checkbox"/> Other <input type="checkbox"/> Prefer not to say</p>
<p>21. What is your ethnic group?</p>	<p>White</p>

- Welsh English Scottish Northern Irish
 British Irish Gypsy or Irish Traveller

Any
other
White

background (please state)

Mixed

- White and Black Caribbean
 White and Black African White and Asian
 Any other mixed background (please state)

Asian

or Asian British

- Indian Pakistani Bangladeshi Chinese

Any
other
Asian

background (please state)

Black or Black British

- Caribbean African

Any
other
Black

background (please state)

**Other
ethnic
group**

(please state)

	<input type="checkbox"/> Prefer not to say
22. What is your religion or belief?	<input type="checkbox"/> No religion <input type="checkbox"/> Buddhist <input type="checkbox"/> Christian <input type="checkbox"/> Hindu <input type="checkbox"/> Jewish <input type="checkbox"/> Muslim <input type="checkbox"/> Sikh <input type="checkbox"/> Atheist <input type="checkbox"/> Agnostic <input type="checkbox"/> Any other religion (please state) <div style="border: 1px solid black; height: 40px; width: 100%;"></div> <div style="text-align: right;"><input type="checkbox"/></div> Prefer not to say
23. Do you or anyone in your household currently receive any of the following? (Please tick all that apply)	<input type="checkbox"/> Income Support <input type="checkbox"/> Jobseeker's Allowance <input type="checkbox"/> Employment and Support Allowance <input type="checkbox"/> Pension Credit Guarantee Credit <input type="checkbox"/> Universal Credit <input type="checkbox"/> Are named on, or entitled to, a valid NHS tax credit exemption certificate <input type="checkbox"/> I am not currently receiving benefits <input type="checkbox"/> Would prefer not to say
24. Which ONE of the following categories best describes the employment status of the main income earner in your household? (before retirement if now retired)	<input type="checkbox"/> Semi or unskilled manual worker (such as caretaker, non-HGV driver, shop assistant etc.) <input type="checkbox"/> Skilled manual worker (such as bricklayer, carpenter, plumber, HGV driver etc.) <input type="checkbox"/> Supervisory or clerical/ junior managerial/ professional/ administrative (such as office worker, student doctor, salesperson etc.) <input type="checkbox"/> Intermediate managerial/ professional/ administrative (such as foundation doctor, solicitor, board director of a small organisation, middle manager in large organisation etc.) <input type="checkbox"/> Higher managerial/ professional/ administrative (such as registrar or experienced doctor, solicitor, board director in a large organisation, top level civil servant etc.) <input type="checkbox"/> Student <input type="checkbox"/> Casual worker – not in permanent employment <input type="checkbox"/> House husband/ housewife/ homemaker <input type="checkbox"/> Unemployed or not working due to long-term sickness <input type="checkbox"/> Full-time carer of other household member <input type="checkbox"/> Would rather not say

Thank you for taking the time to complete this questionnaire. Once our consultation closes on 18 December 2023, all responses will be independently analysed by Explain Market Research. Views and feedback will be presented as part of the evidence and data to inform the decision on the location of the future Principal Treatment Centre for children with cancer in south London and much of south east England. We hope to make this decision in early 2024.

Please visit

<https://www.transformationpartnersinhealthandcare.nhs.uk/childrenscancercentre/> email us at england.childrenscancercentre@nhs.net or call us on 0800 135 7971 for more information about this programme and other ways to have your say.

If you would like to keep up to date with what is happening with this programme, or find out about other ways you can stay involved as the changes are implemented once a decision has been made on the location of the future children's cancer centre, please share your email address and we will be in touch.

We will not use your contact details for any other purposes.

Now please return your completed questionnaire in an envelope addressed to FREEPOST CHILDRENS CANCER CENTRE.

There is no need to buy a stamp – the postage is free.

Your response must reach us by midnight on 18 December 2023 – that is when the consultation closes.



Telling us what you think



Easy read questions



What our consultation is about

We are **NHS England**

We want people in **London** and the **South East** to take part in our **consultation**. A **consultation** is a way to find out what people think about a new plan.

We want to move most children's cancer services so more are in the same place, with intensive care. This will be the future **Principal Treatment Centre**

We want to give children with cancer the best care. Cancer services for children in other parts of London and the south east will not change or move.

You can read more about our plan in the **easy read summary**



How to answer

Please put a mark in the box or next to the answer that suits you best.

Some questions need longer answers. For these questions, we ask you to write in the box.

You can ask someone to give you support to answer the questions and fill out the form, if you want to.

You don't have to answer every question if you don't want to.

When you have finished, please put the filled in questionnaire in an envelope. Then write on the front FREEPOST CHILDRENS CANCER CENTRE and put it in a postbox. It won't need a stamp.

We will keep your answers private. No one will know who you are. Please only give the information we ask for— don't tell us other personal details.





Section 1: Questions about you

1. Why are you answering these questions/who are you?

Put a mark in the box that matches the best answer for you.

I am a child or young person	<input type="checkbox"/>
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I am a parent, carer or someone else that can speak out for a child	<input type="checkbox"/>
---	--------------------------

I work for a children's cancer charity	<input type="checkbox"/>
--	--------------------------

I am from the public	<input type="checkbox"/>
----------------------	--------------------------

I work in cancer care at one of the current sites	<input type="checkbox"/>
---	--------------------------

I work for the NHS	<input type="checkbox"/>
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I work in cancer research	<input type="checkbox"/>
---------------------------	--------------------------

I am a volunteer	<input type="checkbox"/>
------------------	--------------------------

Something else – please tell us where this is	<input type="text"/>
---	----------------------



**3. If you are a parent or carer, has your child ever had cancer?
If you are a young person, have you ever had cancer?**



Yes



No

4. Have you or your child had treatment at the Royal Marsden Hospital or St George's Hospital?



Yes



No



If you said yes to either of these, please go to question 5. If you said no, please go to **question 6** on the next page.

5. How long did you or your child have care for cancer?

We are having cancer care now

We had cancer care 12 years ago

We haven't had cancer care in the last 2 years

We had cancer care and now the cancer has come back

Something else



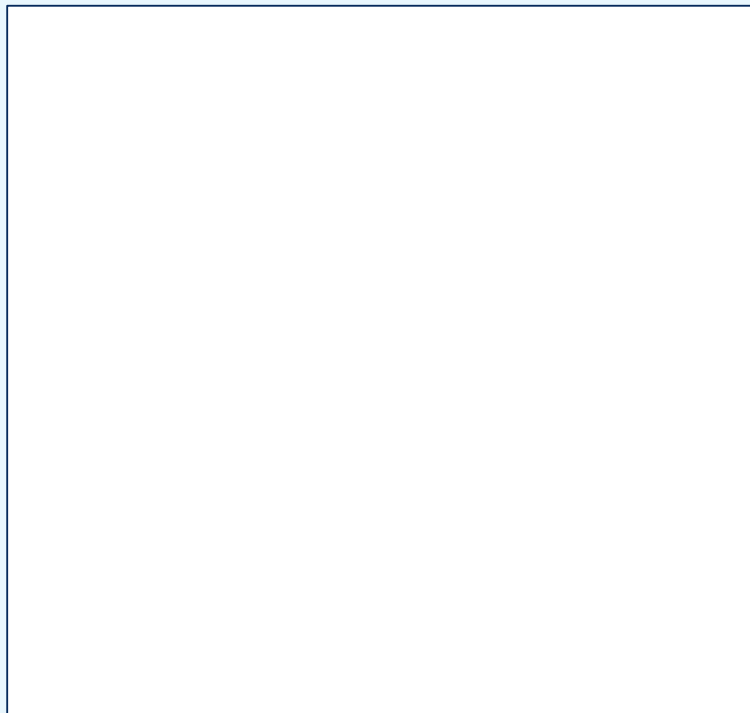
Section 2: Why we want to make changes

You can read about why we want to make changes in our **easy read booklet** This will help you understand more about our plans.

We need to change where the **Principal Treatment Centre** is. It needs to have intensive care on site.

We want to know what you think about how we will do this.

6. What matters to you most about a Principal Treatment Centre?Please write your answer in the box



Section 3: Questions about travel

We know a lot of people are worried about travelling with sick children.



We want to know what you think about moving to a new hospital site and what that means for you and your travel.

7. Please tell us how important travel will be if we move the site. Put a mark in the box that matches your answer. The higher the number the more important it is. 1 is not at all important, 3 is neither important nor unimportant, and 5 is very important.

A) I think parking on the site will be..



1

NOT AT ALL
IMPORTANT

2



3

NEITHER
IMPORTANT NOR
UNIMPORTANT

4



5

VERY
IMPORTANT

DON'T
KNOW /
NOT SURE

B) I think having public transport close to the site will be..



1

NOT AT ALL
IMPORTANT

2



3

NEITHER
IMPORTANT NOR
UNIMPORTANT

4



5

VERY
IMPORTANT

DON'T
KNOW /
NOT SURE



Questions about travel

C) I think getting help with parking and travel charges will be..



1

NOT AT ALL
IMPORTANT

2



3

NEITHER
IMPORTANT NOR
UNIMPORTANT

4



5

VERY
IMPORTANT

DON'T
KNOW /
NOT SURE

D) I think the cost to travel by public transport will be..



1

NOT AT ALL
IMPORTANT

2



3

NEITHER
IMPORTANT NOR
UNIMPORTANT

4



5

VERY
IMPORTANT

DON'T
KNOW /
NOT SURE



Questions about travel

E) I think having somewhere to stay nearby for my family will be..



1

2

3

4

5

NOT AT ALL
IMPORTANT

NEITHER
IMPORTANT NOR
UNIMPORTANT

VERY
IMPORTANT

DON'T
KNOW /
NOT SURE

F) Something else – please write your answer in the box






Section 4: Questions for patients , families and staff

These questions are for patients, families and staff who use or work for the **Principal Treatment Service** now.




8. Please tell us how important it will be to have support and information that makes it easier to move.

Put a mark in the box that matches your answer. The higher the number the more important it is. 1 is not at all important, 3 is neither important nor unimportant, and 5 is very important.

A) Being made to feel safe and OK about when the changes will happen is..

					
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1	2	3	4	5	DON'T KNOW / NOT SURE
NOT AT ALL IMPORTANT		NEITHER IMPORTANT NOR UNIMPORTANT		VERY IMPORTANT	




B) Getting support and information I/we need about the changes is..

					
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1	2	3	4	5	DON'T KNOW / NOT SURE
NOT AT ALL IMPORTANT		NEITHER IMPORTANT NOR UNIMPORTANT		VERY IMPORTANT	






Questions for patients , families and staff




C) Knowing which staff will move to the new treatment centre is..

					
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1	2	3	4	5	DON'T KNOW / NOT SURE
NOT AT ALL IMPORTANT		NEITHER IMPORTANT NOR UNIMPORTANT		VERY IMPORTANT	

D) Being able to see where the new treatment centre will be is..

					
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1	2	3	4	5	DON'T KNOW / NOT SURE
NOT AT ALL IMPORTANT		NEITHER IMPORTANT NOR UNIMPORTANT		VERY IMPORTANT	

E) Having information about how to get to the new site safely is..

					
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
1	2	3	4	5	DON'T KNOW / NOT SURE
NOT AT ALL IMPORTANT		NEITHER IMPORTANT NOR UNIMPORTANT		VERY IMPORTANT	



Questions for patients, families and staff

F) Being a part of how the new site looks and feels is..



1

NOT AT ALL
IMPORTANT

2



3

NEITHER
IMPORTANT NOR
UNIMPORTANT

4



5

VERY
IMPORTANT

DON'T
KNOW /
NOT SURE

G) Knowing more about any changes to research trials during the move is..



1

NOT AT ALL
IMPORTANT

2



3

NEITHER
IMPORTANT NOR
UNIMPORTANT

4



5

VERY
IMPORTANT

DON'T
KNOW /
NOT SURE

H) Having information to help with my travel is..



1

NOT AT ALL
IMPORTANT

2



3

NEITHER
IMPORTANT NOR
UNIMPORTANT

4



5

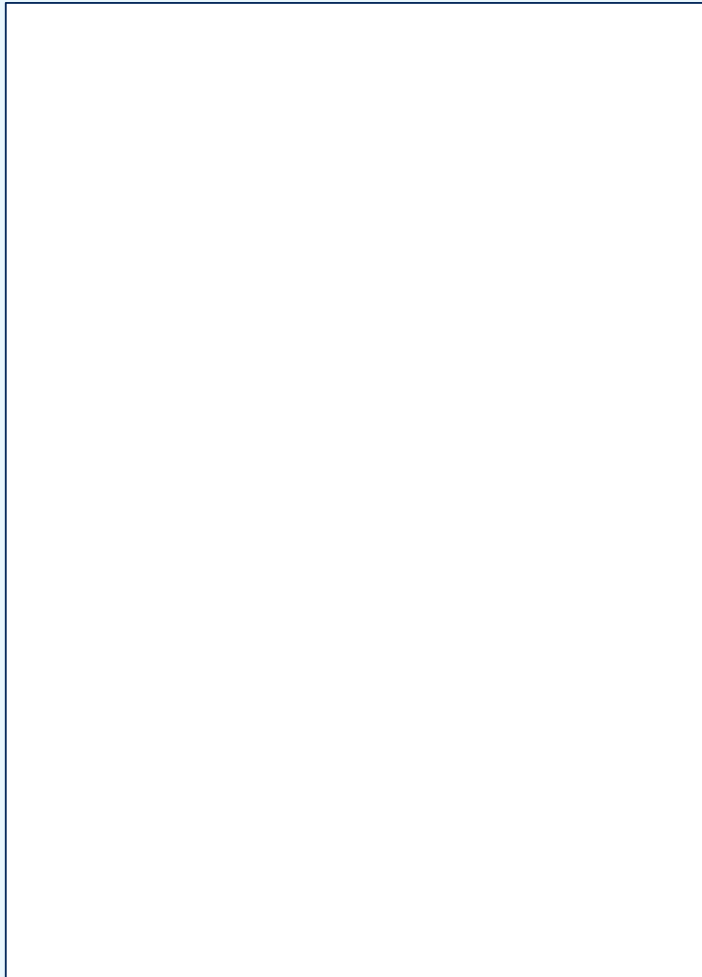
VERY
IMPORTANT

DON'T
KNOW /
NOT SURE



Questions for patients , families and staff

9. Please tell us about anything else you might need to get support for you or your family.
Write your answer in the box



Section 5: Thinking about Evelina London

This option means that services would move to Evelina London. Treatments using X-rays for children with cancer would move to University College Hospital.

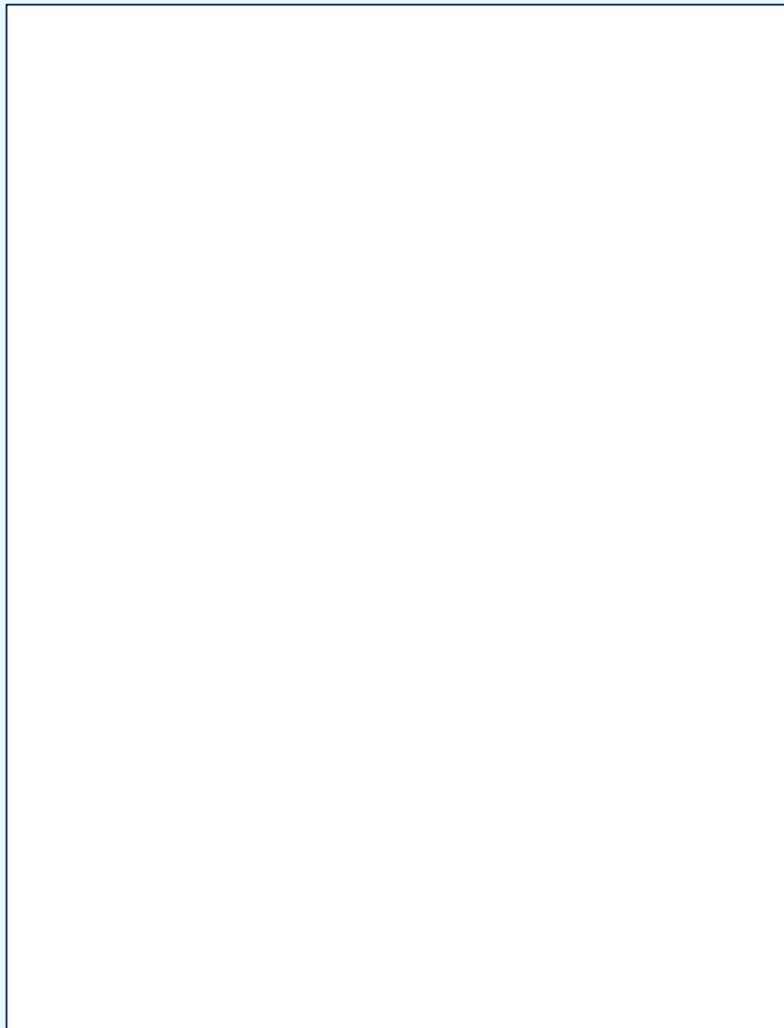
10. Please tell us what you think the good things are about this option. Write your answer in the box

11. Please tell us the not so good things about this option. Write your answer in the box



Thinking about Evelina London

12. If services moved here, is there anything else we could do to make the move better for you? Write your answer in the box



Section 6: Thinking about St George's Hospital

This option means that services would move to St George's Hospital. Treatments using Xrays for children with cancer would move to University College Hospital.

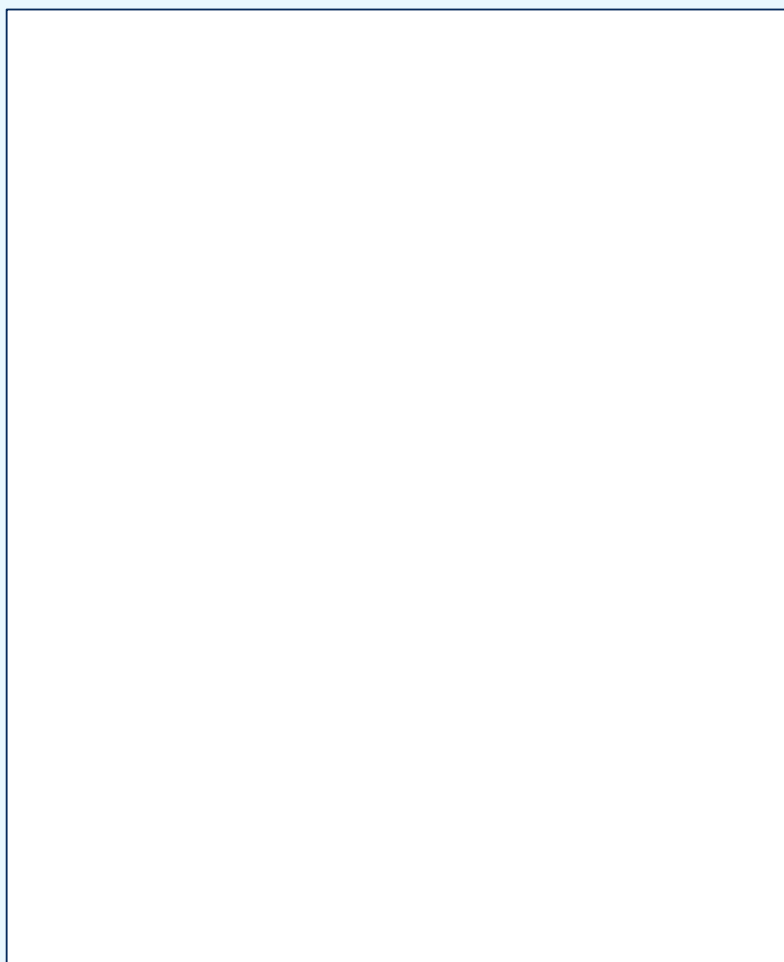
13. Please tell us what you think the good things are about this option. Write your answer in the box

14. Please tell us the not so good things about this option. Write your answer in the box



Thinking about St George's Hospital

15. If services moved here, is there anything else we could do to make the move better for you? Write your answer in the box



Section 7: Thinking about moving site

16. We would need to move treatments using x-rays for children with cancer from The Royal Marsden to University College Hospital. What do you think about this plan? Please write your answer in the box



17. Is there anything else you want to tell us?

Please write your thoughts or ideas in the box



Questions about you

18. Please tell us how old you are

I am 15 years old or under

I am 16-18 years old

I am 19-25 years old

I am 26-40 years old

I am 41-65 years old

I am 66-74 years old

I am 75 years old or over



Questions about you



19. Please tell us your gender– put a mark in the box that is right for you

MALE

FEMALE

TRANS
GENDER

NON-BINARY

I DON'T WANT TO SAY

20. Is your gender the same as when you were born?

YES

NO

I DON'T WANT TO SAY

21. Do you have a disability?– please tell us in the box



Questions about you



22. Please tell us your sexuality

HETEROSEXUAL

LESBIAN

GAY

BISEXUAL

DON'T WANT TO SAY

SOMETHING ELSE



Questions about you



23. What is your ethnic group? This means your culture or race Please put a mark in the box that matches your answer

WHITE

BLACK

MIXED

ASIAN

OTHER

Please tell us more in the box if you want to



Questions about you



24. What is your religion or belief? Please put a mark in the box that matches your answer

NO RELIGION

ATHEIST OR AGNOSTIC

BUDDHIST

CHRISTIAN

HINDU

JEWISH

MUSLIM

SIKH



Questions about you



25. Please tell us how people earn money in your house– they might be working, get benefits or something else.

Write your answer in the box

26. Please tell us about the job the main person who earns money in your house does.

Write your answer in the box



Thank you!



Thank you for filling out your answers.

We will look at all the information and use what you have told us to help us make the best decision.

We think we will decide where the centre will be moved to in early 2024. You can go to this website for more information:

<https://www.transformationpartners.nhs.uk/childrenscancercentre/>

If you want to stay in touch, please write your email in the box. We will let you know how you can get updates and be involved with us.

Now please put this filled-in questionnaire in an envelope and write on the front FREEPOST CHILDRENS CANCER CENTRE. Then put it in a postbox. It won't need a stamp.



21.4 Appendix D – Easy read respondent profiling

The tables below cover the demographic breakdown for the easy read questionnaire. To note the full list of demographic questions asked in the easy read questionnaire were not as comprehensive as those asked in the main questionnaire.

Demographic	Percentage	Count
Gender		
Male	30%	13
Female	70%	31
Transgender	0%	0
Non-binary	0%	0
Other	0%	0
Prefer not to say	0%	0
Sexuality		
Heterosexual/straight	0%	0
Bisexual	0%	0
Gay	0%	0
Lesbian	0%	0
Other	0%	0
Prefer not to say	100%	10
Disability		
Yes – disability	8%	4
No – disability	48%	23
Prefer not to say	44%	21
Age		
Under 15	2%	1
16-18	0%	0
19-25	4%	2
26-40	17%	8
41-65	53%	25
66-74	15%	7
75 or over	9%	4
Prefer not to say	0%	0

Table 2 Demographic Breakdown for Easy Read Questionnaire



Demographic	Percentage	Count
Ethnicity		
White	56%	27
Black	2%	1
Mixed	4%	2
Asian	17%	8
Other	6%	3
Prefer not to say	15%	7
Religion		
Christian	45%	21
No religion	26%	12
Muslim	0%	0
Hindu	9%	4
Atheist or agnostic	4%	2
Jewish	0%	0
Buddhist	0%	0
Sikh	0%	0
Prefer not to say	17%	8

Table 3 Demographic Breakdown for Easy Read Questionnaire

Stakeholder group	Percentage	Count
I am a child or young person	5%	2
I am a parent, carer or someone else that can speak out for a child	25%	11
I work for a children's cancer charity	0%	0
I am from the public	25%	11
I work in cancer care at one of the current sites	7%	3
I work for the NHS	30%	13
I work in cancer research	2%	1
I am a volunteer	5%	2
Something else	0%	0
Unknown	2%	1

Table 4 Demographic Breakdown for Easy Read Questionnaire



21.5 Appendix E – Main questionnaire respondent profiling

The table below gives a breakdown of respondents by stakeholder group as well as grouping stakeholders to align with those used in the stakeholder findings chapters.

Demographic	Percentage	Count
Stakeholder group – full list		
Member of the public	16.46%	283
Member of NHS staff - who works for another part of the NHS	12.45%	214
Parent, carer or advocate for a child or young person - who has never had cancer	11.75%	202
Member of NHS staff - who currently works for the Principal Treatment Centre at St George's Hospital	11.69%	201
Member of NHS staff - who currently works for Evelina London	8.67%	149
Member of NHS staff - who currently works for the Principal Treatment Centre at The Royal Marsden Hospital	6.86%	118
Parent, carer or advocate for a child or young person - who has previously been treated for cancer	5.64%	97
Member of NHS staff - other members of staff supporting children's services	4.89%	84
Parent, carer or advocate for a child or young person - who is currently having treatment for cancer	3.49%	60
Member of NHS staff - who works for a Paediatric Oncology Shared Care Unit in London or the south east	2.56%	44
Sibling/other relative or a friend of a child or young person - who has previously been treated for cancer	1.92%	33
Other public body/stakeholder/political representative	1.28%	22
Child or young person - who has previously been treated for cancer	0.87%	15
Voluntary organisation	0.76%	13
Child or young person - who has never had cancer	0.70%	12
Sibling/other relative or a friend of a child or young person - who has never had cancer	0.64%	11
Child or young person - who is currently having treatment for cancer	0.52%	9
Member of research organisation such as The Institute of Cancer Research	0.41%	7
Member of NHS staff - who work for the Paediatric Operational Delivery Network	0.41%	7



Children's cancer charity	0.35%	6
Sibling/other relative or a friend of a child or young person - who is currently having treatment for cancer	0.35%	6
Other - please provide details below	4.19%	72
Prefer not to say	3.96%	68
Stakeholders grouped		
Children & young people who have been affected by cancer	1.40%	24
Family members and advocates of children and young people who have been affected by cancer	11.40%	196
Children, young people and families with no experience of using cancer services	13.09%	225
Affected clinical and non-clinical staff	27.17%	467
Other clinical and non-clinical staff	20.19%	347
Members of the public	16.46%	283
Organisations and public representatives	2.79%	48
Other	4.19%	72
Prefer not to say	3.96%	68

The below tables gives a breakdown of the respondents by demographic. The first table includes sex and gender, sexuality, disability and age. The second table breaks respondents down by geography. The third table shows NET ethnicity and socio-economic segmentation.

Demographic	Percentage	Count
Sex and Gender		
Male	26.88%	462
Female	66.78%	1148
Transgender	0.29%	5
Non-binary	0.12%	2
Other	0.12%	2
Prefer not to say	5.82%	100
Sexuality		
Heterosexual/straight	84.29%	1449
Bisexual	1.34%	23
Gay	1.40%	24
Lesbian	0.87%	15
Other	0.47%	8
Prefer not to say	11.63%	200
Disability		
Yes – disability	7.10%	122
No – disability	84.76%	1457



Prefer not to say	8.14%	140
Age		
Under 15	0.12%	2
16-18	0.35%	6
19-25	2.56%	44
26-40	28.45%	489
41-65	53.17%	914
66-74	7.04%	121
75 or over	3.37%	58
Prefer not to say	4.94%	85

Demographic	Percentage	Count
Geography		
Brighton and Hove	0.87%	15
East Sussex	1.11%	19
West Sussex	2.04%	35
Kent	5.53%	95
Medway	0.87%	15
South east London	15.47%	266
South west London	45.84%	788
Surrey	15.13%	260
Somewhere else	11.05%	190
Unknown	2.09%	36

Table 5 Demographic Breakdown for Main Questionnaire

Demographic	Percentage	Count
NET Ethnicity		
NET White	65.62%	1128
NET Ethnic minority groups (not including white minority groups)	18.09%	311
Other	7.16%	123
Prefer not to say	9.13%	157
Socio-economic group		
SEG ABC1 ⁵³	77.25%	1328
SEG C2DE ⁵⁴	7.45%	128

⁵³ Socio-economic groups AB (Higher and intermediate managerial/administrative/professional occupations) and C1 (Supervisory, clerical and junior managerial/administrative/professional occupations).

⁵⁴ Socio-economic groups C2 (Skilled manual occupations) and DE (Semi-skilled and unskilled manual occupations; unemployed and lowest grade occupations).



Would rather not say	15.3%	263
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Table 6 Demographic Breakdown for Main Questionnaire

The table below details the breakdown of main questionnaire responses by occupation, socio-economic group, and additional income support.

Demographic	Percentage	Count
Occupation		
Higher managerial/ professional/ administrative	35.19%	605
Intermediate managerial/ professional/ administrative	28.04%	482
Supervisory or clerical/ junior managerial/ professional/ administrative	14.02%	241
Skilled manual worker	2.62%	45
Semi or unskilled manual worker	1.16%	20
House husband/ housewife/ homemaker	1.11%	19
Student	0.7%	12
Full-time carer of other household member	0.7%	12
Unemployed or not working due to long-term sickness	0.64%	11
Casual worker - not in permanent employment	0.52	9
Would rather not say	15.3%	263
Socio-economic group		
SEG ABC1 ⁵⁵	77.25%	1328

⁵⁵ Socio-economic groups AB (Higher and intermediate managerial/administrative/professional occupations) and C1 (Supervisory, clerical and junior managerial/administrative/professional occupations).



SEG C2DE ⁵⁶	7.45%	128
Would rather not say	15.3%	263
Additional income support		
I am not currently receiving benefits	81.59%	1161
Universal Credit	3.51%	50
Pension Credit Guarantee Credit	0.91%	13
Employment and Support Allowance	0.84%	12
Are named on, or entitled to, a valid NHS tax credit exemption certificate	0.77%	11
Jobseeker's Allowance	0.42%	6
Income Support	0.28%	4
Would rather not say	12.58%	179

Table 7 Demographic Breakdown for Main Questionnaire

Demographic	Percentage	Count
Ethnicity		
White - English	41.42%	712
White - British	12.91%	222
Asian or Asian British - Indian	5.24%	90
White - Any other white background	3.61%	62
White - Irish	3.14%	54
Black or Black British - African	2.73%	47
Mixed - White and Asian	2.09%	36
White - Welsh	1.98%	34
White - Scottish	1.92%	33
Black or Black British - Caribbean	1.57%	27
Asian or Asian British - Any other Asian background	2.04%	35
Asian or Asian British - Pakistani	1.11%	19
Asian or Asian British - Chinese	1.11%	19

⁵⁶ Socio-economic groups C2 (Skilled manual occupations) and DE (Semi-skilled and unskilled manual occupations; unemployed and lowest grade occupations).



Mixed - White and Black Caribbean	0.76%	13
Mixed - White and Black African	0.52%	9
Asian or Asian British - Bangladeshi	0.41%	7
White - Northern Irish	0.35%	6
Mixed - any other mixed background	0.47%	8
White - Gypsy or Irish Traveller	0.29%	5
Any other Black background	0	0
Other	7.16%	123
Prefer not to say	9.13%	157
Religion		
Christian	45.26%	778
No religion	28.91%	497
Muslim	3.96%	68
Hindu	3.43%	59
Atheist	2.85%	49
Agnostic	1.40%	24
Buddhist	0.93%	16
Jewish	0.81%	14
Sikh	0.17%	3
Other	0.99%	17
Prefer not to say	11.29%	194

Table 8 Demographic Breakdown for Main Questionnaire

21.5.1 Respondents profile by stakeholder group

	Children & young people (affected)	Family members, advocates (affected)	Children and families (non-cancer connection)	Clinical and non-clinical staff (affected)	Clinical and non-clinical staff (not affected) ⁵⁷	Members of the public	Organisations and public representatives
Age							
Under 15	0%	0.51%	0.44%	0%	0%	0%	0%
16-18	8.33%	0%	1.78%	0%	0%	0%	0%
19-25	8.33%	1.02%	1.33%	3.64%	3.46%	2.12%	0%
26-40	33.33%	23.47%	31.56%	38.97%	32.85%	14.84%	22.92%

⁵⁷ Non affected staff includes any NHS member of staff not working at the Principal Treatment Centre at The Royal Marsden or St George's as well as the Evelina London.



41-65 ⁵⁸	45.83%	64.80%	58.22%	53.10%	55.91%	43.82%	33.33%
66-74	4.17%	4.08%	3.11%	0.64%	3.46%	21.91%	20.83%
75 or over	0%	1.53%	1.33%	0%	0.29%	11.31%	2.08%
Prefer not to say	0%	4.59%	2.22%	3.64%	4.03%	6.01%	20.83%
Sex and Gender							
Male	25.00%	22.96%	24.00%	23.55%	28.53%	33.22%	33.33%
Female	70.83%	70.41%	73.33%	70.88%	64.84%	61.48%	47.92%
Transgender	0%	0.51%	0%	0.21%	0%	0.71%	0%
Non-binary	0%	0%	0%	0%	0.29%	0.35%	0%
Other	0%	0.51%	0%	0%	0.29%	0%	0%
Prefer not to say	4.17%	5.61%	2.67%	5.35%	6.05%	4.24%	18.75%
Disability							
Yes	12.50%	7.65%	8.00%	3.21%	6.05%	9.54%	8.33%
No	87.50%	85.20%	83.56%	91.86%	86.46%	80.21%	68.75%
Prefer not to say	0%	7.14%	8.44%	4.93%	7.49%	10.25%	22.92%
Other	0%	0%	0.44%	0.43%	0.29%	0.35%	4.17%
Prefer not to say	8.33%	10.71%	7.56%	10.06%	12.68%	14.13%	18.75%

⁵⁸ It is important to highlight the number of respondents who classified themselves as children or young people, yet selected age ranges which would not apply to this stakeholder type. These respondents were either parents responding on behalf of their child or young people who have previously been affected by cancer when they were a child. One cause of this is there was no category available for someone who is not a child but has been affected by cancer whether previously having treatment at the Principal Treatment Centre at The Royal Marsden and St. George's or somewhere else.



	Children & young people (affected)	Family members, advocates (affected)	Children and families (non-cancer connection)	Clinical and non-clinical staff (affected)	Clinical and non-clinical staff (not affected)	Members of the public	Organisations and public representatives
NET Ethnicity							
NET White	79.17%	81.63%	61.78%	65.31%	56.77%	67.14%	68.75%
NET Ethnic minority groups (not including white minority groups)	16.67%	9.18%	18.67%	18.42%	21.04%	15.55%	8.33%
Other	0%	2.55%	12.44%	7.49%	12.68%	8.13%	2.08%
Prefer not to say	4.17%	6.63%	7.11%	8.78%	9.51%	9.19%	20.83%
Socio-economic group							
SEG ABC1	54.17%	71.94%	80.44%	83.94%	83.29%	70.32%	72.92%
SEG C2DE	25.00%	13.78%	8.00%	3.64%	3.17%	9.89%	0%
Would rather not say	20.83%	14.29%	11.56%	12.42%	13.54%	19.79%	27.08%
Additional income							
Income Support	0%	0.61%	1.04%	0.26%	0%	0%	0%
Jobseeker's Allowance	0%	0%	1.55%	0.26%	0%	0.42%	0%
Employment and Support Allowance	0%	3.07%	0.52%	0.26%	0.35%	1.69%	0%
Pension Credit Guarantee Credit	0%	1.23%	0.52%	0.26%	0%	2.53%	6.25%
Universal Credit	23.81%	9.20%	3.11%	1.31%	1.05%	4.64%	0%
Named on, or entitled to, a valid NHS tax credit exemption certificate	0%	2.45%	0.52%	0.52%	0.70%	0.42%	0%
Not currently receiving benefits	57.14%	73.62%	81.35%	89.79%	86.01%	74.26%	71.88%
Would rather not say	19.05%	11.66%	12.95%	8.38%	11.89%	17.30%	21.88%



	Children & young people (affected)	Family members, advocates (affected)	Children and families (with no experience of cancer services)	Clinical and non-clinical staff (affected)	Clinical and non-clinical staff (not affected)	Members of the public	Organisations and public representatives
ICB Region							
NHS South West London ICB	25.00%	33.16%	54.22%	45.18%	42.07%	57.95%	45.83%
NHS South East London ICB	12.50%	10.71%	14.67%	17.56%	17.29%	13.07%	18.75%
NHS Surrey Heartlands ICB	16.67%	18.88%	16.89%	16.49%	15.27%	11.66%	10.42%
NHS Sussex ICB	8.33%	11.22%	4.44%	1.71%	3.75%	3.53%	2.08%
NHS Kent and Medway ICB	25.00%	18.37%	4.89%	2.78%	7.20%	4.24%	2.08%
Somewhere else	12.50%	6.12%	4.44%	13.92%	12.39%	7.77%	18.75%
Unknown	0%	1.53%	0.44%	2.36%	2.02%	1.77%	2.08%

	Children & young people (affected)	Family members, advocates (affected)	Children and families (with no experience of cancer services)	Clinical and non-clinical staff (affected)	Clinical and non-clinical staff (not affected)	Members of the public	Organisations and public representatives
Religion							
No religion	25.00%	36.73%	32.44%	29.76%	25.65%	27.21%	22.92%
Buddhist	0%	0.51%	0%	0.43%	2.31%	1.41%	2.08%
Christian	37.50%	48.47%	41.78%	43.90%	42.07%	51.24%	41.67%
Hindu	4.17%	0.51%	3.56%	3.43%	4.90%	3.18%	2.08%
Jewish	0%	0.51%	0%	1.50%	0.86%	0.35%	4.17%
Muslim	16.67%	1.53%	8.00%	2.57%	5.19%	2.83%	0%
Sikh	0%	0%	0.44%	0%	0%	0.71%	0%
Atheist	0%	1.02%	4.00%	3.21%	3.75%	3.53%	0%
Agnostic	8.33%	0.51%	0.44%	1.28%	1.44%	1.41%	6.25%
Other	0%	0.51%	0%	1.71%	1.44%	0.71%	0%



Prefer not to say	8.33%	9.69%	9.33%	12.21%	12.39%	7.42%	20.83%
Sexuality							
Heterosexual/straight	87.50%	86.22%	89.33%	85.01%	81.27%	83.39%	77.08%
Bisexual	0%	1.02%	1.33%	1.93%	1.73%	1.06%	0%
Gay	4.17%	1.02%	0.44%	1.71%	2.88%	0.35%	0%
Lesbian	0%	1.02%	0.89%	0.86%	1.15%	0.71%	0%
Other	0%	0%	0.44%	0.43%	0.29%	0.35%	4.17%
Prefer not to say	8.33%	10.71%	7.56%	10.06%	12.68%	14.13%	18.75%

Table 9 Demographic Breakdown for Main Questionnaire



21.6 Appendix F – respondent profile for qualitative engagement work

Demographic	Count
Age	
Under 15	148
16-18	31
19-25	18
26-40	31
41-65	68
66-74	0
75 and above	3
Prefer not to say	3
Gender	
Male	103
Female	143
Prefer not to say	1
Ethnicity grouped	
NET White	192
NET Ethnic minority groups (excluding white minorities)	111
Prefer not to say/not captured	12
ICB Region	
South West London	31
South East London	27
Sussex	55
Surrey	39
Kent and Medway	48
Somewhere else	47

Table 10 Demographic Breakdown for Qualitative Research



Demographic	Count
Stakeholder group	
Child or young person who is currently or previously been treated for cancer	51
Family members, carers for children who are currently or previously been treated for cancer	101
Children and families with no experience of cancer services	97
Affected clinical and non-clinical staff ⁵⁹	87
Other clinical and non-clinical staff	239
Members of the public	6
Organisations and public representatives	147
Disability	
Yes	45
No	0
Sexuality	
Heterosexual	41
Bisexual	2
Gay/Lesbian	0
Prefer not to say	54
SEG	
ABC1	56
C2DE	9
Prefer not to say	4
Additional income support	
Receiving additional income	35
Not currently in receipt of benefits	17
Prefer not to say	2
Religion	
Christian	52
No Religion	68
Muslim	1
Hindu	3
Sikh	2
Atheist	0
Buddhist	0
Jewish	0
Prefer not to say	3

Table 11 Demographic Breakdown for Qualitative Research

⁵⁹ Staff currently working for the Principal Treatment Centre at The Royal Marsden or St George's Hospital, and staff working at the Evelina London.



Demographic	Count
Stakeholder group	
Child or young person who is currently or previously have been treated for cancer	51
Family members, carers for children who are currently or previously have been treated for cancer	101
Children and families with no experience of cancer services	97
Affected clinical and non-clinical staff ⁶⁰	87
Other clinical and non-clinical staff	239
Members of the public	6
Organisations and public representatives	147
Disability	
Yes	45
No	0
Sexuality	
Heterosexual	41
Bisexual	2
Gay/Lesbian	0
Prefer not to say	54
SEG	
ABC1	56
C2DE	9
Prefer not to say	4
Additional income support	
Receiving additional income	35
Not currently in receipt of benefits	17
Prefer not to say	2
Religion	
Christian	52
No Religion	68
Muslim	1
Hindu	3
Sikh	2
Atheist	0
Buddhist	0
Jewish	0
Prefer not to say	3

Table 12 Demographic Breakdown for Qualitative Research

⁶⁰ Staff currently working for the Principal Treatment Centre at The Royal Marsden or St George's Hospital, and staff working at the Evelina London.





21.7 Appendix G: Key findings overall charts

21.7.1 Future Principal Treatment centre

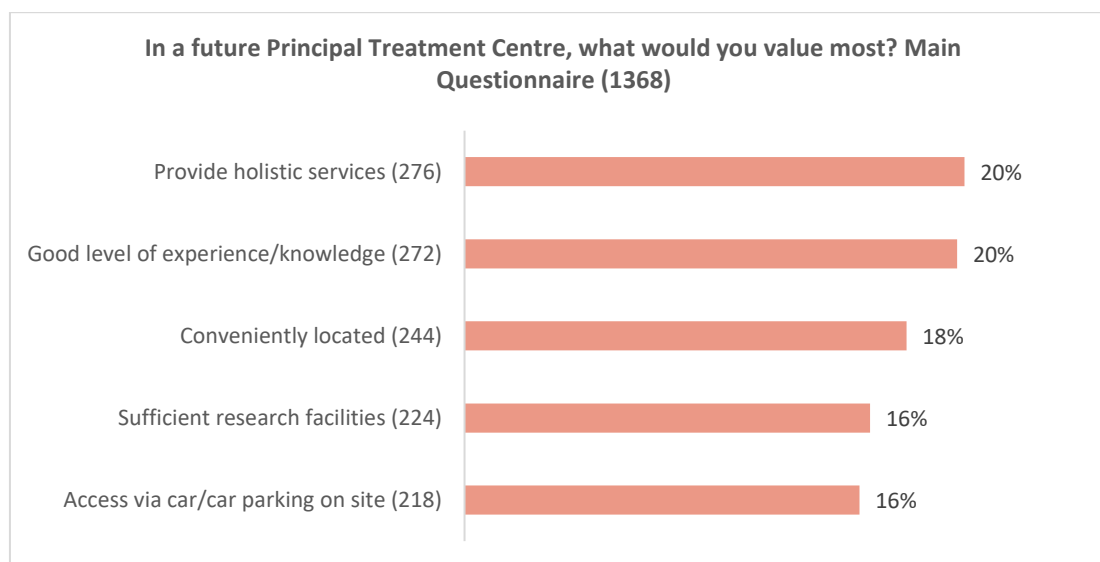


Figure 96 Future Principal Treatment Centre, Most Valued (Main Questionnaire)

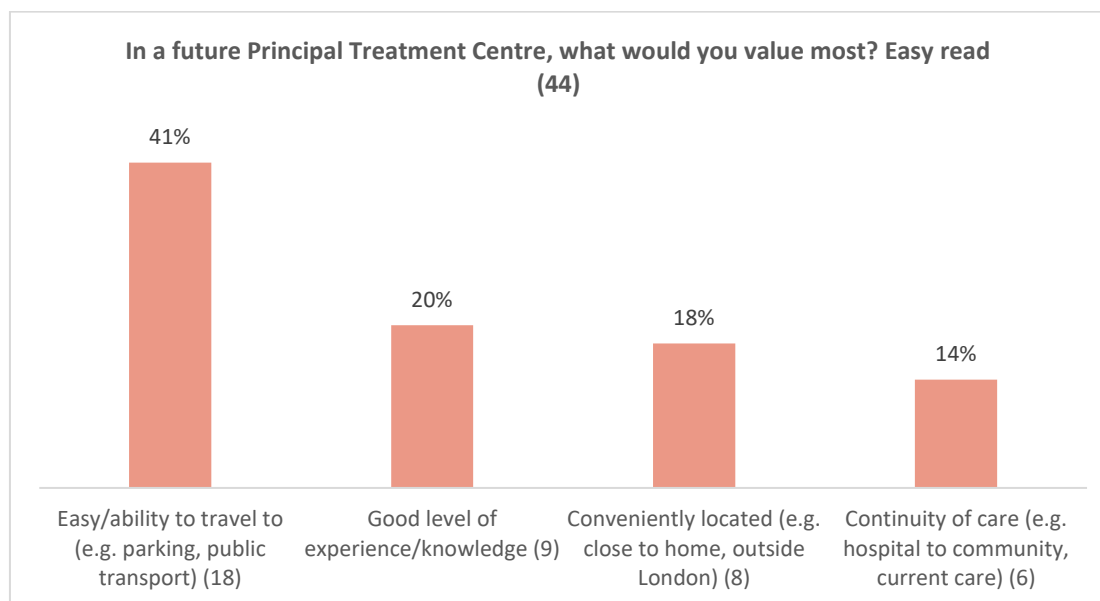


Figure 97 Future Principal Treatment Centre Most Valued (Easy Read)

21.7.2 Travel and access



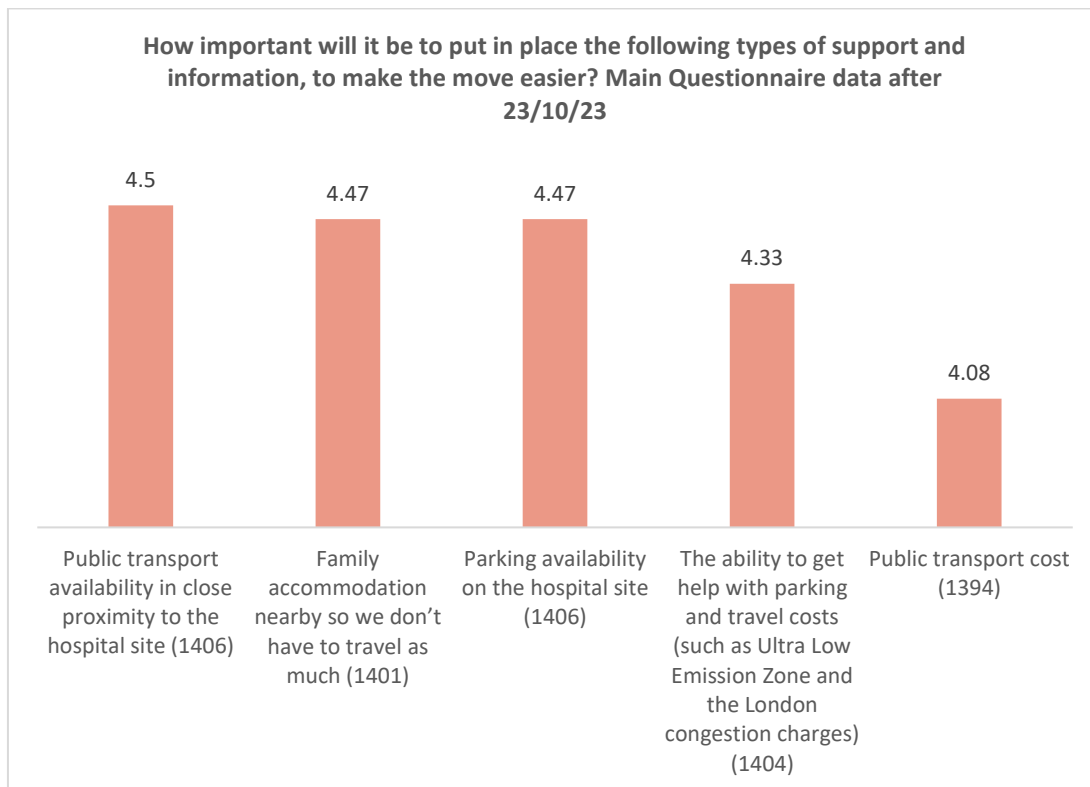


Figure 98 Accessibility for Families, Support and Information needed (main questionnaire after 23/10/23)





Figure 99 Accessibility for Families, Important travel information (easy read questionnaire after 23/10/23)

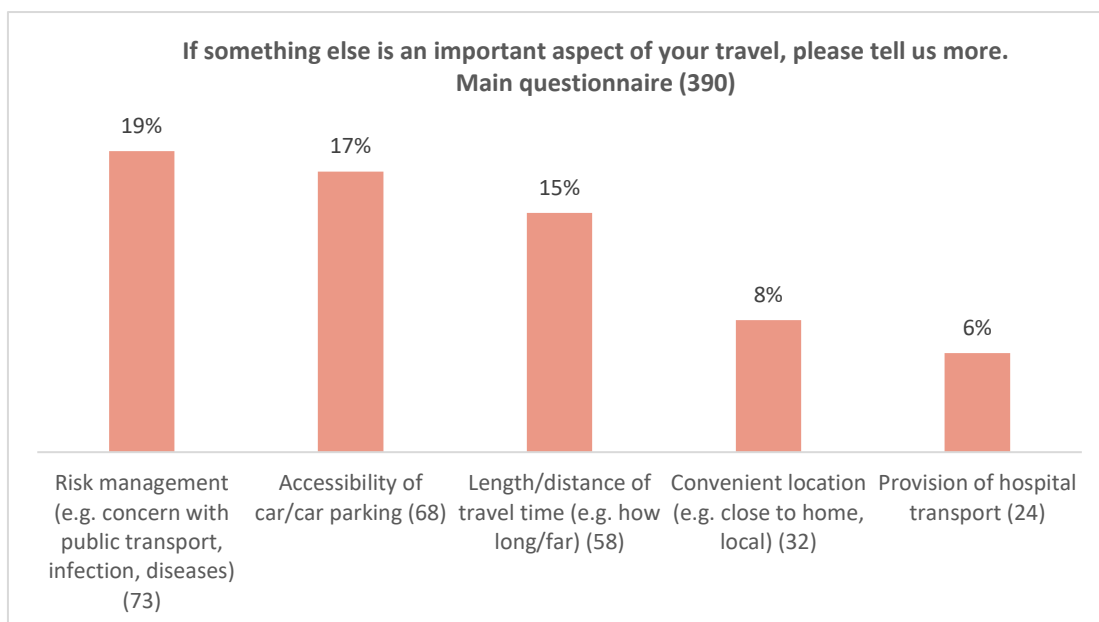


Figure 100 Accessibility for Families, Important aspect to travel (Main questionnaire)



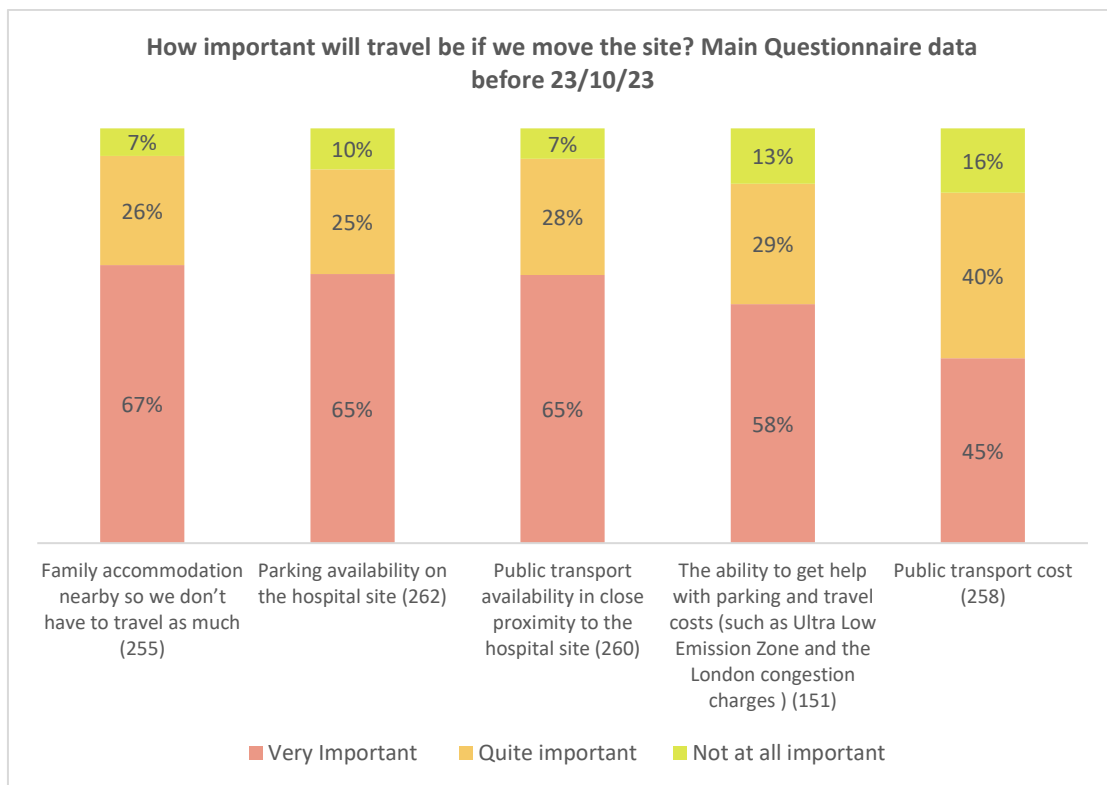


Table 13 Accessibility for Families, Important travel information (easy read questionnaire after 23/10/23)

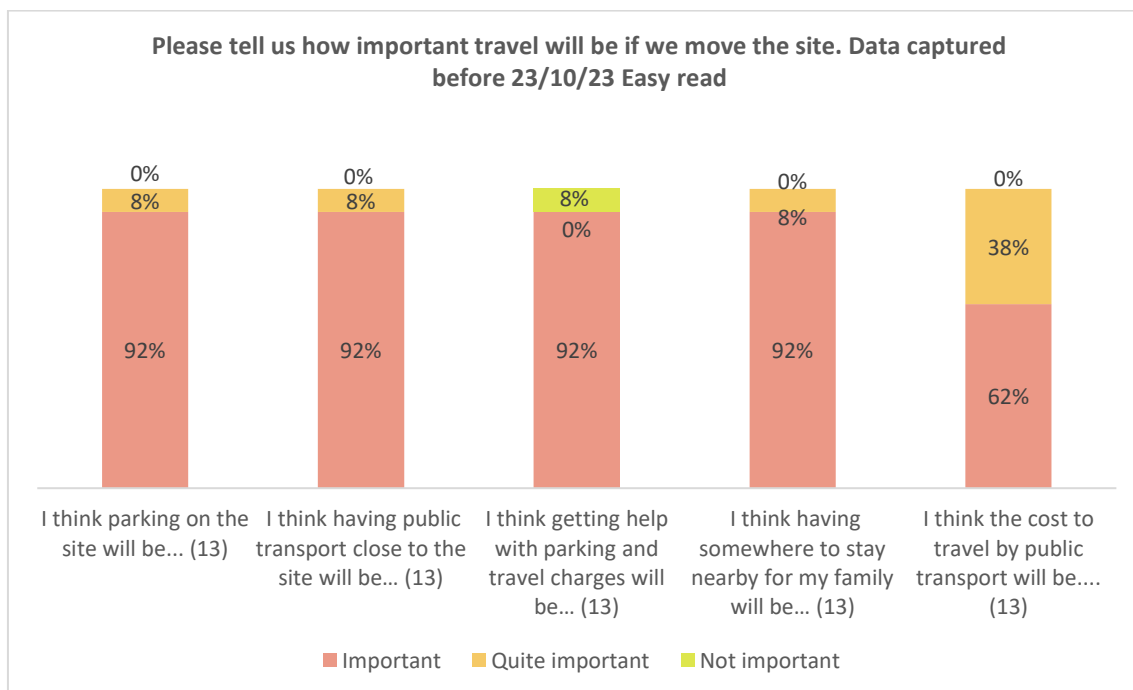


Figure 101 Accessibility for Families, Important travel (easy read questionnaire after 23/10/23)





21.7.3 Support and information

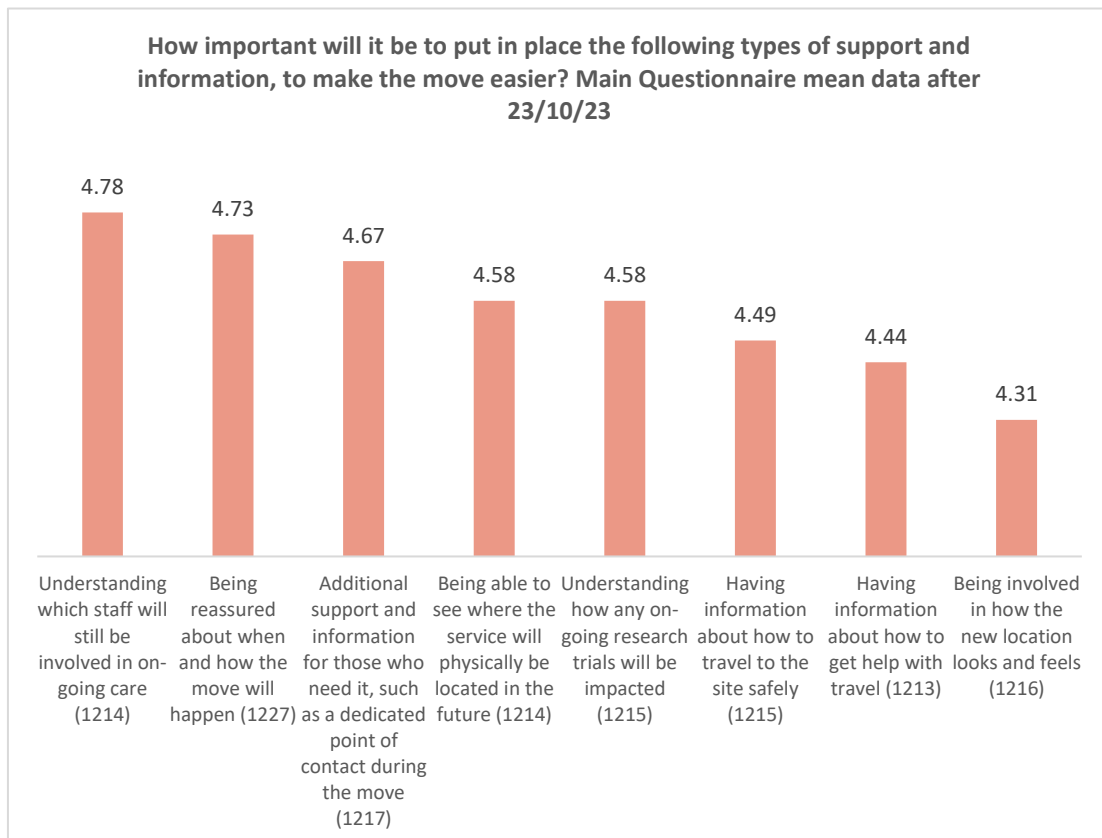
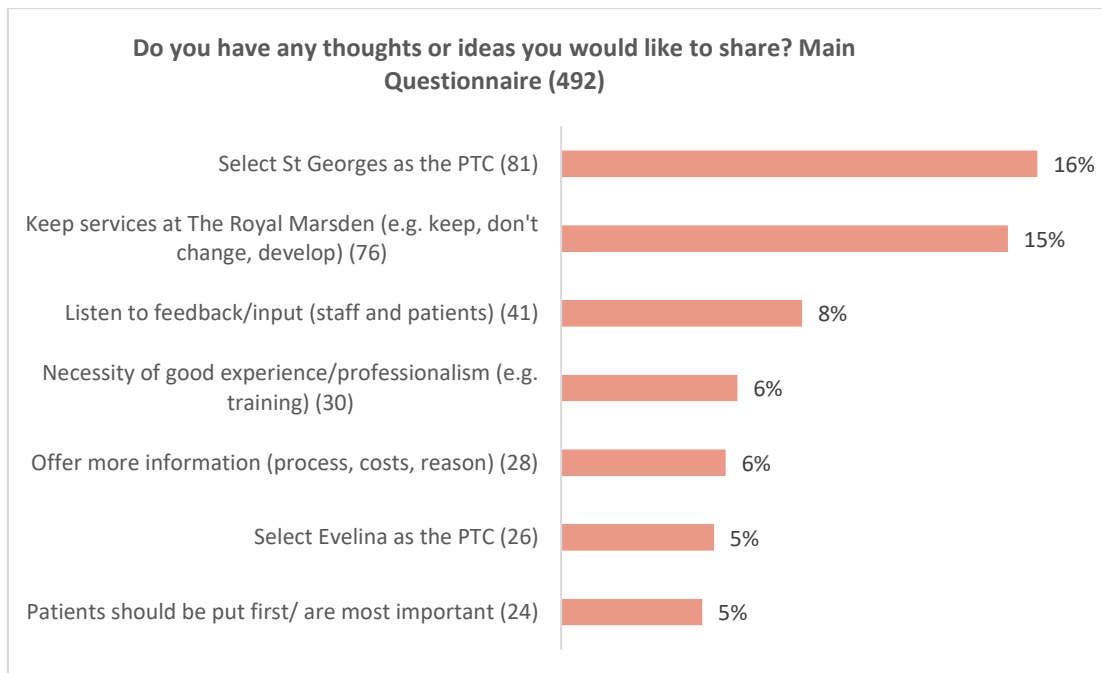


Figure 102 Accessibility for Families, Support and Information needed mean (main questionnaire after 23/10/23)



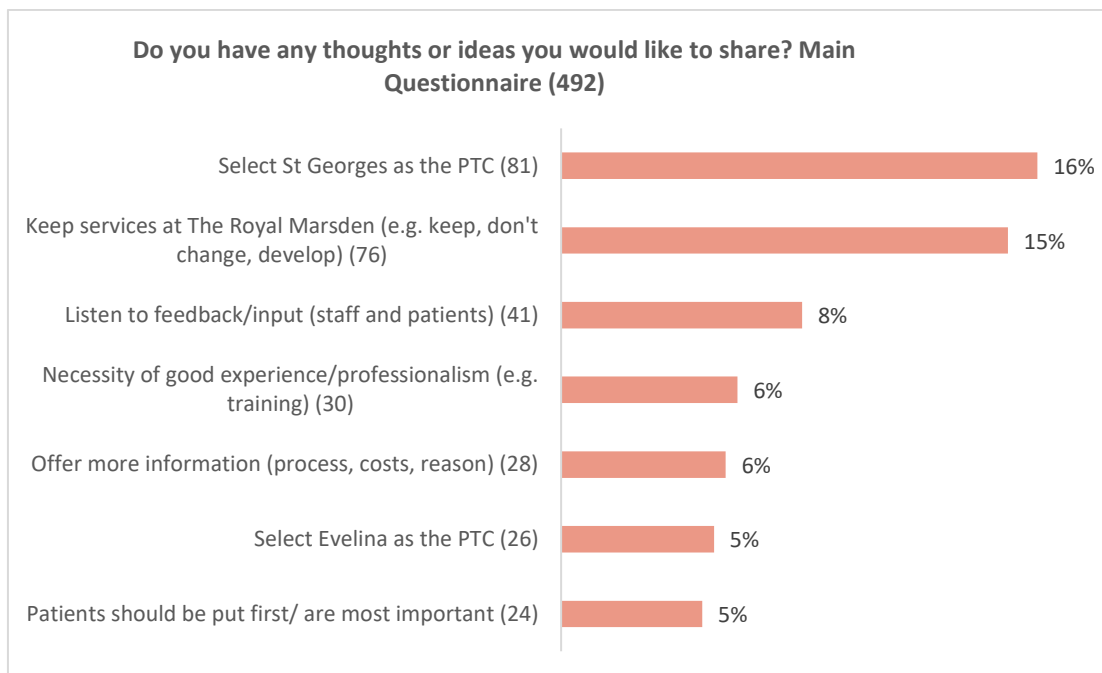


Figure 103 Accessibility for Families, Other thoughts and ideas

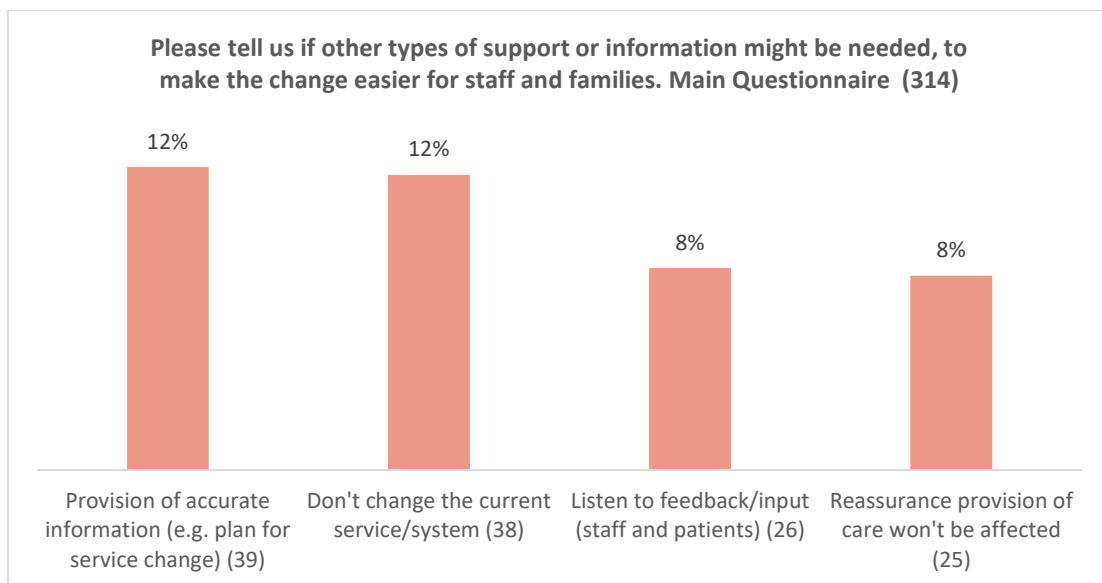


Figure 104 Accessibility for Families, Other support or information needed (Main Questionnaire)



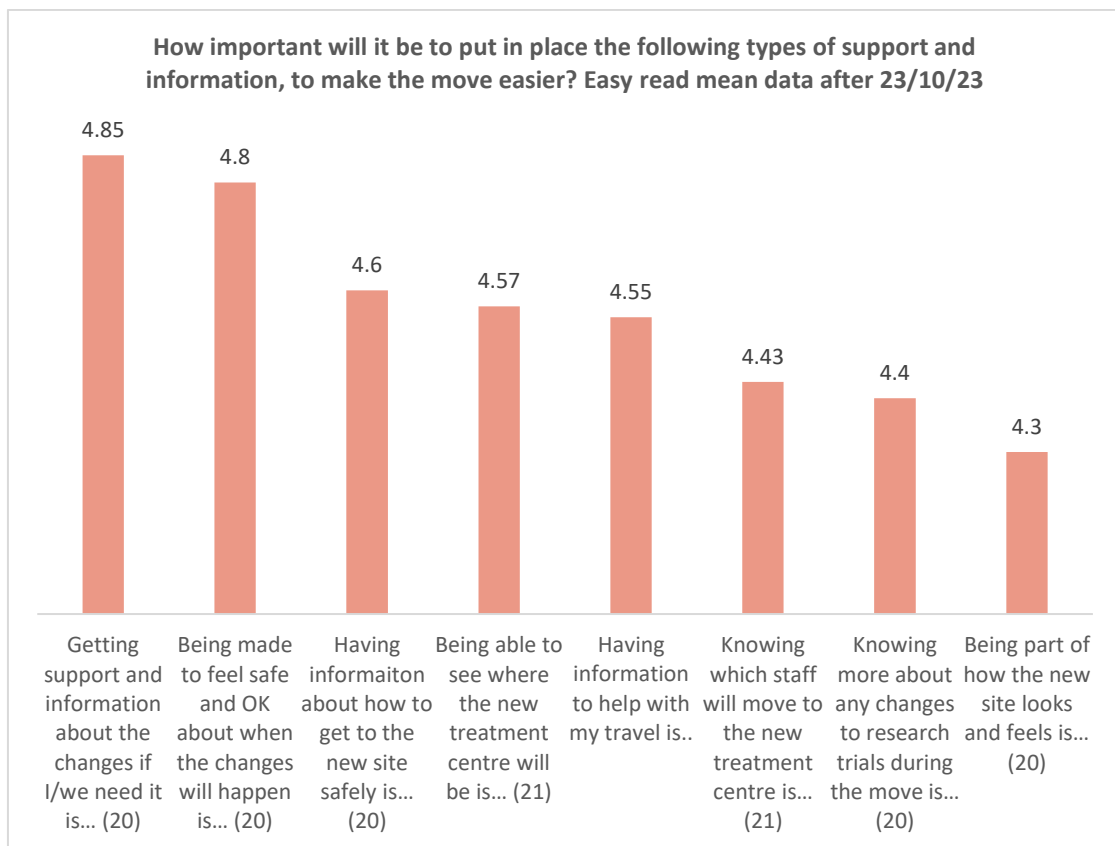


Figure 105 Accessibility for Families, Support and Information needed (easy read questionnaire before 23/10/23)



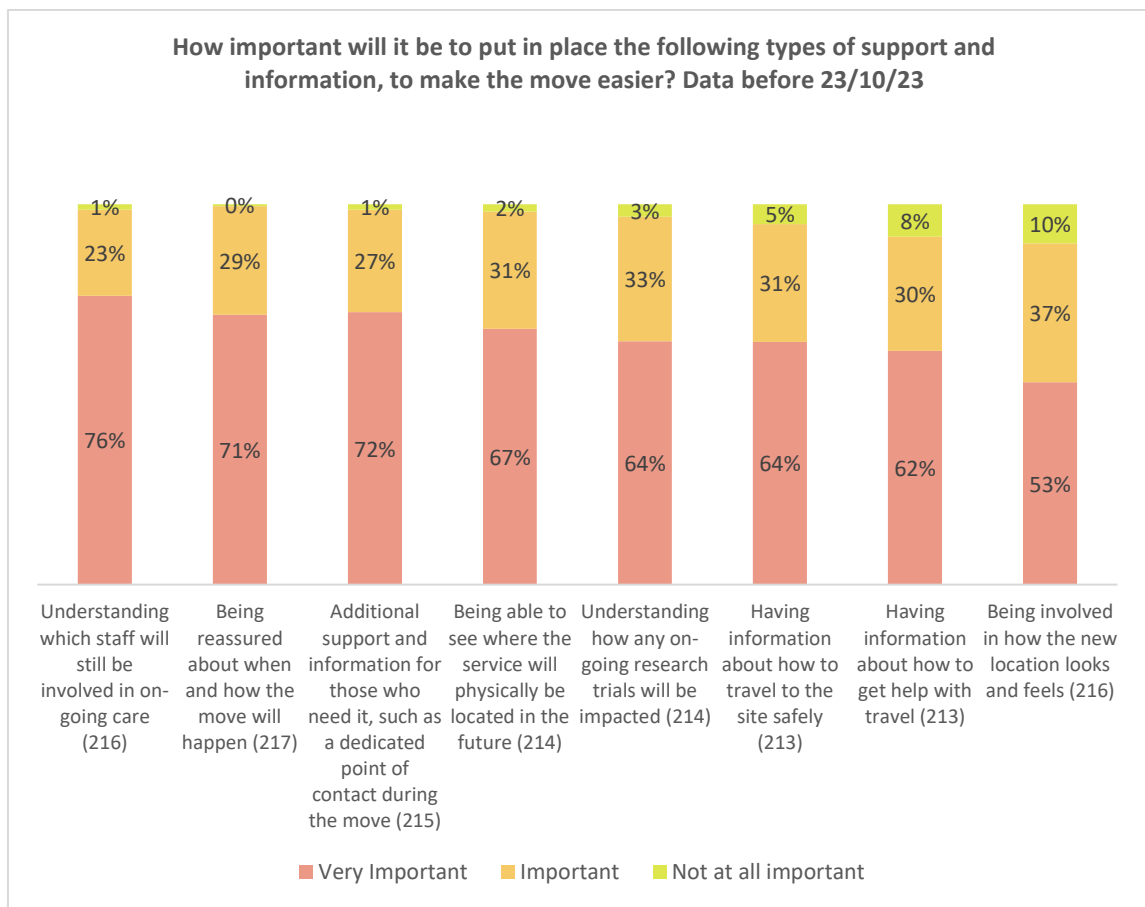


Figure 106 Accessibility for Families, Support and Information needed (main questionnaire before 23/10/23)



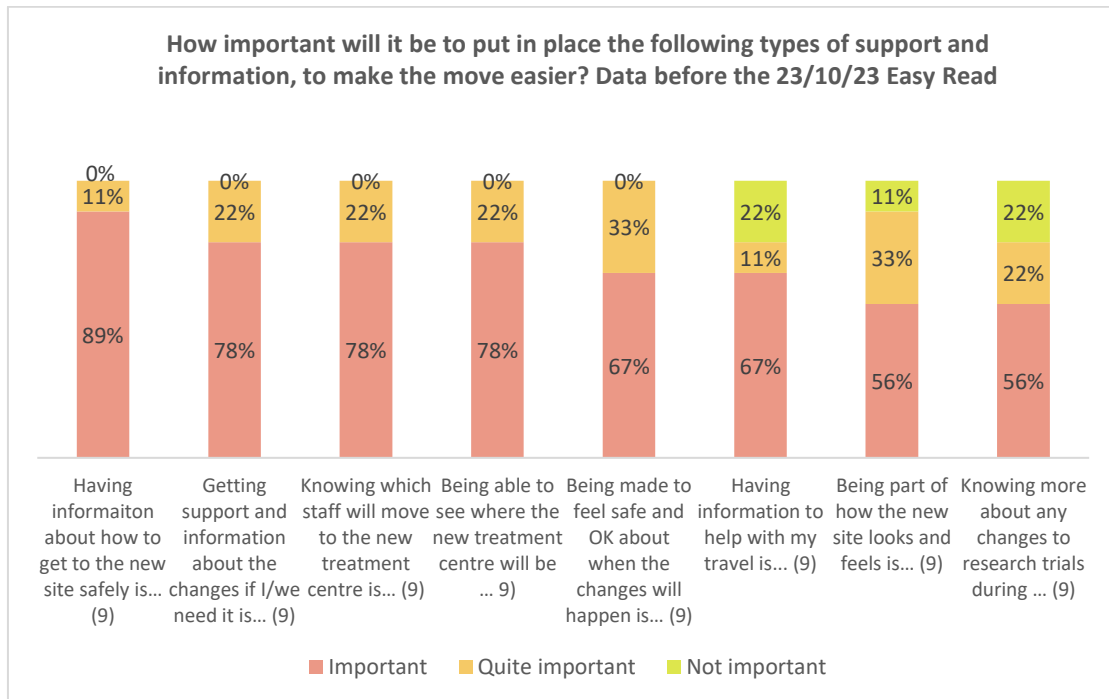


Figure 107 Accessibility for Families, Support and Information needed (easy read questionnaire before 23/10/23)



21.7.4 Other ideas

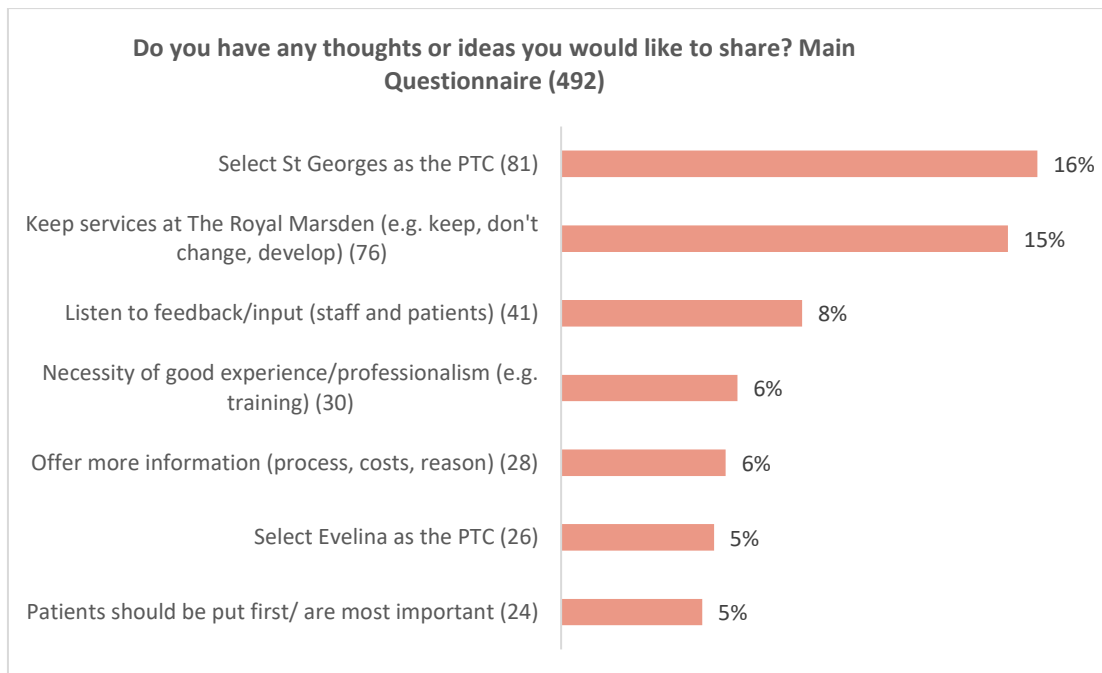


Figure 108 Other ideas and comments, shared ideas (Main Questionnaire)



21.8 Appendix H - Data captured before the 23/10/23 across ICB region

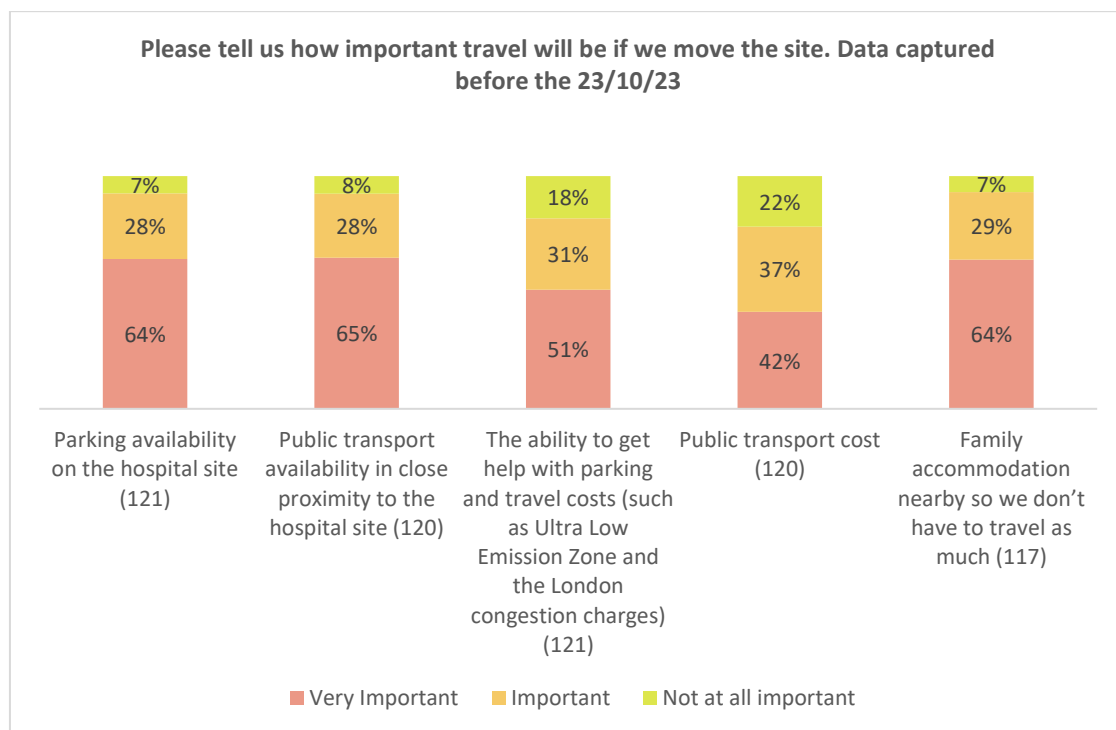


Figure 109 NHS South West London ICB, Importance of Travel, Before 23/10/23

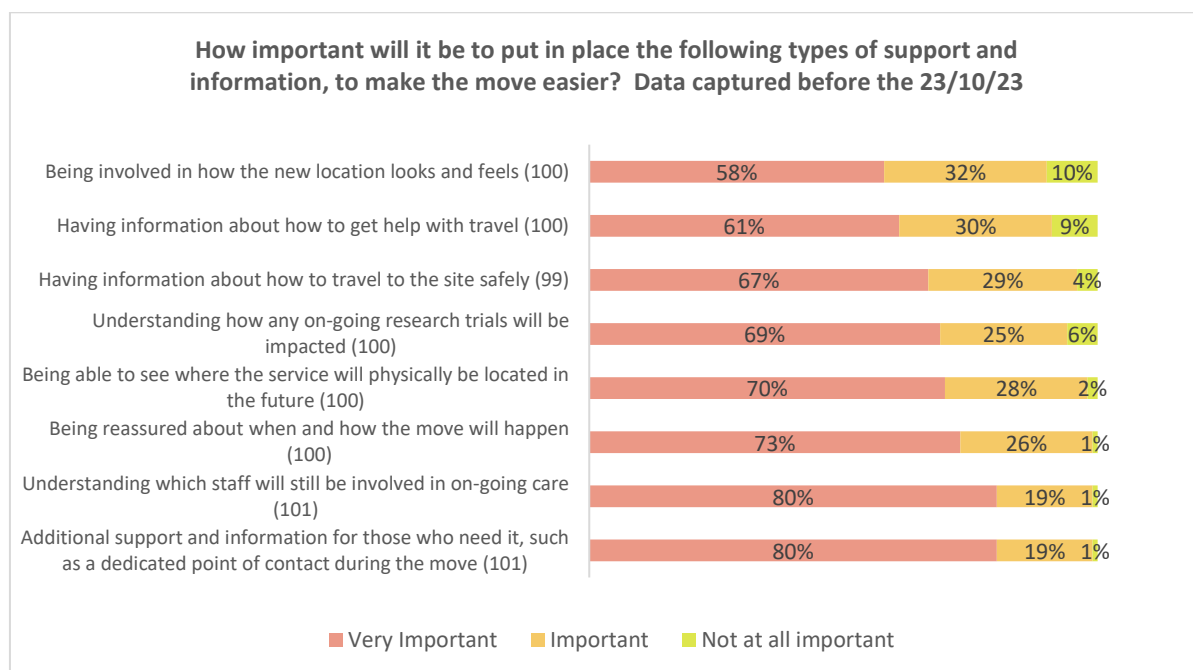


Figure 110 NHS South West London ICB, Support and Information, Before 23/10/23



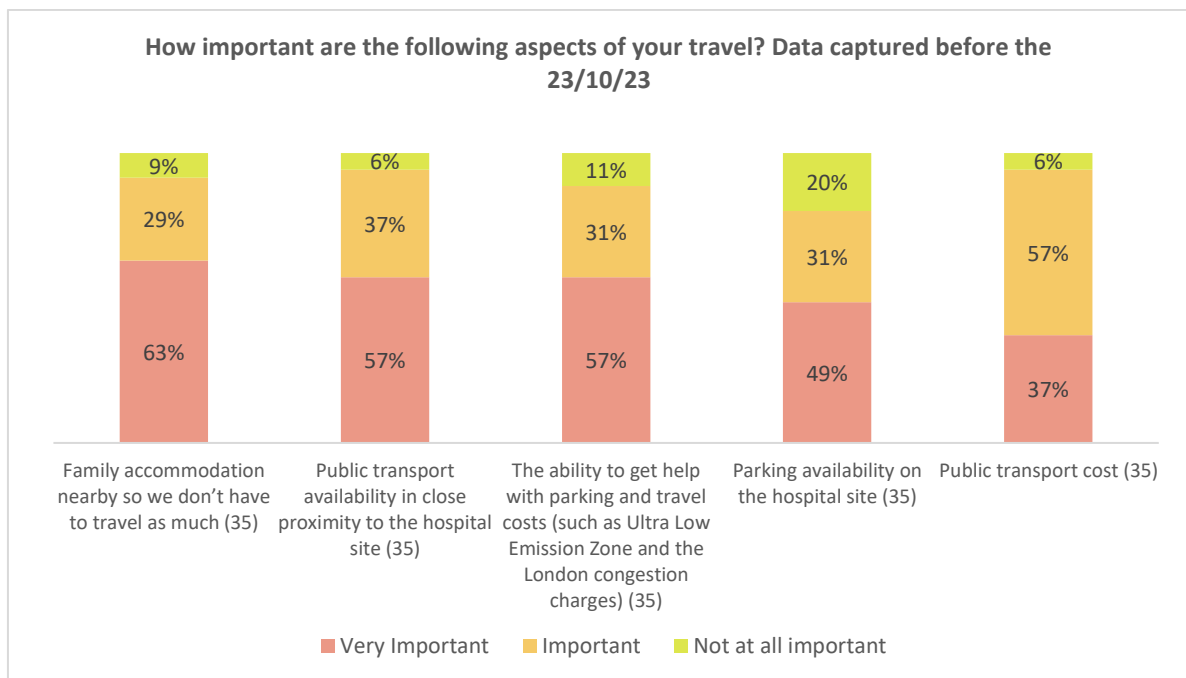


Figure 111 NHS South East London ICB, Importance of Travel, Before 23/10/23

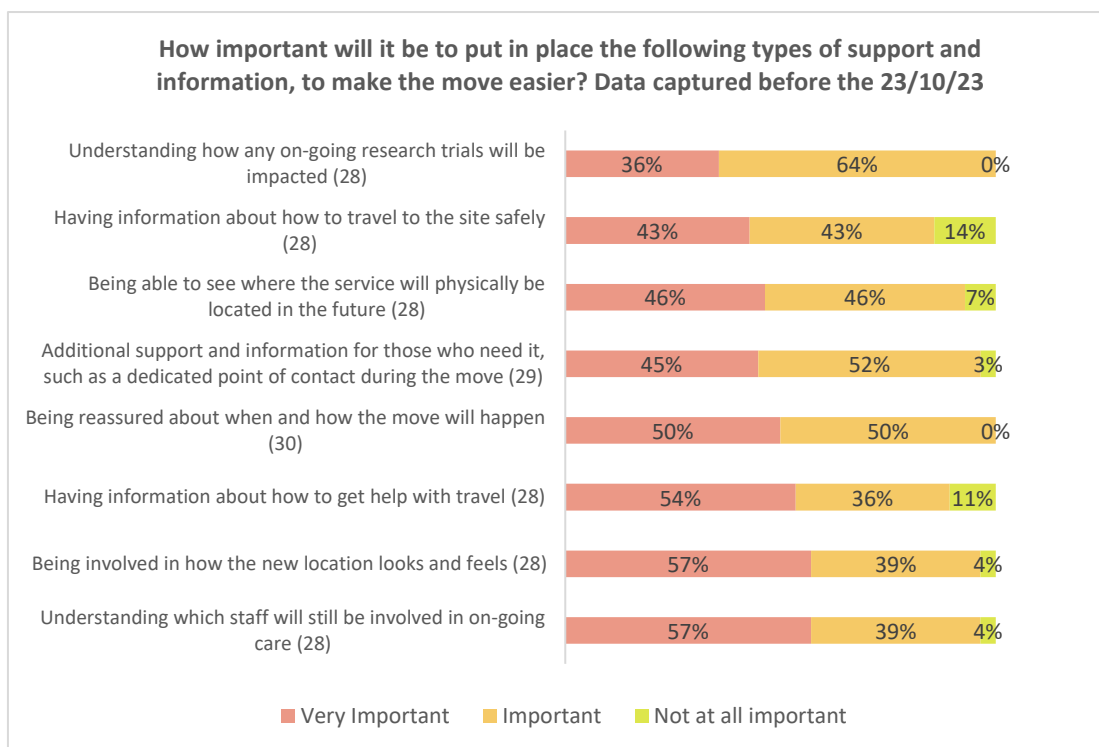


Figure 112 NHS South East London ICB, Support and Information, Before 23/10/23



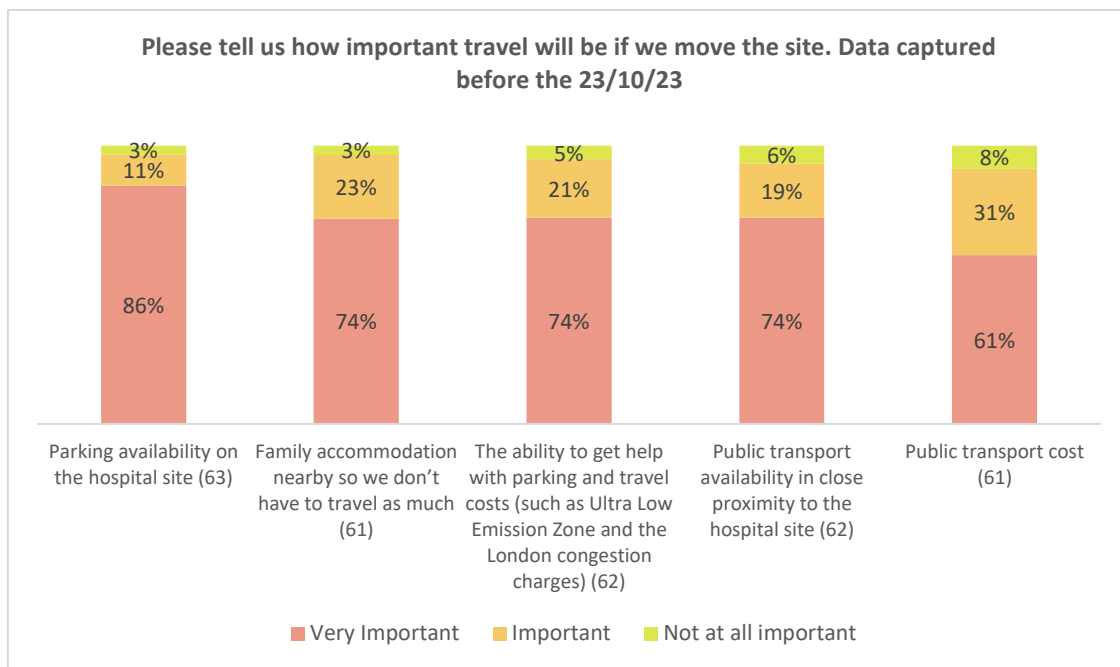


Figure 113 NHS Surrey Heartlands ICB, Importance of Travel, Before 23/10/23

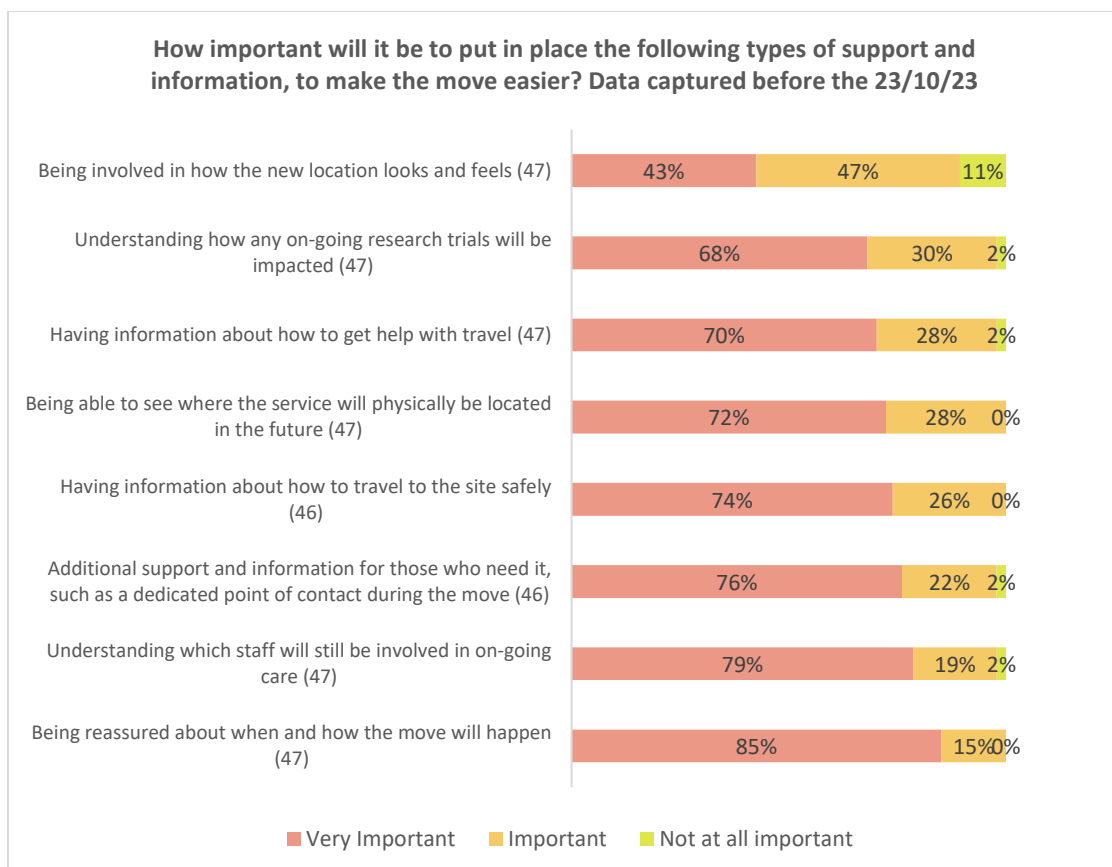


Figure 114 NHS Surrey Heartlands ICB, Support and Information, Before 23/10/23



Data for respondents within the Sussex ICB region captured before 23 October 2023 has not been presented here for questions seven and eight due to only having a base size of ten. due to low base sizes for both these questions of around 5 respondents from Kent and Medway responding to this question, data captured before the 23rd of October has not been reflected here.



21.9 Appendix I – demographic tables for each ICB area by questionnaire responses

	NHS South West London ICB (788)	NHS South East London ICB (266)	NHS Surrey Heartlands ICB (260)	NHS Sussex ICB (69)	NHS Kent and Medway ICB (110)
Total	45.84%	15.47%	15.13%	4.01%	6.40%
Gender					
Male	26.14%	28.20%	22.31%	20.29%	26.36%
Female	68.40%	65.04%	73.08%	72.46%	65.45%
Transgender	0.38%	0.00%	0.00%	1.45%	0.91%
Non-binary	0.00%	0.38%	0.00%	0.00%	0.00%
Other	0.00%	0.38%	0.00%	0.00%	0.00%
Prefer not to say	5.08%	6.02%	4.62%	5.80%	7.27%
Sexuality					
Heterosexual/straight	84.64%	83.08%	86.54%	81.16%	87.27%
Bisexual	1.78%	1.88%	0.38%	1.45%	0.00%
Gay	1.54%	2.26%	0.00%	2.90%	0.00%
Lesbian	0.51%	1.88%	0.00%	1.45%	1.82%
Other	0.63%	0.75%	0.00%	0.00%	0.00%
Prefer not to say	10.91%	10.15%	13.08%	13.04%	10.91%

Table 14 A breakdown of gender and sexuality demographics based on ICB.



	NHS South West London ICB (788)	NHS South East London ICB (266)	NHS Surrey Heartlands ICB (260)	NHS Sussex ICB (69)	NHS Kent and Medway ICB (110)
Disability					
Yes – disability	7.87%	4.89%	6.54%	11.59%	10.00%
No – disability	84.52%	85.34%	85.00%	84.06%	83.64%
Prefer not to say	7.61%	9.77%	8.46%	4.35%	6.36%
Age					
Under 15	0.13%	0.00%	0.00%	0.00%	0.00%
16-18	0.25%	0.00%	1.15%	0.00%	0.91%
19-25	2.54%	2.26%	3.46%	2.90%	0.91%
26-40	29.19%	36.47%	24.62%	23.19%	24.55%
41-65	53.55%	47.37%	56.15%	55.07%	59.09%
66-74	7.11%	6.02%	5.00%	10.14%	7.27%
75 or over	3.43%	3.01%	3.85%	4.35%	1.82%
Prefer not to say	3.81%	4.89%	5.77%	4.35%	5.45%
Occupation					
Higher managerial/ professional/ administrative	34.39%	36.84%	33.85%	27.54%	26.36%
Intermediate managerial/ professional/ administrative	29.06%	31.58%	26.92%	28.99%	26.36%
Supervisory or clerical/ junior managerial/ professional/ administrative	13.96%	12.78%	17.31%	11.59%	16.36%
Skilled manual worker	1.78%	3.76%	3.08%	10.14%	2.73%
Semi or unskilled manual worker	1.14%	0.38%	1.15%	2.90%	2.73%
Casual worker - not in permanent employment	0.51%	0.38%	0.77%	0.00%	0.91%
Student	0.38%	0.38%	2.31%	0.00%	0.00%
House husband/ housewife/ homemaker	1.40%	0.75%	1.15%	1.45%	1.82%
Full-time carer of other household member	0.89%	0.00%	0.00%	0.00%	1.82%
Unemployed or not working due to long-term sickness	0.63%	0.38%	0.38%	1.45%	1.82%
Would rather not say	15.86%	12.78%	13.08%	15.94%	19.09%



Table 15 A breakdown of disability, age and occupation demographics based on ICB.

	NHS South West London ICB (788)	NHS South East London ICB (266)	NHS Surrey Heartlands ICB (260)	NHS Sussex ICB (69)	NHS Kent and Medway ICB (110)
Socio-economic group					
SEG ABC1	77.41%	81.20%	78.08%	68.12%	69.09%
SEG C2DE	6.73%	6.02%	8.85%	15.94%	11.82%
Would rather not say	15.86%	12.78%	13.08%	15.94%	19.09%
Additional income support					
I am currently not receiving benefits	80.85%	84.28%	81.25%	82.76%	74.73%
Universal Credit	3.65%	3.06%	1.92%	5.17%	5.49%
Pension Credit Guarantee Credit	1.37%	0.00%	0.48%	1.72%	1.10%
Employment and Support Allowance	0.61%	0.00%	0.96%	0.00%	3.30%
Are named on, or entitled to, a valid NHS tax credit exemption certificate	0.76%	0.87%	0.48%	0.00%	2.20%
Jobseekers allowance	0.61%	0.00%	0.00%	1.72%	1.10%
Income support	0.30%	0.00%	0.48%	0.00%	0.00%
Would rather not say	13.22%	11.79%	15.87%	8.62%	12.09%
Religion					
Christian	46.19%	41.73%	48.46%	46.38%	46.36%
No religion	26.14%	34.21%	31.92%	39.13%	30.00%
Muslim	5.33%	2.63%	2.69%	1.45%	3.64%
Hindu	4.44%	1.50%	2.69%	0.00%	0.91%
Atheist	3.30%	4.14%	1.54%	0.00%	0.91%
Agnostic	1.78%	1.13%	1.15%	1.45%	0.91%
Buddhist	1.02%	1.13%	0.00%	1.45%	2.73%
Jewish	0.25%	0.38%	0.00%	0.00%	0.91%
Sikh	0.25%	0.00%	0.00%	0.00%	0.00%
Other	0.51%	1.88%	0.77%	1.45%	1.82%
Prefer not to say	10.79%	11.28%	10.77%	8.70%	11.82%

Table 16 A breakdown of ICB region by socio-economic group, additional income support and religion



	NHS South West London ICB (788)	NHS South East London ICB (266)	NHS Surrey Heartlands ICB (260)	NHS Sussex ICB (69)	NHS Kent and Medway ICB (110)
Stakeholder Group					
Children & young people who have been affected by cancer	0.76%	1.13%	1.54%	2.90%	5.45%
Family members and advocates of children and young people who have been affected by cancer	8.25%	7.89%	14.23%	31.88%	32.73%
Children, young people and families non-cancer connection	15.48%	12.41%	14.62%	14.49%	10.00%
Affected clinical and non-clinical staff	26.78%	30.83%	29.62%	11.59%	11.82%
Other clinical and non- clinical staff	18.53%	22.56%	20.38%	18.84%	22.73%
Members of the public	20.81%	13.91%	12.69%	14.49%	10.91%
Organisations and public representatives	2.79%	3.38%	1.92%	1.45%	0.91%
Other	3.55%	4.51%	3.46%	2.90%	3.64%
Prefer not to say	4.19%	3.38%	2.31%	1.45%	1.82%

Table 17 A breakdown of Stakeholder Groups based on ICB.



	NHS South West London ICB (788)	NHS South East London ICB (266)	NHS Surrey Heartlands ICB (260)	NHS Sussex ICB (69)	NHS Kent and Medway ICB (110)
Ethnicity					
White – English	36.55%	37.59%	55.38%	57.97%	51.82%
White – Welsh	1.90%	1.13%	1.92%	4.35%	0.91%
White – Scottish	1.65%	3.76%	0.77%	0.00%	0.91%
White – Northern Irish	0.63%	0.38%	0.00%	0.00%	0.00%
White – British	10.79%	14.66%	15.00%	18.84%	12.73%
White – Irish	4.44%	2.63%	0.77%	1.45%	1.82%
White – Gypsy or Irish Traveller	0.25%	0.00%	1.15%	0.00%	0.00%
White – Any other white background	3.68%	4.89%	3.08%	0.00%	1.82%
Mixed – White and Black Caribbean	0.76%	0.75%	0.38%	0.00%	3.64%
Mixed – White and Black African	0.63%	0.38%	0.77%	0.00%	0.00%
Mixed – White and Asian	2.28%	1.13%	2.31%	0.00%	5.45%
Mixed – Any other Mixed background	0.76%	0.00%	0.00%	0.00%	0.00%
Asian or Asian British – Indian	6.47%	4.51%	4.62%	0.00%	0.00%
Asian or Asian British – Pakistani	1.90%	0.38%	0.38%	0.00%	0.91%
Asian or Asian British – Bangladeshi	0.63%	0.00%	0.00%	0.00%	0.00%
Asian or Asian British - Chinese	1.27%	1.50%	0.38%	0.00%	0.91%
Asian or Asian British - Any other Asian background	1.90%	1.13%	0.77%	0.00%	1.82%
Black or Black British - Caribbean	1.90%	2.26%	0.38%	1.45%	0.91%
Black or Black British - African	2.16%	4.51%	0.77%	4.35%	4.55%
Any other Black background	0.00%	0.00%	0.00%	0.00%	0.00%
Other	10.28%	10.15%	2.69%	4.35%	3.64%
Prefer not to say	9.14%	8.27%	8.46%	7.25%	8.18%

Table 18 A breakdown of ethnicity demographics based on ICB





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Final sign off: Rebecca Crinson