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

End of Public Consultation Update

East Sussex HOSC

07 March 2024

Presentation

Introduction

We are here today to share information about the key findings of our public consultation; our priorities for this next phase; to gather your views and answer your questions.

Agenda:

- Recap of the process thus far
- End of public consultation update
- Decision-making process update
- Next steps

We hope that the Committee finds this session helpful - we welcome any questions.

Background and context

- Specialist children's cancer services in England are led and coordinated by Principal Treatment Centres.
- The service for children living in Brighton and Hove, East Sussex, Kent, Medway, south London and most of Surrey is provided in partnership between The Royal Marsden NHS Foundation Trust at its site in Sutton, and St George's Hospital in Tooting, south west London.
- The service they provide is safe and high quality - but they are not all on the same site as a children's intensive care unit.
- The current Principal Treatment Centre does not and cannot comply which means very specialist cancer services currently provided on The Royal Marsden site need to move.
- The consultation helped us to understand the impact of implementing either of the two options being considered for the future location of the Principal Treatment Centre as well as the impact of moving conventional radiotherapy from The Royal Marsden to University College Hospital.

Radiotherapy

Both options in our consultation propose that children's conventional radiotherapy moves from The Royal Marsden to University College Hospital in central London.

Why things need to change

1. Hospital transfers of very sick children for intensive care add risks and stress
2. The intensive care team is not currently able to provide face to face advice on the care of children on the cancer ward
3. There is a need to improve children and families' experience when patients require intensive care and other specialist children's services
4. National clinical requirements for Principal Treatment Centres are set by NHS England. They say very specialist cancer treatment services for children – like those at The Royal Marsden – MUST be on the same site as a level 3 children's intensive care unit and other specialist children's services. This is non-negotiable.
5. Although it offers a wide range of innovative treatments, the current Principal Treatment Centre is excluded from giving a specific type of new treatment, and others expected in the future

Shortlisted options

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

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

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

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

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

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

**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 others services. A range of these services were considered 'fixed-points' and were not part of the public consultation. Further detail available in our consultation document, available on our website here*

Evelina London Proposal

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

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

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

- Guy's and St Thomas' would offer parking for children and families accessing children's cancer care. They would be able to reimburse parking, and support parents of children with cancer to access reimbursement for ULEZ and congestion zone charges.
- Guy's and St Thomas' has a dedicated patient transport team.
- Evelina London's volunteers would support families as mobility assistants, especially families with disabilities. There would also be a volunteer driver scheme.

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

St George's Proposal

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

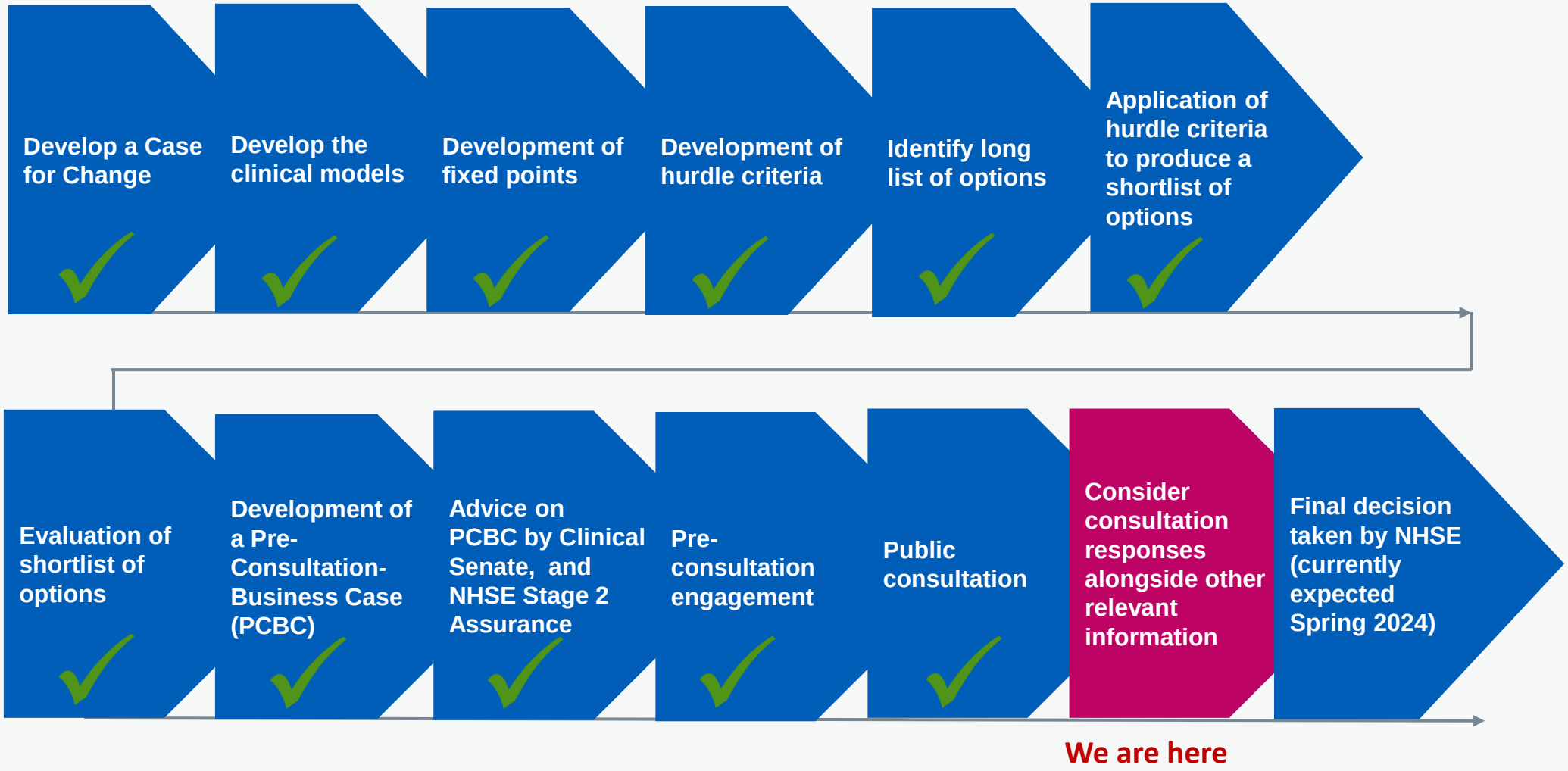
If the future Principal Treatment Centre was at St George's, it would have:

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

- St George's would offer parking for children and families accessing children's cancer care. They would be able to reimburse parking, and support parents of children with cancer to access reimbursement for ULEZ charges.
- St George's has a dedicated patient transport team.
- St George's helps families with travel arrangements for appointments and to make the journey home by taxi or patient transport after a hospital stay.

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

The formal reconfiguration process



Public Consultation: Tuesday 26th September – midnight Monday 18th December 2023

- A range of documents were made available from the start of consultation to support the public, including staff and patients, to consider the two options. NHS England led communication and engagement activity throughout the consultation period supported by specialists.

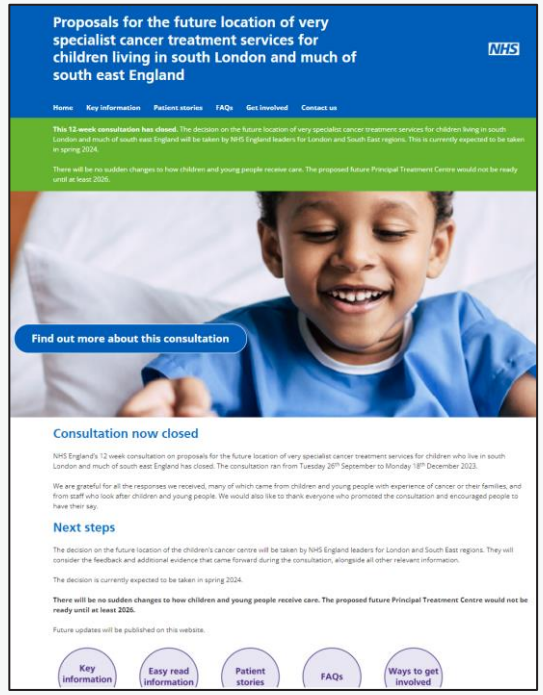
- As we launched the public consultation, we were clear that we wanted to use it as an opportunity to:

  - Listen, acknowledge and understand the feedback to support decision-makers to determine the best decision for the future of this service
  - Ascertain a thorough understanding of what a wide range of people think about the proposals – both strengths and challenges
  - Gather insights to support the design of any mitigating actions to address concerns and issues

- We remain open-minded about both options.

- We believe that the consultation has been fair, robust and comprehensive. We are grateful for all the responses received, many of which came from children and young people with experience of cancer or their families, and from staff who look after children and young people.

- The consultation responses have been analysed by an independent external organisation and written up in a report that has now been published on our website.



Consultation website snapshot

End of Public Consultation Update

NHS England

Public Consultation activity – a summary

Communications activity included:

These activities were supported by our partners including the Trusts involved and Integrated Care System colleagues.

- Letters directly to patients, distributed by Trusts on our behalf and shared by the Facebook group run by parents
- Animation subtitled in different languages
- Printed posters and documents at hospitals
- Briefing and FAQs for staff to help them answer families' questions
- Toolkits for partners to raise awareness through their networks
- Media release and media interviews
- Content on social media including Facebook campaign
- Meetings to brief stakeholders about the consultation
- Proactive phone calls to organisations

Engagement activity included:

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

- Community focus groups
- Play specialist sessions on wards
- Public listening events
- Joining community events with people representing equalities groups
- 1:1 interviews
- Site visits to spend time in outpatient areas
- Focus groups with staff and other stakeholders
- Meetings with wider clinical colleagues, MPs, Overview and Scrutiny Committee leads

Key Stakeholders

The consultation was open to all. However, there were a number of specific stakeholder groups that the consultation targeted. It was important that these groups were represented in the consultation feedback. The level of engagement of these groups was tracked and activity modified to maximise opportunity for their engagement. Following the mid-point we took a number of actions to gather feedback from stakeholders who we had heard less from at that point.

Groups directly impacted	Other key stakeholder groups:	Communities with specific protected characteristics*:
• Children and young people with cancer or who have experienced cancer (and their families) • Clinical and non-clinical NHS staff from The Royal Marsden, St George's Hospital, Evelina London Children's Hospital	• 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	• People from ethnic minorities • Families with poor literacy skills and/or language barriers • People with autism • People with physical disabilities • People literacy skills and/or language barriers • People with mental health issues • Families with caring responsibilities • Looked after children and young people • Families experiencing financial difficulties or who live in the most deprived areas**

*List does not reflect all protected characteristics rather those identified as likely to be more/most impacted.
**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.

Explain's Independent Consultation Report – Summary*

** Please note that the content of the following slides is extracted from the independent consultation report produced by Explain Research. These are extracts only and do not reflect all findings from the full report (available on our website).*

Consultation report: responses & reach

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.

2,669 Formal responses to consultation *

604,895 Prompts to organisations and individuals to share their views**

Consultation survey

- **1,763 survey responses** of which:
  - 319 from affected staff working within the PTC
  - 233 from children, young people (CYP) and their families/carers

Face-to-Face engagement

- **831 people** reached through face-to face activities across **115 engagement sessions**
- **144 people** were children, young people, their families and staff currently experiencing/working in the PTC - engaged over **58 community sessions**
- **309 people were from equalities groups** highlighted in the early equalities impact assessment - engaged over **25 community sessions**

Other feedback

- **45 official organisational responses**
- **30 emails/ telephone calls** from a range of stakeholders (e.g. members of the public, charity and community organisations, research/academic staff, NHS staff, councillors)

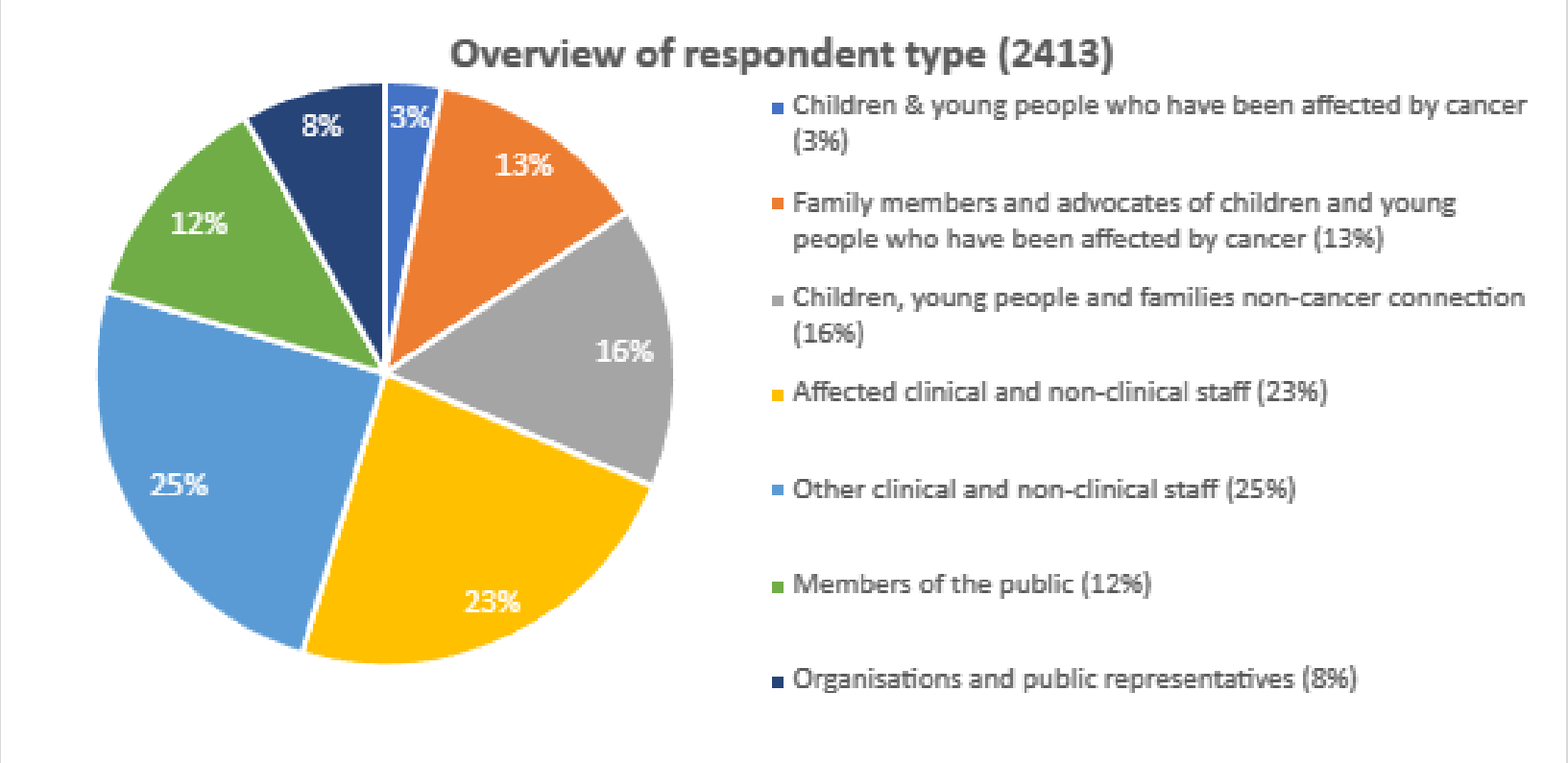
Alongside the consultation a group of parents also launched a petition:

Petition

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

* Comprised of 1,763 survey responses, 831 individuals through face-to-face work, 45 official organisational responses, 30 emails/telephone calls
** Comprised of social media reach, email distribution, social media campaign views

Overall reach: respondents to the consultation



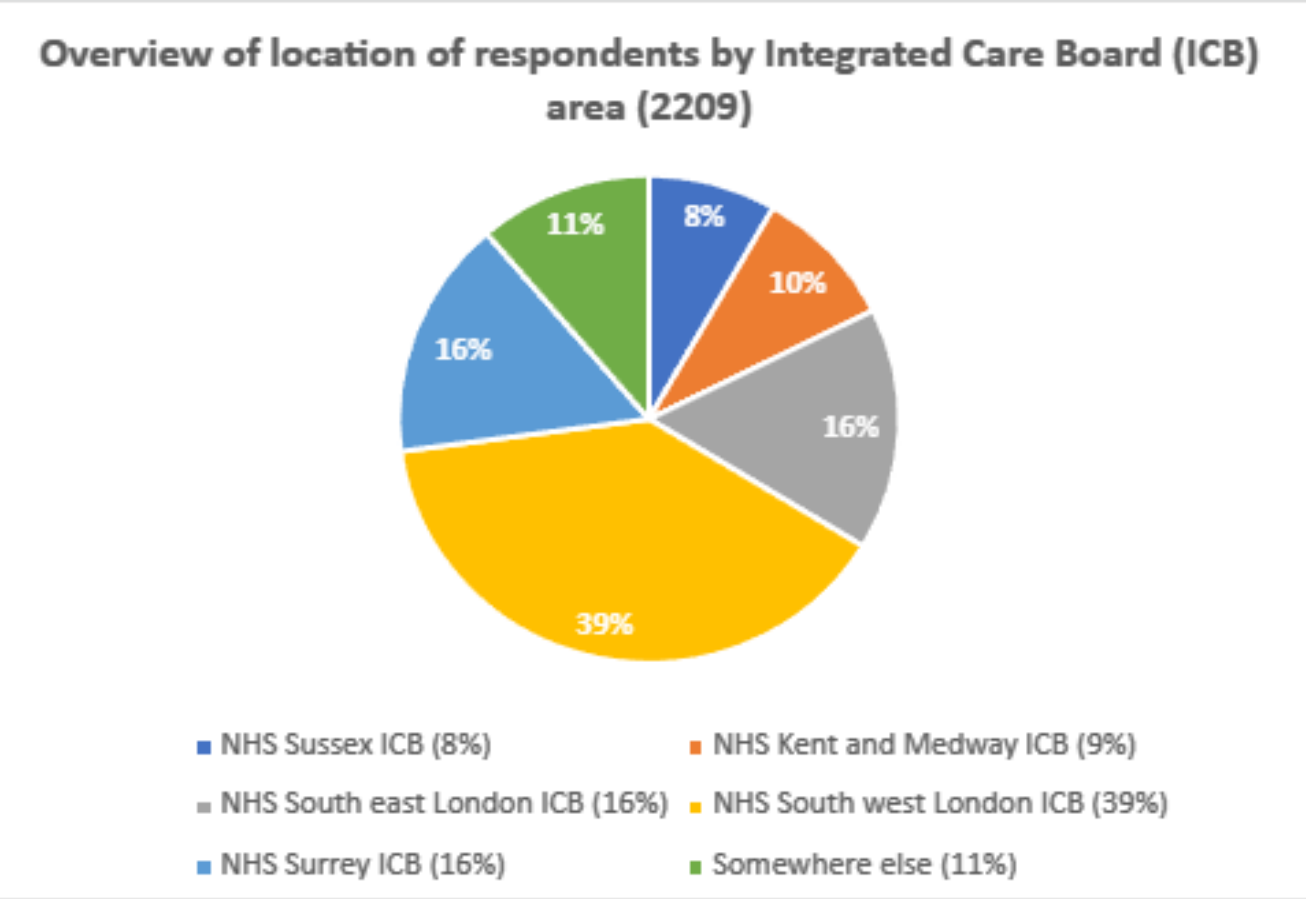
Summary

- **Good reach to affected and other clinical and non-clinical staff** working in children's cancer or wider services (RMH: 155; St George's: 216)
- Although many opportunities were given, response rates from children and young people who have been affected by cancer were lower than hoped. 13% **of responses came from parents and/or advocates for this group.**
- **Significant response from those without direct experience of cancer services**

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

Extract: Explain Consultation Report - Executive Summary. Note 'affected staff' defined as staff at the hospitals where the PTC is currently, or could be.

Overall reach: geographical location



Overview of responses 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%

Summary

- The **greatest response was from those in the NHS South West London ICB area**, of whom most were staff and members of the public
- **Good reach into NHS Surrey, NHS South East London and NHS Sussex ICB areas** – when comparing this to the proportion of recipients of the current service across those geographies
- **The lowest response rate was from NHS Sussex ICB area**
- When looking at the numbers of children and young people and their families/ advocates with experience of cancer services, **geographical reach is more representative of the patient cohort of the current Principal Treatment Centre**

NHS Sussex ICB: Demographic we heard from

A breakdown of the questionnaire feedback from respondents living in the NHS Sussex ICB area.

- 69 responses to the questionnaire (4% of the total) were from people living in the NHS Sussex ICB area. 31.9% of these responses were from family members of children with cancer.
- Of those Sussex 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 (55.1%) were aged 41-65
    - 11.6% were disabled (more than the other areas).
    - 8.6% were receiving additional income support
    - 15.9% were from socio-economic groups C2DE - more than the other ICB areas.

Note: Socio-economic group ABC1 reflects A (higher, managerial, administrative and professional occupations) B (Intermediate managerial, administrative and professional) and C1 (Supervisory, clerical & junior managerial, administrative, professional occupations)

Overall reach: summary of strengths and gaps

Key demographic strengths of the consultation

- **Ethnicity:** broadly reflective of the population across Integrated 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/within 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 Integrated Care Board regions.

Note: Socio-economic group ABC1 reflects A (higher, managerial, administrative and professional occupations) B (Intermediate managerial, administrative and professional) and C1 (Supervisory, clerical & junior managerial, administrative, professional occupations)
Extract: Explain Consultation Report - Executive Summary

Consultation report: Feedback on attributes people said they would value in the future PTC

When thinking about the future Principal Treatment Centre, respondents shared key attributes that they would value:

Survey responses highlighted:

- 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*
- Specialist knowledge of and experience in children's cancer care
- A convenient location, particularly in terms of access by car
- Strong research facilities and track record

Other suggestions:

- 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.
- 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.

Consultation report: Feedback for the *Evelina* option

Some feedback on the Evelina London option from the consultation report is summarised below. **More detail is included in the consultation report.**

Strengths raised

- 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 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.

Challenges raised

- It has a lack of experience and expertise in children's cancer care and treating children's cancer
- It does not provide neurosurgery
- Whilst it conducts a wide range of 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

Extract: Explain Consultation Report - Executive Summary

Consultation report: Staff feedback for the *Evelina* option

In addition, NHS staff highlighted the additional feedback. More detail is included in the consultation report.

Strengths [also] raised by staff

- 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 would help with a smooth transition of the Principal Treatment Centre
- It is considered by some staff to be a good place to work.

Challenges [also] raised by staff

- 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.

Extract: Explain Consultation Report - Executive Summary

Consultation report: Feedback for the *St George's* option

Some feedback on the St George's option from the consultation report is summarised below. **More detail is included in the consultation report.**

Strengths raised

- 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.

Challenges raised

- 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 for children and young people receiving treatment for cancer.

Extract: Explain Consultation Report - Executive Summary

Consultation report: Staff feedback for the *St George's* option

In addition, NHS staff highlighted the additional feedback. More detail is included in the consultation report.

Strengths [also] raised by staff

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

Challenges [also] raised by staff

- 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.

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Consultation report: Feedback for Radiotherapy proposal

Outline of feedback on proposals for conventional radiotherapy. **More detail is included in the consultation report.**

Strengths raised

- There are benefits associated with consolidating radiotherapy expertise and services in one location
- Existing knowledge and experience of staff at University College Hospital
- Other treatments available there e.g. proton beam therapy

Challenges raised

- 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.

Extract: Explain Consultation Report - Executive Summary

Consultation report: Challenges affecting both proposals

More detail is included in the consultation report.

Challenges affecting both proposals

- 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. This related to both staff expertise and experience and the attributes of the healthcare spaces at The Royal Marsden (Oak Centre, 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 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.

Extract: Explain Consultation Report - Executive Summary

Other ideas put forwards

A range of other ideas were put forward; including some alternative proposals. This included:

- A **risk-adapted model that retains the Principal Treatment Centre at The Royal Marsden and St George's.** This proposes that services continue to be provided at The Royal Marsden with patients who, upon diagnosis are deemed likely to require intensive care receiving their care at St George's.

- A **3-stage solution**, which involves:
  - adoption of the risk-adapted model outlined above, then
  - 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
  - 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

In the questionnaire, there was a final question asking for any other thoughts or ideas. The top three themes were:

- **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.

Extract: Explain Consultation Report - Executive Summary

Case for change

Through the public consultation, many respondents took the opportunity to voice their opinion about the case for change.

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.

Challenges raised

- 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.

Extract: Explain Consultation Report - Executive Summary

Criticism of consultation

Although not a key theme, some respondents across the stakeholder groups and the catchment area expressed criticism of the consultation. This feedback focused on:	How NHS England will continue to address the concerns raised by respondents
- The perception that the consultation was biased or the result already decided, because Evelina London had been identified as the preferred option	It is established law that it is appropriate for public consultations to put forward a preferred option, along with the evidence to support this in the consultation materials. This does not impact our ability to maintain an open mind as to the right final decision for the benefit of patients. A decision on the future location of services has not been made. It is currently expected that NHS England leaders will take a decision in Spring 2024; in taking a decision they will consider all relevant information including feedback from the public consultation. They will also have regard to their statutory functions and Triple Aim duties.
- 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	Our pre-consultation engagement ran from April to August 2023 and involved a range of activities. In total, we had 739 responses to this phase of engagement, which included 27 engagement sessions, 313 responses to online surveys and seven ward visits. This feedback has been listened to and helped to shape our approach to consultation. Further detail in our pre-consultation report here. All feedback from the consultation will be considered and will inform the decision-making business case. Much of the feedback will also be valuable to informing the Implementation phase.
- The perception that there was a lack of financial detail, and financial scrutiny, associated with the proposals.	In line with formal NHS processes, it was determined that both proposals were affordable in revenue and capital terms ahead of public consultation. The pre-consultation business case contained appropriate financial information and further financial detail will be included in the decision-making business case.

Extract: Explain Consultation Report - Executive Summary with commentary from NHS England

Suggestions to address challenges

Across engagement activities, people were asked to provide suggestions to minimise or reduce any negative effects of the service change.

Suggestions are really valuable and will be used by NHS England and other stakeholders to support our ongoing work.

Access to healthcare

1. Improvement of children's cancer care closer to home
2. Working together with the team that manages POSCUs

Travel

1. Improvement to the provision of effective and free hospital transport; expending eligibility criteria for this
2. Dedicated parking spaces
3. Reimbursing travel costs/charges for all visitors to child in hospital
4. Supporting families with travel costs in advance of travel
5. Support with flexible appointment times and overnight accommodation

Facilities

1. Outdoor spaces dedicated to children cancer patients
2. Guaranteed parental accommodation on or very close to the Principal Treatment Centre
3. Dedicated, separate entrance to the Principal Treatment Centre

Research

1. Using The Royal Marsden @ model to safeguard continuity of research and funding

Staffing

1. Using The Royal Marsden @ model to support staff retention and recruitment
2. Implementing a staff retention package for staff who move to the new Principal Treatment Centre, specifically relating to costs
3. Flexible working contracts
4. Assurances to staff that their role is safeguarded

Extract: Explain Consultation Report - Executive Summary (summary from)

Sussex (East and West) and Brighton and Hove: consultation feedback

Good points for options

Evelina London: specialist children's hospital, provides a good level of service, public transport to Evelina London is accessible

St George's Hospital: good level of experience, well connected (for example with The Royal Marsden), established service

Radiotherapy: good idea; good to centralise services and expertise.

Potential challenges for options

Evelina London: far to travel to, lack of previous experience/expertise, cost of travel (e.g. congestion, Ultra Low Emission Zone and parking charges)

St George's Hospital: accessibility issues including car/parking issues, public transport issues, travel issues generally

Radiotherapy: too far, importance of good facilities, for example family accommodation.

What is important to people

Travel priorities: family accommodation nearby, parking on site, ability to get help with the costs of parking and travel charges

Support and information priorities: understanding which staff will still be part of ongoing care, reassurances about how and when the move will happen, extra support and information for those who need it

NB. This slide reflects feedback that was most prominent in survey responses from people who identified that they live within this Integrated Care Board (ICB) area (as set out in the relevant chapter of the independent Consultation Report prepared by Explain Research

Decision-making Process

Consideration of themes

Activity is underway within NHS England to consider themes from the consultation feedback, including (but not limited to):

- Consider all feedback received including new information, discuss mitigations and develop recommendations
- Requesting supplementary information from Trusts where applicable
- Continued work on reviewing the risks and mitigations in relation to both options

Decision on the future location of the children's cancer centre

Who

The decision will be taken by NHS England leaders for London and South East regions.

How

NHS England leaders will take a decision on which option will give them the greatest confidence it will deliver the best quality care for children with cancer in the future. They will look at all evidence available to them, i.e. clinical evidence, workforce and estates information, and the integrated impact assessment etc., including feedback from the public consultation. They will also have regard to their statutory functions and Triple Aim duties.

When

The decision on the future location of the Principal Treatment Centre including the proposed location for conventional radiotherapy, is currently expected to be taken in Spring 2024. The decision-making meeting will be held in public. Details of the meeting will be shared in due course.

Our focus after decision-making

- Once the decision is made, we will work closely with staff in the current service, patients and their families, all the Trusts involved, the cancer network, the Institute of Cancer Research, and other partners to ensure that the move to the future site, wherever it is, is as smooth as possible. All staff involved in the service would have the opportunity to be part of this work. Patients and parents will also be able to help design the new service – the team running the future centre would make sure that people from different groups and communities have the chance to get involved.

- There will be no sudden changes. Services would not move until at least 2026. We expect all the preparations for the future Principal Treatment Centre to take place within two and a half years.

During this time, we will focus on ensuring a smooth transition. Areas of focus include:

- planning and undertaking building work to refurbish existing space for the future centre,
- developing and implementing detailed action plans to address concerns around travel and access
- maintaining the current levels of research activity,
- supporting as many staff as possible from the current service to move to the future centre,
- developing clear patient and family information on the new services, how and when to access them as part of the implementation plan
- putting everything in place for a safe, smooth transfer of patient care.

For more information – please visit our website here

We welcome any questions you may have.

Thank you for your time and we look forward to receiving your formal consultation response