

# Reconfiguration of Children's Cancer PTC serving south London, Kent and Medway, most of Surrey, East Sussex, Brighton and Hove

Presentation to the Brighton & Hove Health Overview and Scrutiny Committee

12 July 2023

# Today we would like to

- Tell you more about plans for the service reconfiguration of the PTC (PTC)
- Share an overview of our work to date including our plans for the forthcoming consultation
- Seek feedback on our plans and on how we work together going forward

# Structure of our presentation

## Agenda

1. Background and case for change
  2. Options development and evaluation
  3. Where are we now
  4. Equality and Health Inequality Impact Assessment
  5. Consultation plan and document, including stakeholder engagement
- Appendix – supporting slides

# 1. Background and case for change

# Caring for children with cancer

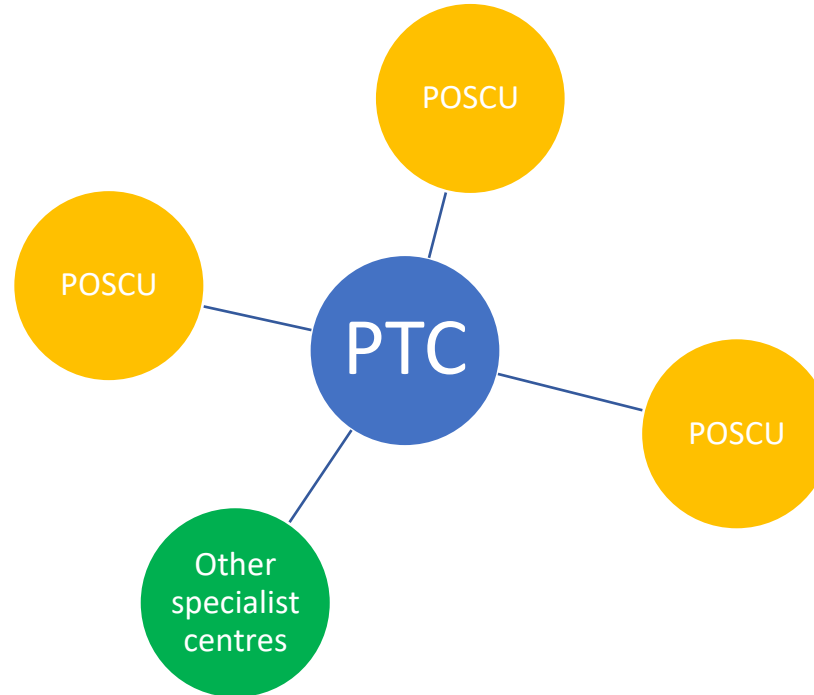
## Principal Treatment Centres (PTCs)

Children with cancer in England receive some of the best care in the world, at the forefront of cutting-edge treatments and technology.

Their care is coordinated and led by PTCs, which provide diagnosis, treatment plans, and highly specialised care for children aged 15 and under with cancer.

PTCs are responsible for making sure each child gets the specific expert care they need for their particular cancer, and for coordinating treatment by different hospitals, if needed. Treatments for cancer in children can be complex and intensive and are often delivered as part of a clinical trial. Children can become acutely ill during treatment, requiring a high level of medical support.

There are 13 PTCs across England.



## Shared care

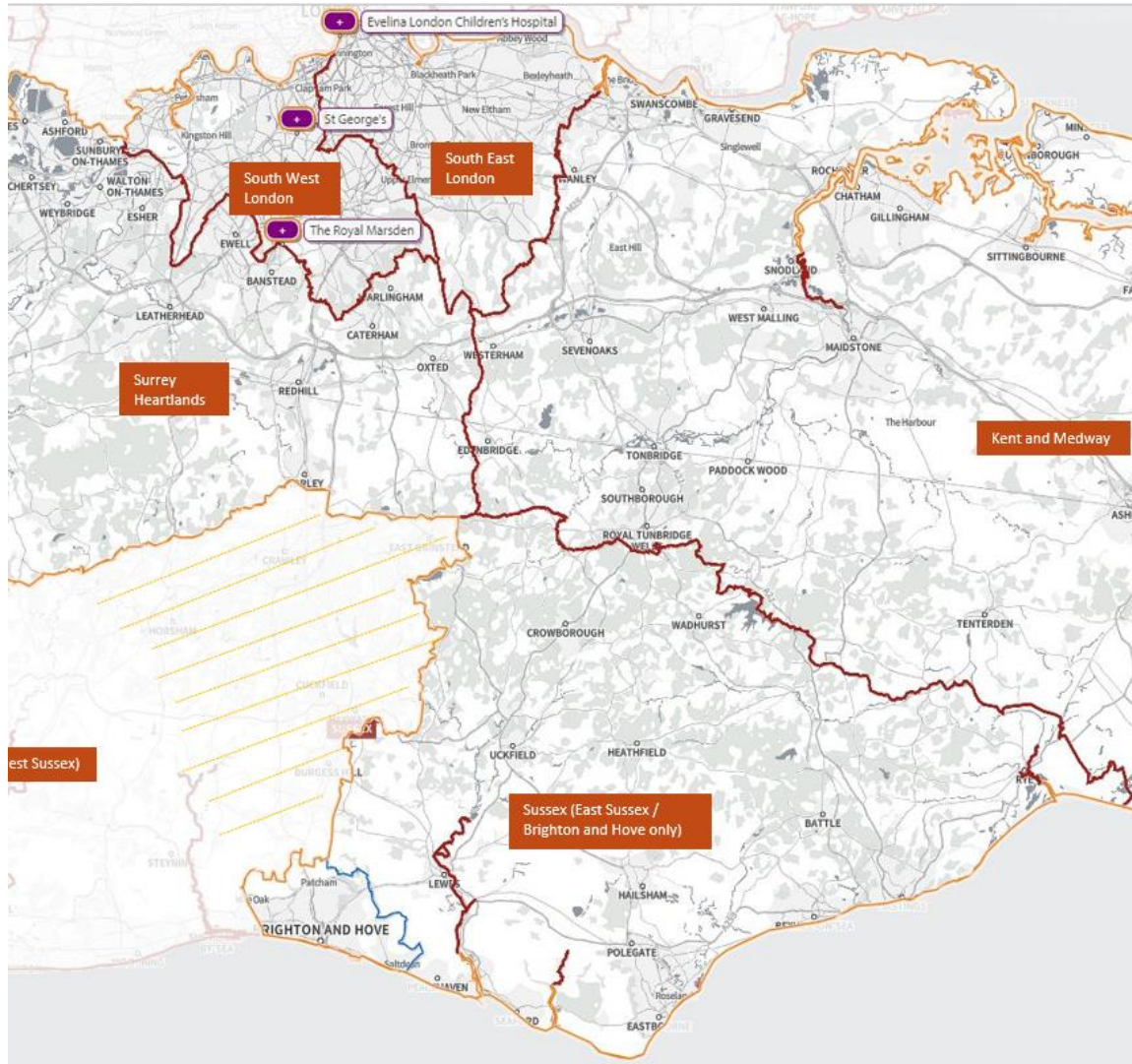
PTCs work in partnership with Paediatric Oncology Shared Care Units (POSCUs) at specified hospitals across their catchment areas, allowing care to be delivered closer to children's homes.

Many children with cancer also receive care in their homes. This can be from staff or 'outreach' services from the PTC, POSCU or staff from children's community nursing teams.

PTCs also coordinate children's care with cancer services that are provided at other specialist centres (if not provided by the PTC), and with national services to ensure children receive the right care at the right time and in the right place.

# The PTC for south London, Kent, Medway, most of Surrey, East Sussex, Brighton and Hove

This PTC is one of 13 across the country. It offers care to patients across a wide catchment area and some patients outside the catchment area who choose to access their care at this PTC. The map below shows the locations of The Royal Marsden, St George's Hospital and Evelina London Children's Hospital. **There is one POSCU (Royal Alexandra Children's Hospital) within Brighton and Hove**



## Children newly diagnosed with cancer

While a diagnosis of cancer clearly has a huge impact on people's lives, it is relatively rare among children.

The rate of diagnosing new cancers among children across Brighton & Hove and East Sussex combined is around **164 cases per million per year**. This means that around **1 child in every 6,100** are diagnosed with cancer each year.

On average, each year there are 7 children newly diagnosed with cancer from Brighton & Hove.

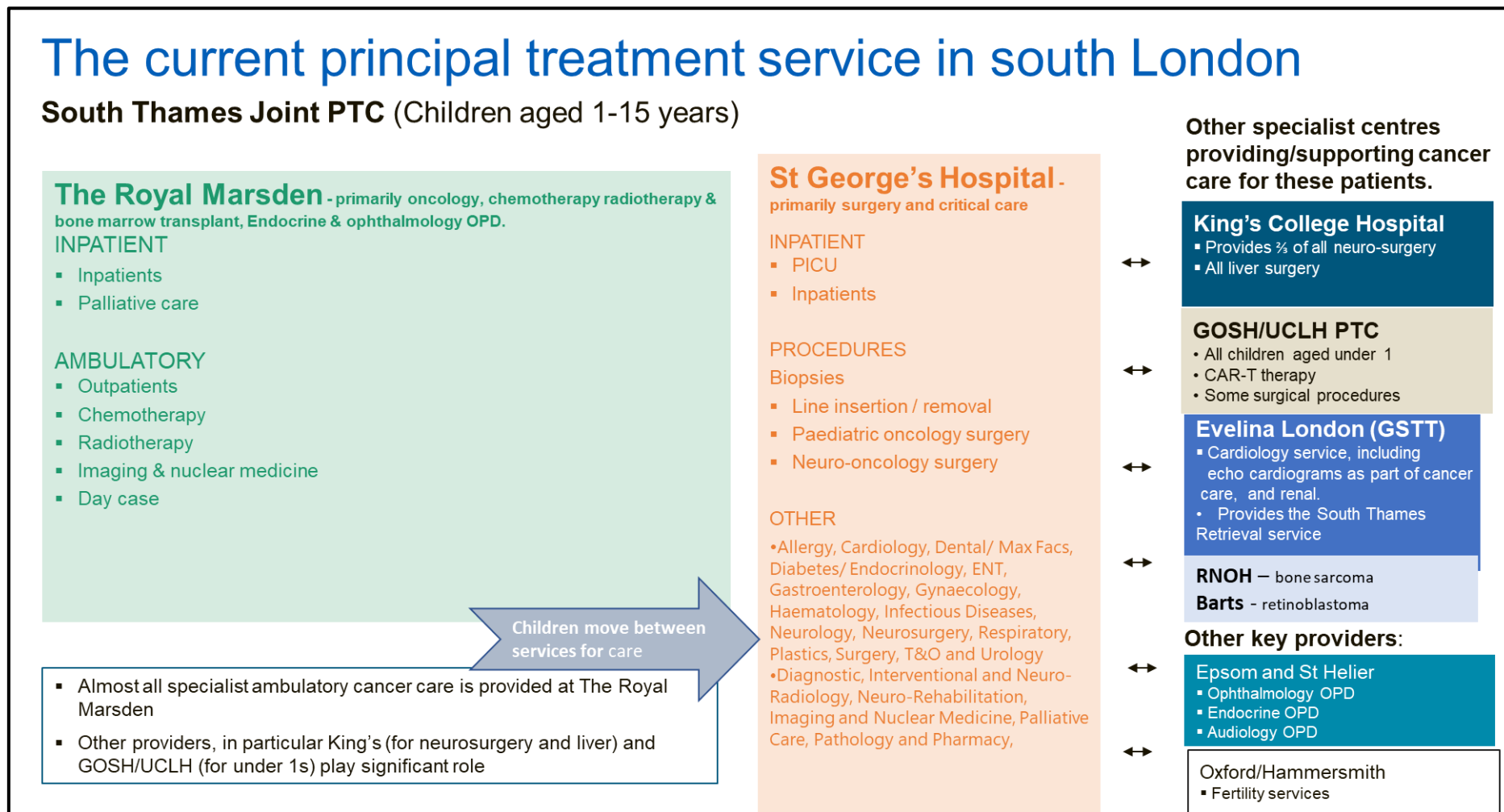
## Children receiving cancer treatment

In total, the PTC treats around 1,400 children per year. Of these, in 2019/20, 22 children (2%) came from Brighton & Hove

All children were seen as an outpatient; 45% also had an inpatient stay.

# The current PTC

- The Royal Marsden provides the majority of inpatient and outpatient care for children with cancer in the PTC catchment area. Care is provided at its Sutton site.
- If children require surgery, critical care and some other specialist children's services they are treated at St George's Hospital in Tooting.
- The Royal Marsden works closely with the Institute of Cancer Research, which is based on its Sutton site, on world leading research into children's cancer care.



*Some children also travel to other London hospitals for care, this is because of the expertise these hospitals have in specialist areas. This will continue in the future too.*



Being on the **same site as a children's intensive care unit and cancer surgery** is now a national requirement for all PTCs in England ([national specification](#) for PTCs, November 2021).

Locating the future PTC on the **same site as children's intensive care** will mean:

- ✓ no more hospital transfers for children who need intensive care\*: very sick children will not need to be transferred eight miles from Sutton to Tooting to receive intensive care. This happens safely but can be very stressful for children, parents, and the staff involved
- ✓ no more hospital transfers for children who the clinical team thinks may need admission to an intensive care unit: pre-emptive transfers to safely manage the inbuilt geographical risk will not be needed
- ✓ fewer admissions to intensive care: some can be avoided if intensive care doctors are able to visit the child on the ward and keep a close eye on progress.

3 Placing the future PTC on the **same site as children's cancer surgery** will:

- ✓ improve patient experience as patients can get more of their care in a familiar place rather than having to find their way around different sites.

Other **benefits** of relocating specialist services for children with cancer include:

- ✓ the ability to provide a service where all PTCs in England are equipped to give complex new treatments which require children's intensive care services to be on-site (such as CAR-T which uses a child's own treated immune cells to treat their cancer)
- ✓ the potential to further develop multidisciplinary team working and research.

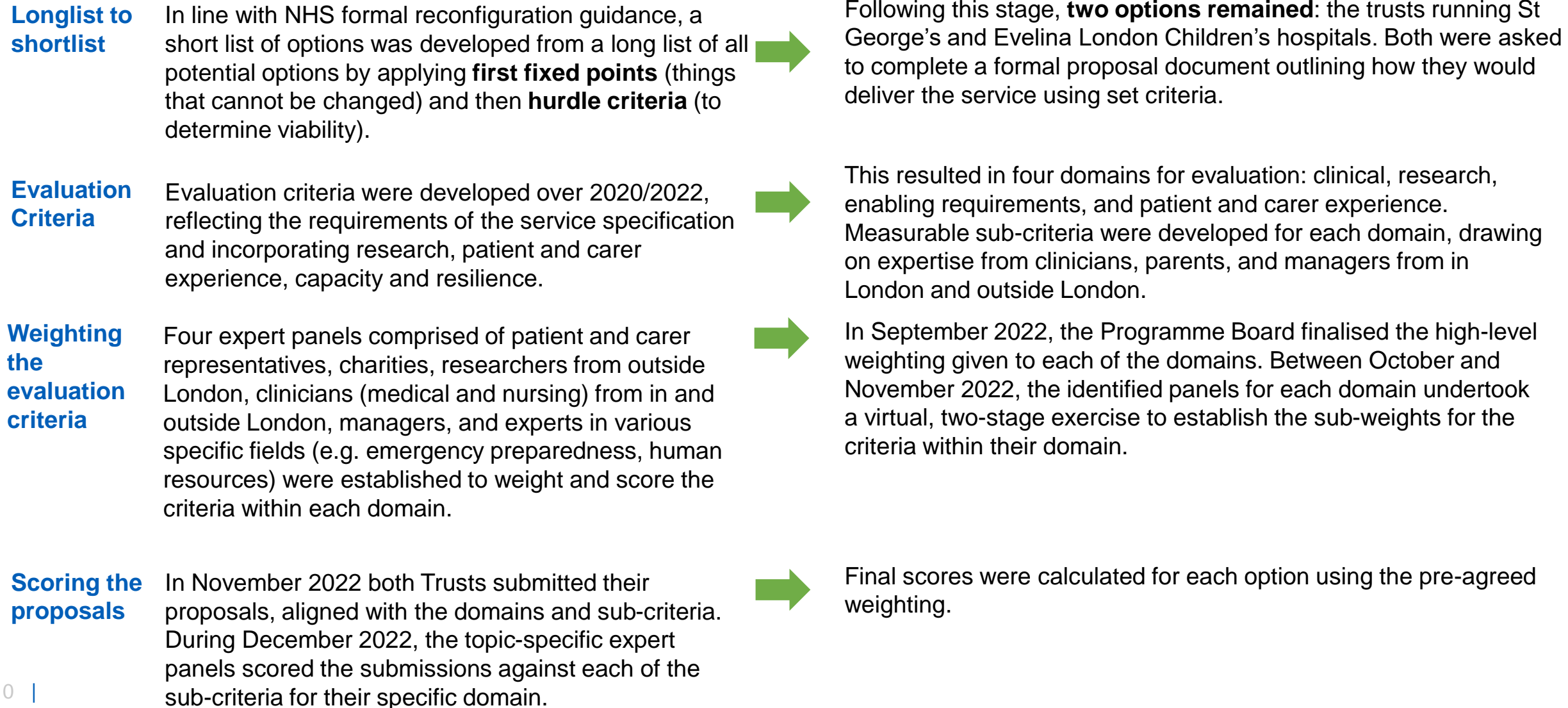
*\*See Appendix for further detail*



## 2. Options development and evaluation

# Summary of options appraisal process

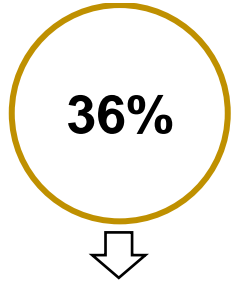
We have already run an option appraisal process – consisting of four elements:



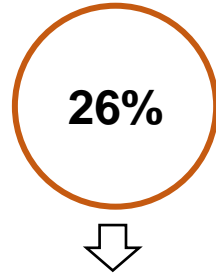
# Final weightings

Programme Board members set the domain weights and expert panels weighted the sub-criteria.

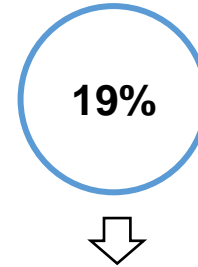
## Clinical domain



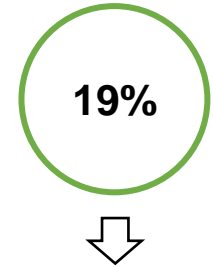
## Patient and carer experience domain



## Enabling domain



## Research domain



**Interdependencies** 35%

**Treatment transfers** 27.5%

**Network effectiveness and system benefits** 19.5%

**Transition** 18%

**Quality of facilities** 25%

**Patient navigation** 23%

**Family support** 21%

**Engagement and collaboration** 16%

**Service accessibility** 15%

**Capacity** 30.5%

**Resilience** 25%

**Organisational support for staff** 23.5%

**Impact on staff** 21%

**Performance and capability** 39%

**People** 32%

**Place** 29%

# There are two strong proposals for the relocated PTC

- Although the services which the **current PTC** in south London provides are safe and high quality, they do not and cannot comply with the national service specification. As it is not a children's hospital, The Royal Marsden does not have a Children's ICU or Children's Cancer Surgery on-site. Children's ICUs are always at hospitals that provide many other specialist children's services. In the context of the change in the service specification, the Royal Marsden is actively contributing to the review process to ensure the very best outcome is achieved for children.
- We are fortunate to have **two strong options** for relocating the PTC which we will be consulting on:
  - **Evelina London Children's Hospital**, which is run by Guy's and St Thomas' NHS Foundation Trust and is based on the St Thomas' site in Lambeth
  - **St George's Hospital**, which is run by St George's University Hospitals NHS Foundation Trust (part of St George's, Epsom and St Helier Group) and is based in Tooting.
- In combination with the new specification for POSCUs, this will enable NHS England London to implement the national vision for children's cancer services, driving continued improvement across the network with enhanced levels of care closer to where children live.

Our vision is that the future centre will lead coordinated children's cancer care of the highest standard across the catchment area. We are ambitious about what we can deliver for our patients by providing care in a specially designed environment that also supports the delivery of new treatments as they become available; continuation of ground-breaking research; and access to clinical trials. We know these things are very important to children with cancer, their families, and the staff who deliver the current service.

# Things to note:

In setting its clinical model, the Programme Board overseeing this reconfiguration made a number of key decisions including:

- No matter which option is chosen, **children will need travel to other London hospitals for the care**, due to the expertise these hospitals have in these specialist areas – services are not going to move as part of the reconfiguration:

Hospital	Services
Royal London Hospital (RLH), Whitechapel	Eye Cancer
Royal National Orthopaedic Hospital (RNOH), Stanmore	Bone Cancer
Great Ormond Street Hospital for Children (GOSH), Bloomsbury	Babies aged 0 to 12 months (all types of cancer)
King’s College Hospital (KCH), Denmark Hill	Liver Cancer
St George’s Hospital, Tooting and King’s College Hospital, Denmark Hill	Neurosurgery: Cancer of the Brain and Central Nervous System
University College London Hospitals’ Grafton Way building (UCL), near Euston	Proton beam radiotherapy (at one of only two proton beam machines in England)

- **Access** - the PTC must be accessible for all service users in terms of journey time and should therefore be based within Greater London.
- **Timeliness** - once a decision has been made, the new service must ‘go live’ within a 2.5 year implementation timeline
- **Affordability** - so long as both options remain affordable, the cost will not influence the decision. Instead, the decision will focus how to create the best possible service for children with cancer.

# Outcome of scoring

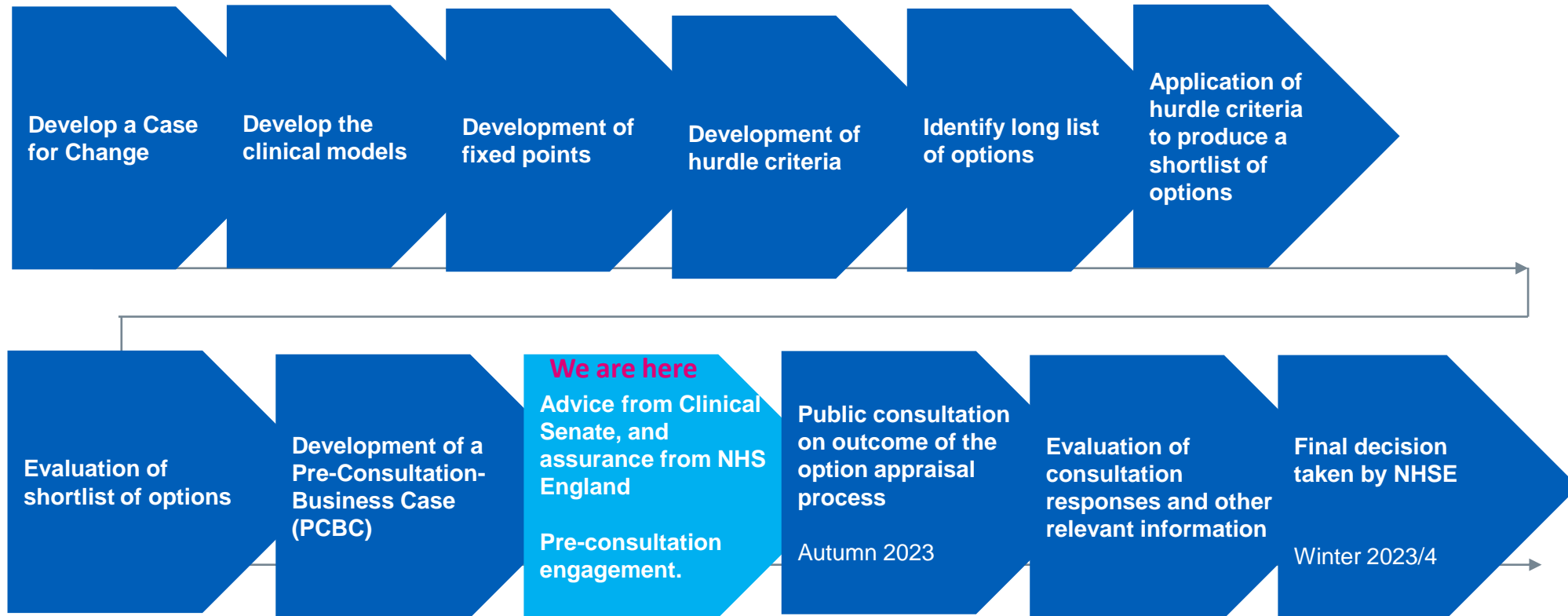
- The Evelina London Children's Hospital option received a higher overall score than the St George's option, scoring higher in three of the four key areas.
- Based on the evidence provided by the evaluation, Evelina London is NHS England London's preferred option at this stage in the process.
- Both options scored highly and are viable options for the location of the future centre. We are very much keeping an open mind.
- NHS England London will only make their final decision on the location of the future centre after hearing the views that come forward during the public consultation and taking account of all other relevant factors.

## 3. Where are we now

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# Where we've been and where we are now



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

*Consultation with Brighton and Hove HOSC will continue in forthcoming months; including during the decision-making phase.*

## 4. Equality and Health Inequality Impact Assessment

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**Purpose of the EHIA**  
To support meeting legal duties including the Public Sector Equality Duty (Equality Act 2010) and the Health and Social Care Act

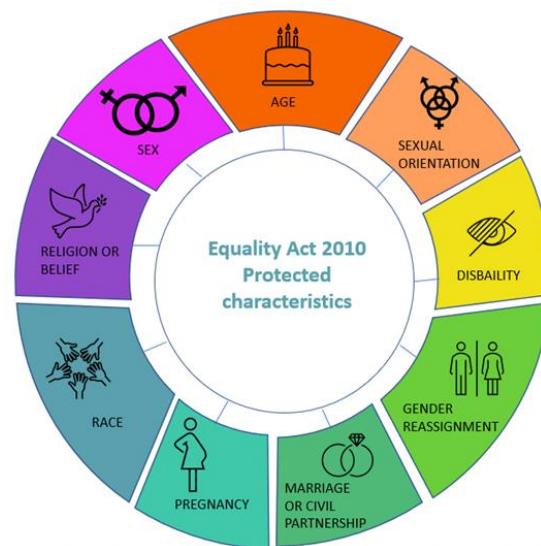
## What changes are we assessing the impact of?

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

### Additional considerations:

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

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



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

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

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

## Sources of information used:

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



## Impacts of travel time differences on health inequalities (access)

When comparing travel times to the current PTC main site (The Royal Marsden) to either future PTC location, travel time analysis shows:

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



## Other impacts:

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

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

For example, patients and/or families:

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

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

## Benefits for improving outcomes and reducing inequalities:

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

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

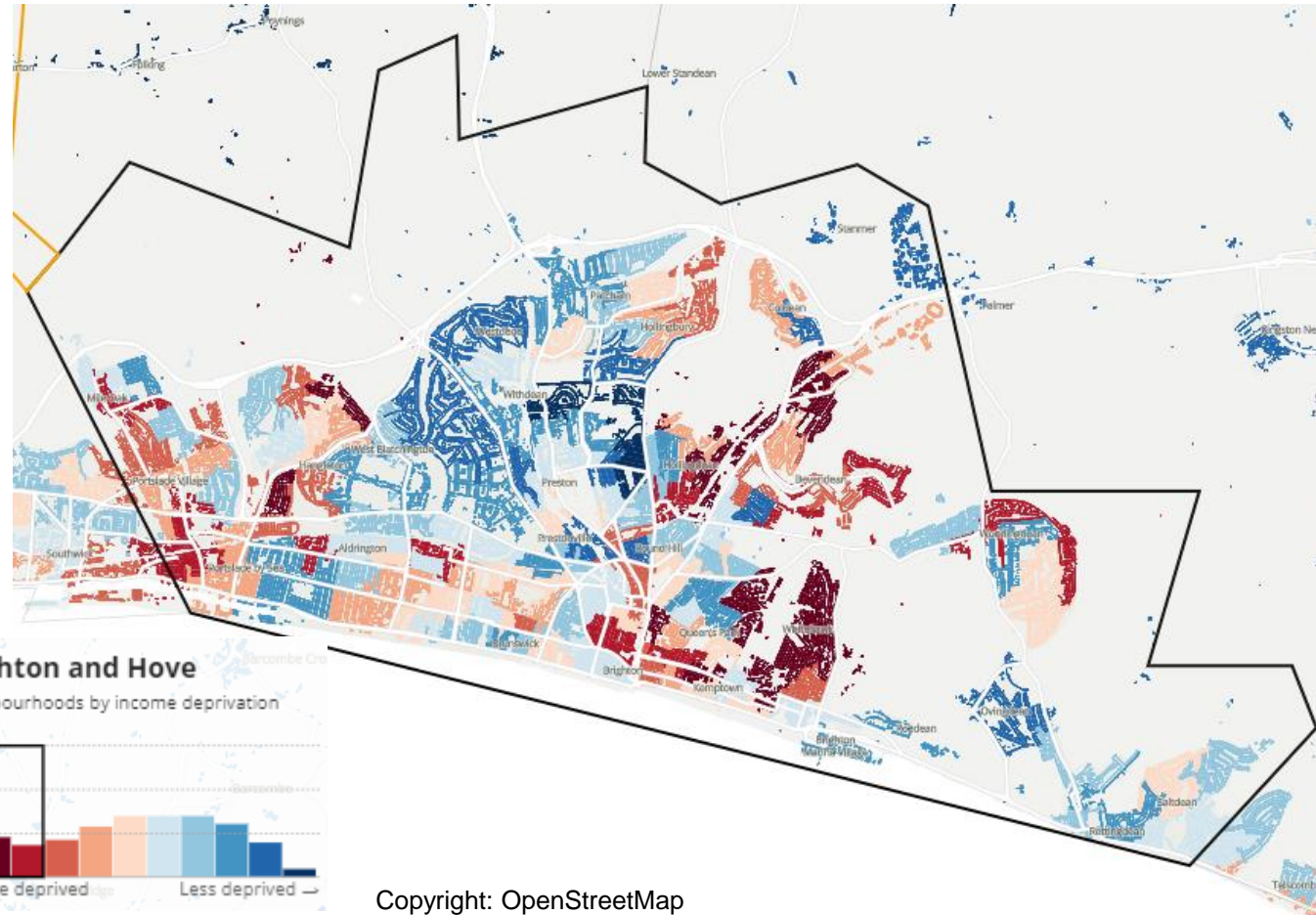
# Equality and Health Inequality Impact Assessment: Travel from Brighton & Hove



Travel time modelling confirms that journeys by public transport to Evelina London would be around 14 minutes faster and 8 minutes faster to St. George's (on average).



Journeys by road vehicle would (on average) be around 50 minutes longer to Evelina London and around 30 minutes longer to St. George's.



Of the 165 neighbourhoods in Brighton & Hove, 27 were among the 20% most income-deprived in England.

[Exploring local income deprivation \(ons.gov.uk\)](https://ons.gov.uk)

The Interim Equalities and Health Inequalities Impact Assessment (to be released as part of the suite of public consultation documents) contains a range of proposals for mitigating the financial impact of patient journeys that may increase as a result of the change in PTC location. A summary is included on the next slide.

Copyright: OpenStreetMap

*Please see Appendix for travel time analysis methodology*



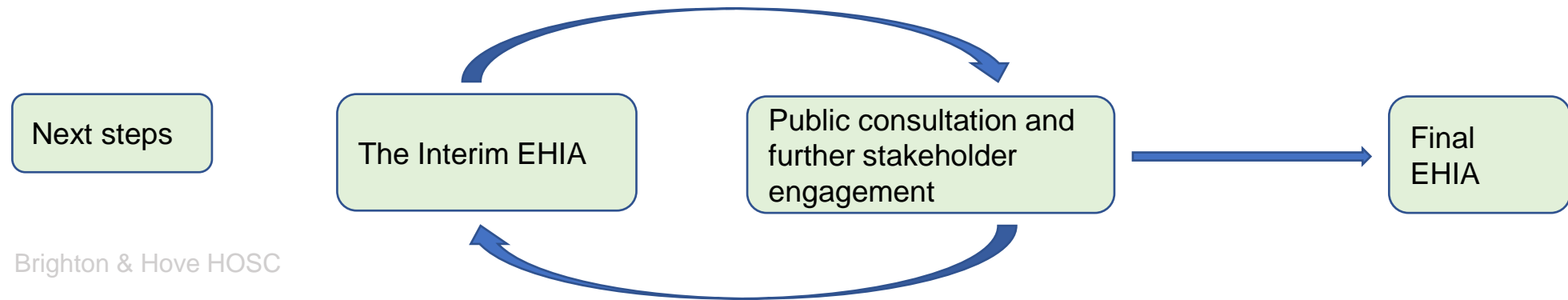
# Equality and Health Inequality Impact Assessment: mitigation & next steps



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

The main themes include:

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



## Other impacts

Alongside the duty to reduce inequalities of outcomes, NHS England – London, have, and will continue to give due regard to:

- The wider impact of the decision made
- The need to contribute towards compliance with the UK net zero emissions target (s. 13NC NHS Act)



## 5. Consultation plan and document, including stakeholder engagement

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# We seek to ensure an inclusive engagement approach

We are:

- Working with **experts in the voluntary and community sector** to include a range of views from within and outside the PTC catchment area
- **Commissioning specialist expert organisations** to ensure we reach EIA groups and children and young people in an effective and appropriate way.
- Learning from Trust and ICB engagement colleagues to develop **relationships** with key stakeholders to be **inclusive of seldom heard, minority and deprived population groups**
- **Using intelligence** from the EHIA to **inform engagement plans** to focus on those most affected and impacted groups
- Historic engagement (via both surveys undertaken) has reached a **range of ages, ethnicities and geographies**

**Planned engagement** (during pre-consultation and consultation) will focus on reaching professionals and different groups:

**Current and recent service users and their families and carers**

**Voluntary and community organisations**

i.e. those supporting children and young people and other communities identified here, including Healthwatch

**Staff**

Most intensively with those working in these services but also informing wider staff groups to understand any impacts

**Health and care partners**

i.e. connected services and other nearby Trusts

**Children and young people from Black and other minority ethnic communities**

**Children with physical and/ or learning disabilities or autism**

**Scrutiny and assurance bodies**

i.e. Overview and Scrutiny Committees and both Clinical Senates across south London and the south east region

**Focus on all geographic areas patients currently come from**

**Focus on all age band between 0-15 years**

# Feedback has informed our approach to date

## Engagement phase

**Early engagement and options appraisal**  
(March 2020 - January 2023)



**Pre-consultation**  
(March 2023 – August 2023)



**Consultation**  
(Autumn 2023)



**Decision- making**  
(Winter 2023/4)

## How engagement is influencing the process

Fed into the development of the case for change and options appraisal process.

Helping us to plan the consultation and understand what some of the key issues may be.

Will help us understand the impact of implementing either proposal and consider mitigations.

Feedback considered, alongside other evidence, to support the decision-making process.



Stakeholders who have been involved in this process to date:

- Parents/carers and children and young people
- Staff Researchers
- Stakeholder group
- Clinical Advisory Group
- Voluntary and community organisations

# Engagement to date – pre-consultation (work in progress)

## Pre-consultation (March 2023 – August 2023)

**Purpose:** Helping us to plan the consultation and understand what some of the key issues may be.

### Activities:

- **Held/attended 6 feedback sessions** with different groups
- Attended informal and formal meetings with **local council Overview and Scrutiny Committees** to discuss the programme and our plans
- **Undertaken 3 ward visits** to speak to parents and families – with further sessions planned
- Using **surveys** to capture feedback from staff and current service users – including asking about travel and access
- Stakeholders are **reviewing and feeding back** on our consultation plan and document

**Impact of engagement:** Refining and updating our consultation plan and document. Creating new information and in different formats to meet communication needs. Working with Trusts t

## Reach and representativeness

**Spoken to over 320 individuals to date** via 1:1 basis, via email, through surveys or at meetings – most with direct experience of receiving or providing the service as well as voluntary and community organisations like **specialist children's cancer charities** and **Healthwatch organisations**.

- from a range of, but not all, geographies within the PTC catchment area
- from a range of ages (both of children, young people and parents/carers)
- who have physical or mental health conditions, disabilities, or illnesses other than their cancer (40%)
- from black, Asian and other minority communities (40%)
- who do not speak English as their first language (23%)
- who had had experience of The Royal Marsden Hospital (100%) or St. George's Hospital (53%) and Evelina London (11%)

The appendix contains a high-level summary of feedback received and how we are acting on what we're hearing

# Travel and access

## **Asking staff, children and young people and parents/ carers about travel and access as part of the pre-consultation phase**

What we know\* is:

- Around 75% of travel to appointments are made by car/taxi, with the remaining 25% by public transport
- Those who use their car/ taxi for transport tend to live outside of London (over 52%)
- Over 30% are already travelling over an hour to get to appointments at The Royal Marsden and over 75% are already travelling over 30 minutes to get to appointments.

## **We are feeding this data into our travel analysis work**

*\*for CYP and families we spoke to with direct experience of current service (n.b. more data to come following St. Georges site visits)*

# Consultation: aims

We have two strong options for the future PTC.

The consultation aims to inform NHS England – London on our decision on which option will offer the best service for children with cancer in the future.

The **purpose of the consultation** is to:

- engage with as many people as possible in the geography affected by this service change and hear their views on the proposals for the future location of the children’s cancer PTC
- understand the impact of implementing either proposal and any mitigations or enhancements that could be put in place
- ensure NHS England - London, as decision-maker, is made aware of any information which may help to inform the options and the decision-making process.

Public consultation is not a vote or referendum, and we are asking stakeholders to consider each proposal in its own right.

Outside scope of consultation:

- Shared care units which provide cancer care to children in local hospitals are not affected by this consultation.
- Cancer services for teenagers and young adults (generally for 16 to 25-year-olds but with some flexibility around ages) will continue to be provided at The Royal Marsden.

# Consultation document – updated following stakeholder feedback

Our preparations for consultation remain ongoing, this includes ongoing review and assurance of our pre-consultation business case and associated consultation materials as part of NHS England's Stage Two assurance process. In parallel with this, we have received a lot of feedback during the pre-consultation phase, there remains ongoing work to review this and reflect it in our documentation.

## Consultation document: proposed content includes

- How people can get involved (including hard copy questionnaire)
- What the consultation is about (and what services won't change)
- Why a change is needed and benefits
- Our proposals
- What the proposed changes would mean
- What children, parents and staff have told us about the impacts
- Developing and assessing our shortlist
- The options
- Other impacts (including travel and other services)
- Scoring outcome
- Our preferred option
- Timetable and next steps

## Appendices/other supporting documents include:

- Summary consultation document
- Easy read document
- Consultation questions
- Consultation plan
- Early engagement feedback report
- Animation
- Factsheets on development, summary and evaluation of the proposals, financial aspects including costs, getting to the two potential sites, transition offer to teenage and young adult service
- Initial Equalities and Health Inequality Impact Assessment (EHIA)
- Feedback from the Clinical Senate



# Consultation: engagement methodology & key questions

## Engagement methodology

- **Writing to current and recent service users and their families/carers**
- **Online events**
- **Targeted sessions with the stakeholder group and other charities/ Voluntary and Community Sector (VCS) organisations** already closely involved with us
- **Community outreach to children and young people and their families with specific characteristics** identified in the equalities impact assessment
- **Creative activities on existing sites with children and young people currently accessing services** (through working with a play therapy organisation)
- **1:1 interviews/ survey completion on existing sites with parents/carers**
- **Attending existing meetings** in the community
- **Survey** (including an easy read version)
- **Wide use of simple animation** to raise awareness and encourage feedback
- **Sharing information through existing contacts and networks** including Facebook group for RM parents
- **Posters with QR codes** linking to online materials
- **Briefings**
- **Offering non-digital channels:** completion of surveys by post, interviews by phone, printed documents in wards/given out by Royal Marsden volunteers/in flats used by long-stay parents

## Consultation questions will focus on:

- Understanding of the case for change
- Views on key aspects of both proposals such as travel, access and research
- Ideas around how to mitigate or enhance impacts
- Understanding how we could make implementing the change easier for those currently in the service

## Appendix: Supporting slides

- Case for Change - references
- Travel time analysis – methodology
- Pre-consultation engagement – who we have contacted
- How stakeholder feedback is influencing our consultation plans and documents

Transferring critically unwell patients is associated with a risk of physiological deterioration and adverse events<sup>(1)</sup> and the emotional and psychological stress for parents should not be underestimated<sup>(2)</sup>. Although specialist transport services have been shown to enhance safety and quality<sup>(3)</sup>, the 2008 “[Safe and Sustainable](#)” framework, produced by clinicians and endorsed by the relevant Medical Royal Colleges, states that paediatric oncology and paediatric intensive care have “absolute dependency, requiring co-location”. It is this clinical advice, backed up by subsequent expert reviews<sup>(4)</sup> that underpins the national service specification requirement.

#### References:

1. Droogh, J.M., Smit, M., Absalom, A.R. *et al.* Transferring the critically ill patient: are we there yet?. *Crit Care* **19**, 62 (2015). <https://doi.org/10.1186/s13054-015-0749-4>
2. Harvey, Edmunds, Ghose. Transporting critically ill children. *Anaesthesia & Intensive Care Medicine* Volume 21, Issue 12, December 2020, Pages 641-648
3. Gilpin Hancock. Referral and transfer of the critically ill child. *BJA Education*, 16 (8): 253–257 (2016)
4. NHS England [board-meeting-item-9-update-on-specialised-services-c-appendix-2.pdf](#) ([england.nhs.uk](http://england.nhs.uk))

# Travel time analysis: methodology

Travel time modelling software was used to generate public transport and car journey travel times for all children (aged 15 and under) living in the PTC catchment to each of the three provider locations, from their “origin” (based on their Lower Super Output Area\* (LSOA) of residence). There are 4,000 LSOAs within the PTC catchment area.

Travel times are for the fastest trip departing from resident origin for arrival at midday on a Wednesday. Metrics used in the analysis are median and longest travel times (minutes) and the proportion of the population within a 60 minute journey time of each provider, by public transport and driving.

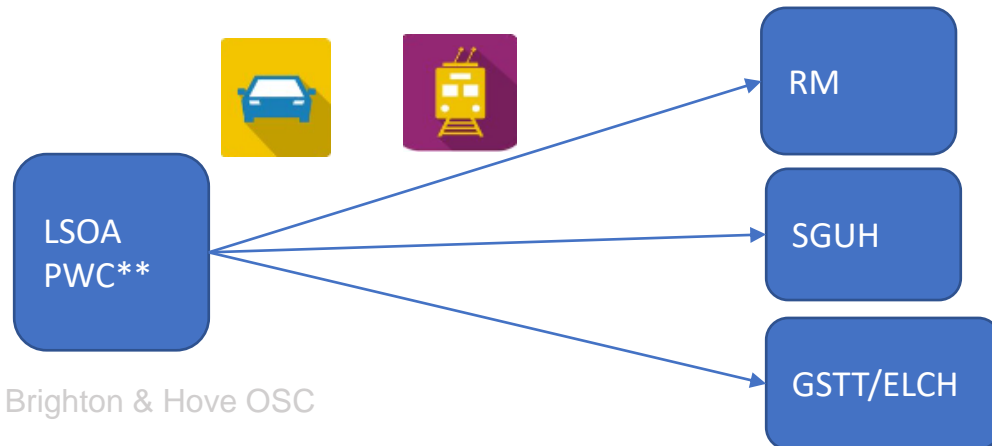
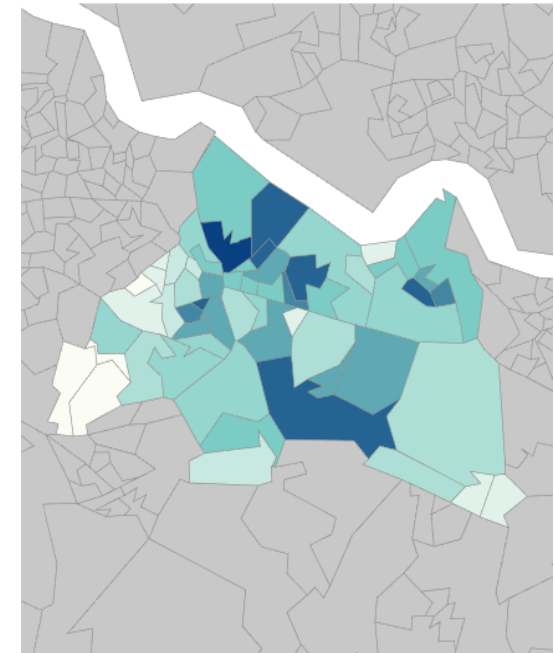
The modelling uses both road networks and timetabled transport networks. The potential combination of travel modes for each journey by public transport are national rail, tram, light rail, tube, bus, coach, ferry, and walking to and from stops and interchange, and walking alone if quicker. A public transport journey was only measured if a station or stop was reachable within an initial 20 minute walking time (only 0.2% of LSOAs did not meet this criteria).

The travel measures are intended to provide a typical indication of the quickest journey from origin to destination for people travelling with no additional requirements. Individual experiences may not completely align with the estimated times.

**\* Note: Lower Super Output Areas (LSOAs)** are a small area geography averaging approximately 1,500 people. Each LSOA has a PWC (population weighted centroid) which represents the centre of the distribution of residents across the LSOA.

Population estimates are available at LSOA level and each LSOA is assigned an [Index of Multiple Deprivation \(IMD\)](#) score and an [urban/rural classification](#). This allows for travel time analysis by these classifications. More information on the IMD is in [Appendix B](#)

Illustration of Lower Super Output Areas (Dartford)



# Early engagement activity (2020-2023)

## Early engagement (March 2020- March 2023)

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

### Activities:

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

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

## Reach and representativeness

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

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

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

**Below is a list of the different types of organisations we have contacted as part of our pre-consultation engagement:**

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

# What we are doing as a result of feedback

- **Updating key documents**

- *Consultation plan*
- *Consultation document*
- *Equalities and Health Inequalities Impact Assessment*
- *Travel Analysis*

- **Creating new documents** to be published at consultation launch

- *Factsheets*
- *Updating our FAQ documents*
- *Posters to enable quick responses to consultation*

- **Strengthening our governance** around patient and public voice

- *National charity representation on our Programme Board*

# What we are doing as a result of feedback

- Working more closely with charities and providers to **help us prepare for consultation**
  - *Offering site visits*
  - *Testing materials to make them children and young people friendly*
  - *Exploring possibilities for creating social media content with children and young people*
  - *Using existing networks like parent groups to reach more people*
- Considering what information can be put in the **public domain**, even **before we launch consultation**
- Seeking **external assurance** around our consultation plans from **The Consultation Institute**
- Producing public **information about how a decision will be made**, what information will be considered and if any weighting will be given to different items



# What we are doing as a result of feedback

- **Rewording our case for change** so that it better describes the benefits and reasons for the change
- Working with Trusts to think now about: **how we can mitigate some of the impacts** that are coming through on feedback (specifically around transfers, travel and access and clinical quality), how they would plan to **involve people in implementing the change** and how **transition could be managed**
- **Seeking additional data** from Trusts around the impacts they have identified to their organisations so that this can be considered in the process
- Meeting with **research organisations** to seek feedback
- Working with Trusts to **strengthen mitigations around travel and access**