

Changes to children's specialised cancer services Principle Treatment Centre Programme – South London & South East England

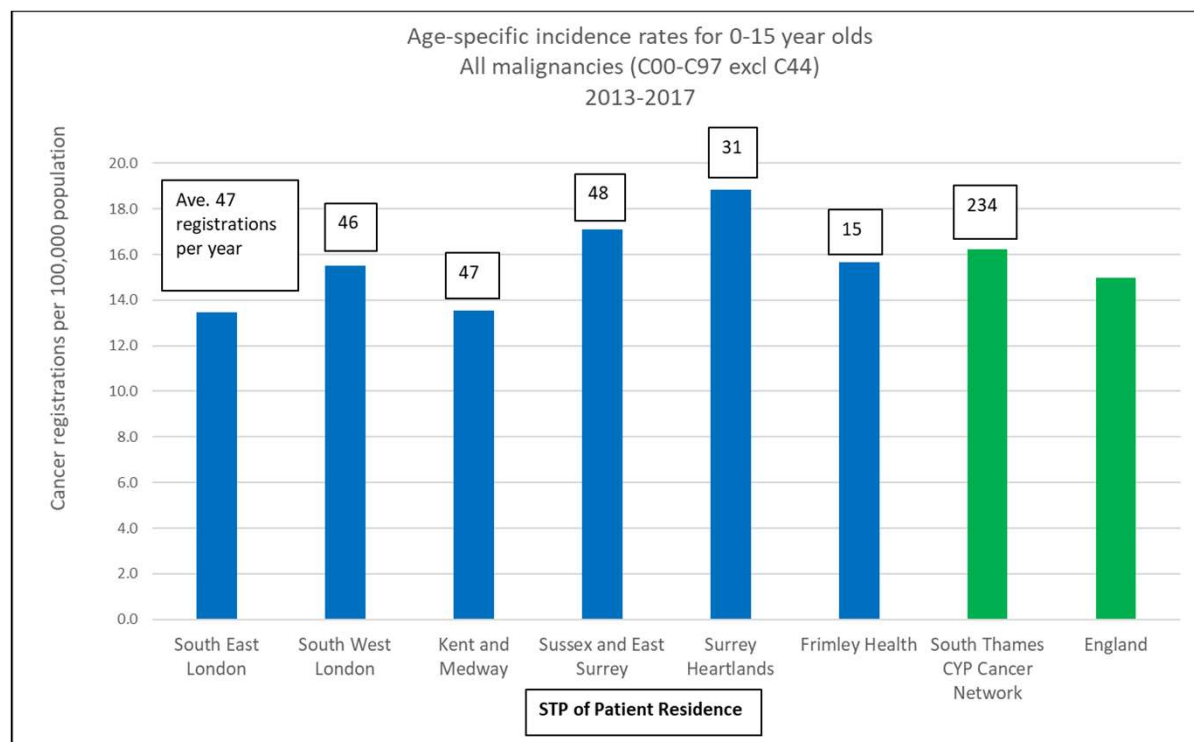
Kent HOSC

January 2023

Purpose of the discussion

- Explain how Children's Cancer services are currently organised and which services are in scope for this service change
- Explain why changes to the current service provision is required i.e. the case for change
- Describe the implications for people from Kent
- Describe the work of the programme to date
- Demonstrate how we have already been engaging to support our thinking
- Outline the broad timeline we are working to
- Discuss next steps – developing a JO SC for this service change

The South Thames Children's Cancer Network: incidence by area of residence



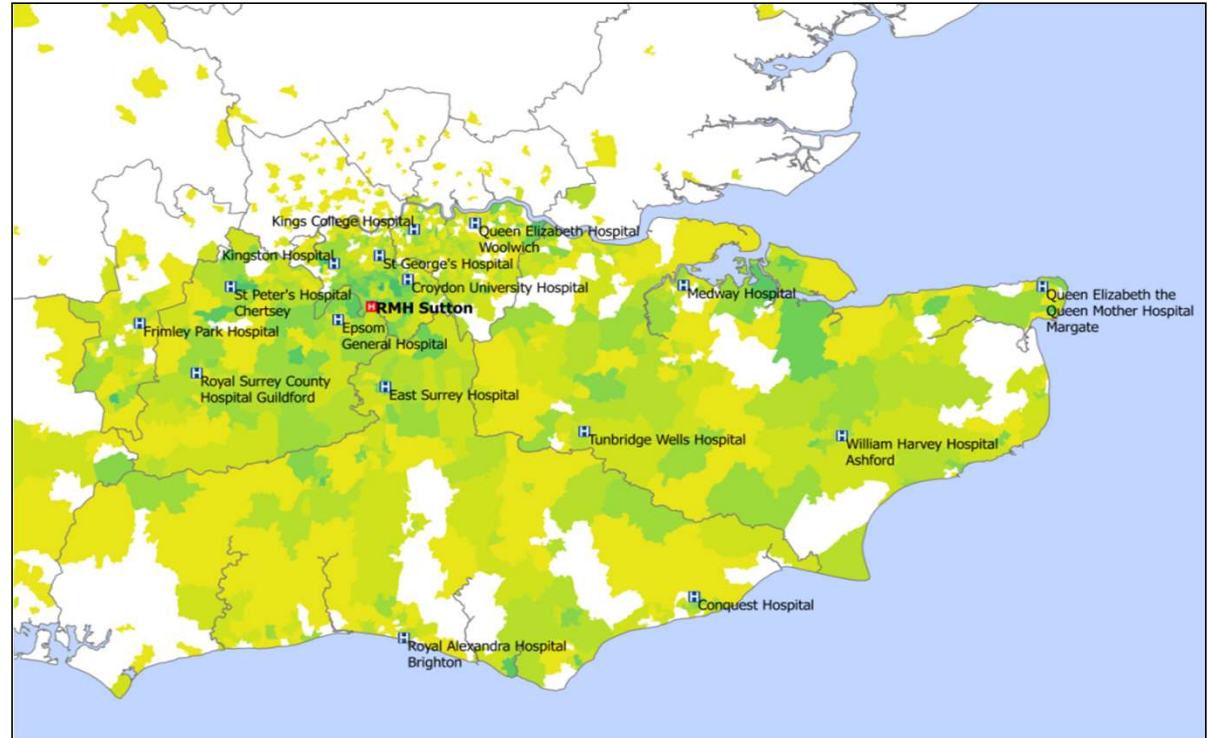
Childhood cancer is relatively rare, and on average 1,400 children (ages 0-15) are diagnosed with cancer in England per year. Most cancers affecting children are different than those affecting adults (e.g. occur in different parts of the body and respond differently to treatments).

The age-specific incidence rates for childhood cancer do not vary significantly across the network and are similar to England. On average there are around 234 new cancer registrations per year amongst residents of the South Thames Cancer Network.

Different cancer types are more common at different ages, with leukaemia being most common in under five year olds, CNS tumours being the most common cancer in those aged 10-14 years, and lymphomas and carcinomas increasing with age

About the programme – the current service

- NHS England is **responsible** for commissioning specialist services, including **children's cancer services for those aged 0-15 years**
- In England on average **1,400 children (under 15 years) are diagnosed with cancer every year** – meaning **very small numbers** of children need to access these services
- **All children and young people** in the UK who are diagnosed with cancer are treated in **one of 19 Principal Treatment Centres (PTCs)** which are responsible for coordinating and delivering care
- Currently, the joint PTC in this area (**The Royal Marsden NHS Foundation Trust and St George's University Hospitals NHS Foundation Trust**) covers; **Kent and Medway, Surrey, Sussex, south east and south west London**. This PTC received **c400 referrals** per year and has an **active caseload of c1500 patients**.
- **Paediatric Oncology Shared Care services (POSCUs)** allow children and young people with cancer to be treated closer to home so that families do not need to travel long distances to the nearest PTC for some procedures. The map shows the POSCU's associated with the joint PTC in London



Paediatric Oncology Shared Care services associated with the joint PTC run by The Royal Marsden NHS Foundation Trust and St George's University Hospitals NHS Foundation Trust in London.

In 2019/20 107 children from across Kent and Medway accessed the joint PTC. Numbers from other areas are similar.

The current principal treatment service in south London

South Thames Joint PTC (Children aged 1-15 years): c400 referrals per annum
Active caseload of c1500 patients

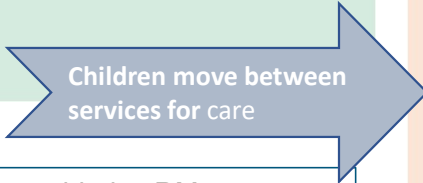
The Royal Marsden (RM) - primarily oncology, chemotherapy radiotherapy & bone marrow transplant

INPATIENT

- Inpatients (18 beds of which 75% used by -16s, c470 admissions pa).
- Palliative care (c100 palliative and symptom patients per year)

AMBULATORY

- Outpatients (c5,800 attendances pa)
- Chemotherapy (c3,600 attendances pa)
- Radiotherapy (c800 treatments pa)
- Imaging & nuclear medicine (3,700 images pa)
- Day case treatment/procedures (1,800 procedures pa)



- Almost all specialist ambulatory cancer care is provided at RM
- Other providers, in particular KCH (for neurosurgery and liver) and GOSH/UCLH (for under 1s) play significant role

St George's Hospital (SGUH) - primarily surgery & critical care

INPATIENT

- PICU (c65 admissions pa, average 1.5 beds)
- Inpatients (4 beds, c135 admissions pa).

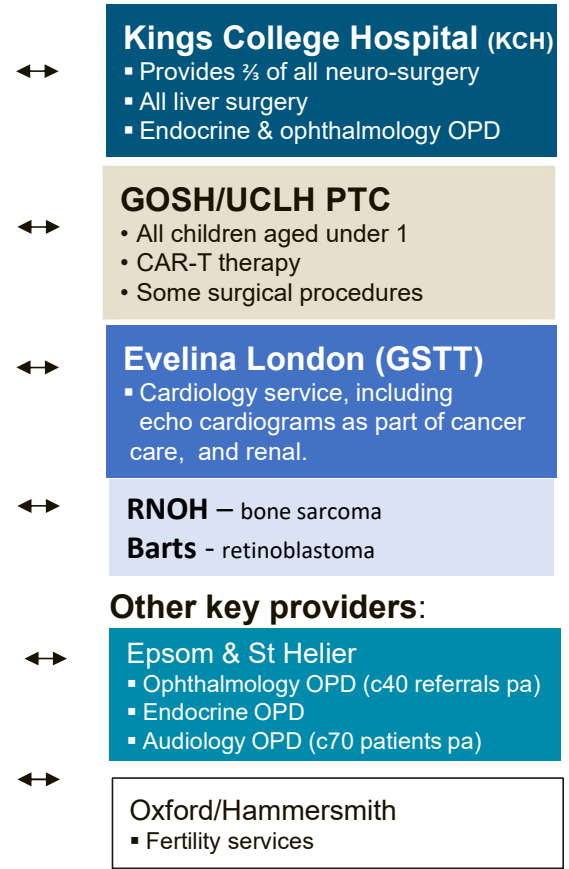
PROCEDURES

- Biopsies (c45 pa)
- Line insertion / removal (c190 pa)
- Surgery incl. neuro-surgery and tumour resections (c20 pa)

OTHER

- Neuro-rehab
- Specialist paed's including gastroenterology, neurology, dental, bronchoscopy/respiratory, infectious diseases, gynae, urology, Max Fax, plastics

Other specialist centres providing/supporting cancer care for South patients.

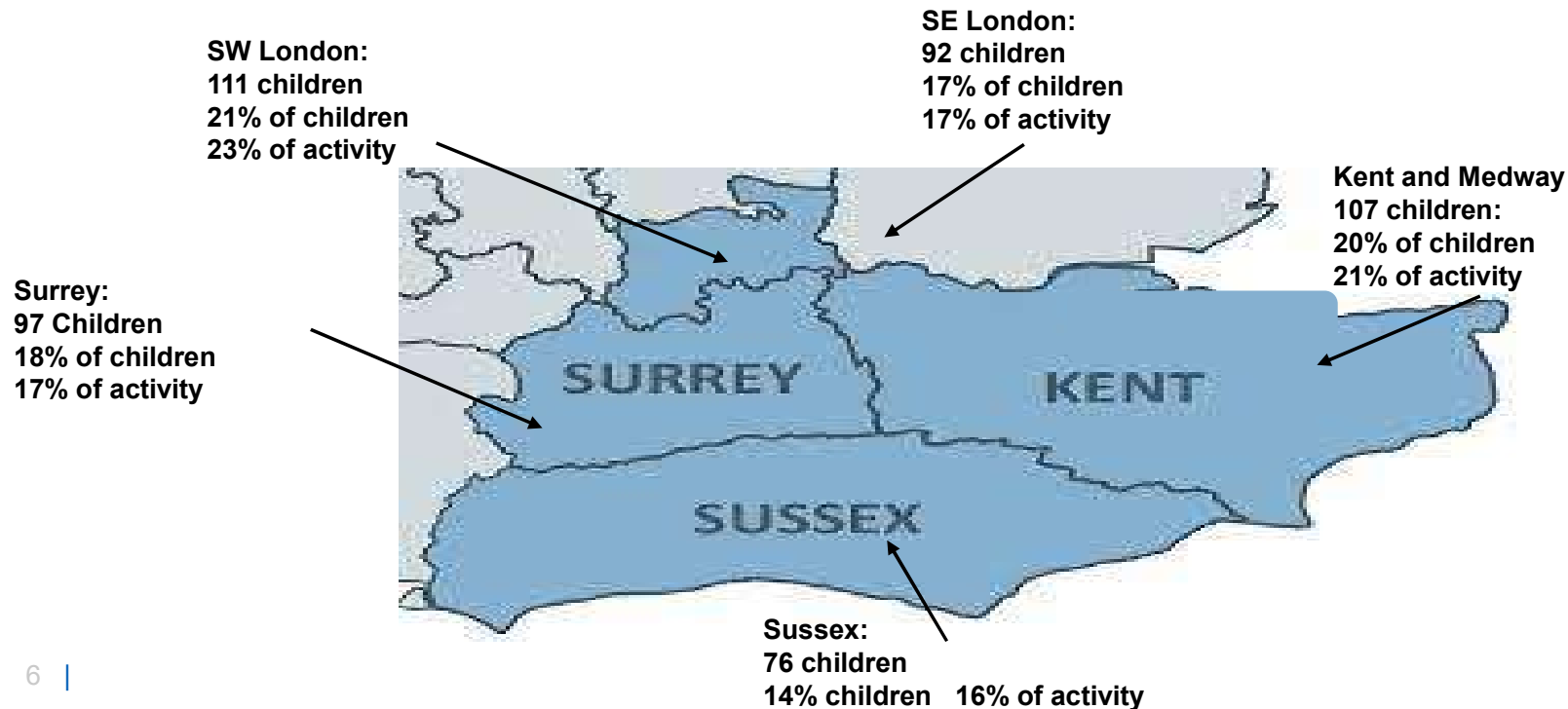


Children accessing inpatient PTC cancer care

Activity at RM and SGUH (2019/20) for those aged 0-15

Overall inpatient activity

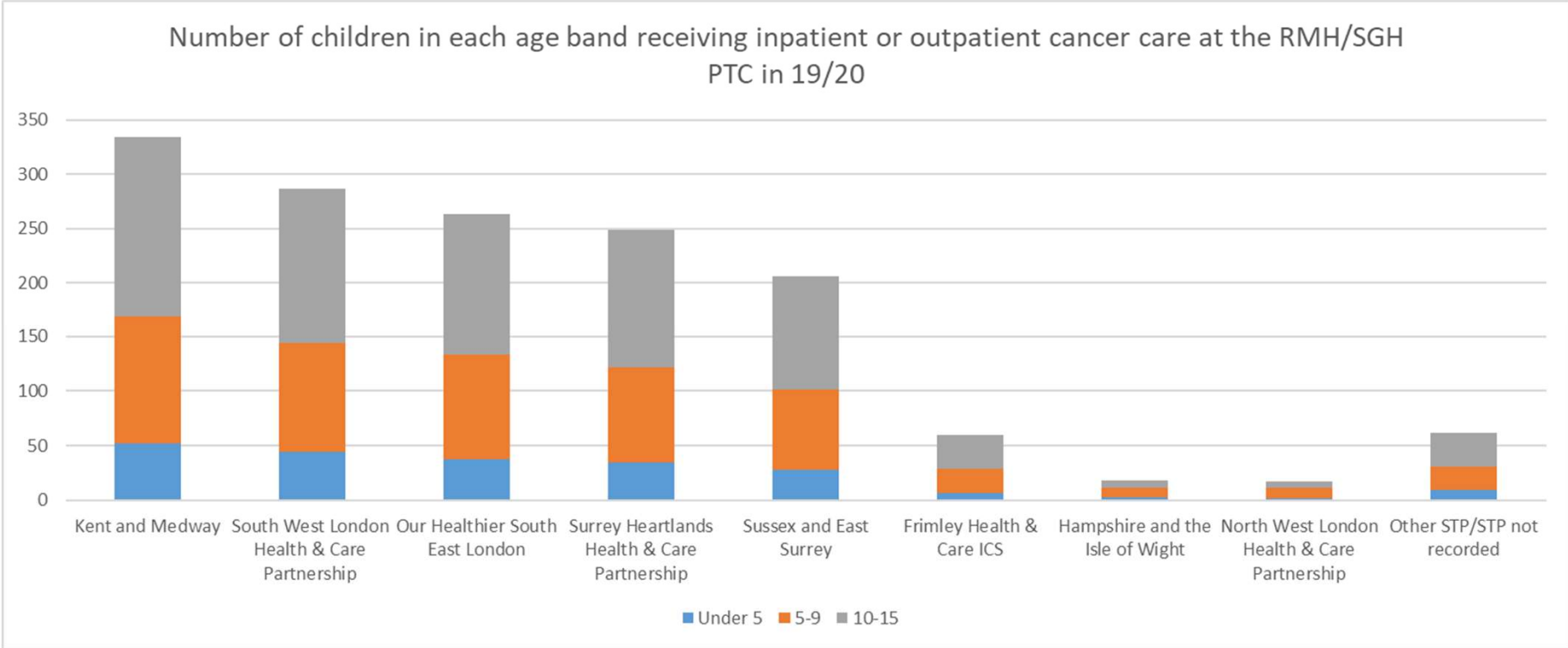
In 19/20, 88% of a total 536 children using the RM/SGUH PTC for inpatient care and 91% of all inpatient activity related to children came from five main areas.



All children accessing PTC cancer care

Activity at RMH and SGUH (2019/20) for those aged 0-15

In 19/20, there were almost 1,400 children aged 0-15 who accessed paediatric cancer care as either an inpatient or outpatient at the primary treatment centre provided by The Royal Marsden and St George’s. 210 of these children were aged under 5, 526 aged 5-9 and 737 aged 10-15.



A new national service specification for PTCs

- Children in the UK currently receive some of the best cancer care in the world, utilising cutting-edge treatments and technology. Following a number of reviews of services nationally, NHS England has worked with professionals and patients and consulted the public on a new set of service specifications which set out how services should be organised in the future. These have been published and are available [here](#). In particular they wanted to:
 - **Improve integration** between different children's cancer services;
 - **Improve experience of care**
 - **Improve participation in clinical trials**
 - Tackle variation, ensuring that patients got the **same high quality care, regardless of where they were treated**
- Standards for Principal Treatment Centres were developed by clinicians, patients, families and providers to ensure that wherever children and young people receive specialist cancer services, it would be the same excellent care across the country from diagnosis to management and follow-up of cancer
- The outcomes of the 2019 consultation on the standards was reflected in a new service specification for PTCs (published [here](#) in November 2021) which includes **a requirement for Principal Treatment Centres to be delivered on site with Paediatric Intensive Care Units**, alongside paediatric surgery, radiology, haematology and paediatric anaesthetics, with ideally a range of other specialist children's services too.
- These specifications set out how services should be provided in future and meet the highest safety considerations, as well as ensuring that services are able to meet the needs of new technologies and treatments.

Changes are needed to meet the new service specification

- London has internationally renowned paediatric cancer services – **the new specification helps strengthen them even further** by creating future facing services able to excel in new treatments modalities making the need for an on-site PICU is even more necessary
- The **Royal Marsden NHS Foundation Trust currently provide high quality and safe specialist children’s cancer services on behalf of London and the south east. The research undertaken by the RMH is outstanding.**
- The current PTC is provided across The Royal Marsden (Sutton site) and St George’s University Hospital NHS Foundation Trust, **but there is no PICU at The Royal Marsden (Sutton site)** meaning the PTC does not comply with the new specification
- Professor Nicholas van As, Medical Director for The Royal Marsden NHS Foundation Trust, has said recently: “it is not economic to provide PICU services with a highly specialised workforce at a greater number of locations including The Royal Marsden, Sutton. Given this decision, The Royal Marsden will not be bidding to remain a PTC but will work in partnership for the benefit of children with either St George’s Hospital, our existing partner, or Evelina London Children’s Hospital.”
- The programme is in the process of undertaking an **options appraisal process** on a shortlist of options, in order that services can be **relocated to comply with the new specification.**

Though the number of children, young people, families and carers using these services is very small, what is provided is vital and specialist care. Therefore, our Programme Board feels that any changes to these services would be significant and we are planning for a formal consultation.

What are the expected benefits of any change?

A service ready for the future

With paediatric intensive care available on the same site as the principal treatment centre for children's cancer, the service will be ready to deliver new types of care, such as immunotherapies to very sick children.

More care delivered on a single site

We won't address all of the service fragmentation in London, but we do want to maximise the number of other specialist children's services delivered on the same site as the PTC, meaning that children will be able to receive care from clinicians skilled in a wider range of specialist care for children. This will not just mean that treatment transfers are reduced, but coordinated holistic care is also increased.

Good treatment for staff

We aim to match and ideally improve on the current training and support offer to staff.

Compliance with the national service specification

The service specification includes standards which are in place to ensure all children receive the best possible care.

10 Compliance in itself should be seen as a very positive step.

Fewer treatment transfers

Streamlining access to critical care will happen immediately once the PTC is on the same site as a PICU. This will remove the need for emergency transfers. Availability of a wider range of clinical specialties on the same site as the PTC should also reduce the limited number of other transfers that also occur currently. Care models that reduce transfers further will be one of the evaluation criteria.

Although The Royal Marsden/St Georges service is safe and offers excellent care, all treatment transfers carry risk, and the aim should be to minimise these where possible.

Managing Risks during the transition

We are assessing the two short-listed options against four key criteria:

- Clinical
- Research
- Patient and Carer Experience
- Enabling support (workforce, capacity, resilience)

We aim, by taking this approach, to protect what is excellent in the current service, including research, and build on this for the future.

We will work with all parties to ensure the benefits of this change are realised.

Work to date

Work has recently restarted on the programme, following a pause due to COVID

A developing governance structure

- Formal programme board – membership includes tertiary trusts in south London providing specialist children’s care, the south east and south west London ICBs, NHS England London and south east regions
- Clinical advisory group
- Communications working group
- Patient and stakeholder advisory group
- Children and young people (CYP) sub-group

Understanding impacts

- Early engagement work undertaken with parents, carers and children and young people
- Development of equalities impact assessment
- Development of a travel analysis

Planning for consultation

- Planning an inclusive and proportionate consultation
- Working with charities and trusts to explore how we can better reach CYP
- Beginning to map organisations and channels in all geographies to make best use of existing relationships

Options appraisal process

- Working with current and potential providers to understand solutions to meet the service specification
- Long list of options developed
- Evaluation criteria created with input from experts including clinicians, parents and carers
- Initial shortlisting undertaken resulting in, a **short list of two options**. With either option, services would cease at The Royal Marsden.
 - St George’s University Hospitals, the partner provider with The Royal Marsden of the current children’s cancer PTC; and
 - Guys and St. Thomas’ NHS Foundation Trust’s Evelina children’s hospital, the largest specialist centre serving south London and the south east of England.
- Further work from November to January to **evaluate both solutions and arrive at a preferred option**

Assurance

- Working with London and south east region Clinical Senates to provide further expert clinical appraisal
- Undertaking NHS England assurance
- Early conversations with affected OSCs

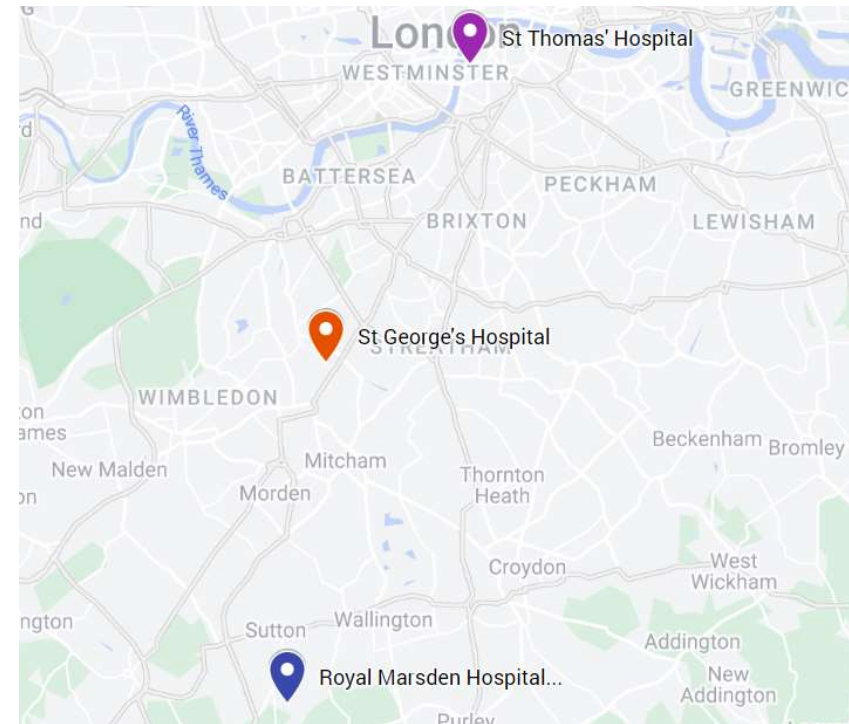
The picture in Kent and Medway

Potential impacts

- In 2019/20 107 children and young people from across Kent (96) and Medway (11) accessed the service - which is similar to numbers from other areas accessing the same service
- Any changes proposed are unlikely to be implemented until 2026, following consultation
- Both options being considered still require travel into London and mean services will cease at the Royal Marsden Hospital
- St. Georges option means travel to the St. Georges Hospital site in Tooting (see map opposite)
- Evelina London option means travelling to St. Thomas' Hospital site near Waterloo (see map opposite)

Involvement in the programme

- Involvement from ICBs, Trusts and the Children and young peoples cancer network in our governance
- As we begin planning for consultation we are working to ensure we are connected with charities and local groups working with children and young people with cancer in Kent and Medway



Map depicting where services may be provided in future (St. Georges Hospital or Evelina London) and where they are currently provided (St. Georges Hospital and the Royal Marsden)

Children who use this PTC come from a broad geography and therefore **we will want to engage all OSCs likely to be affected** as we plan for consultation. We want to discuss with you **the most time and resource efficient way to do this.**

Engagement to date: working with children, young people and parents/carers across London and the south east



During our early engagement, between September 2020 and March 2021 we had :

- **Six meetings** with the stakeholder group, involving 17 parents - who input to discuss engagement plans, options development, domain and sub-criteria content and weightings
- Approximately **62 contacts** with parents/carers /caregivers, which were a combination of meetings, individual conversations with parents (telephone or virtual) and email contacts - to support their participation and engagement
- **208** survey and interview responses to an externally commissioned survey - to understand what was important to children and young people around children's cancer services
- **50** survey responses from the stakeholder group and current inpatients – feeding back around the sub-criteria scoring for the patient experience domain

Engagement was paused until spring 2022 due to COVID pressures.

New activity since autumn 2022:

- Supported a **panel of parents to participate in the options appraisal process**, developing and scoring the patient experience domain.
- **Re-established the stakeholder group**, in November 2022, **to support us as we develop our consultation plan**. This group includes parents, carers and organisations that provide support across London and the south east.
- Started a **children and young people's sub-group**, in January 2023, to support us to understand how we can better engage with CYP as we plan and undertake wider engagement work

How engagement has made a difference

Feedback from children, young people and parents/ carers during this early phase of engagement has already influenced a number of important aspects of the programme. Below is a snapshot.

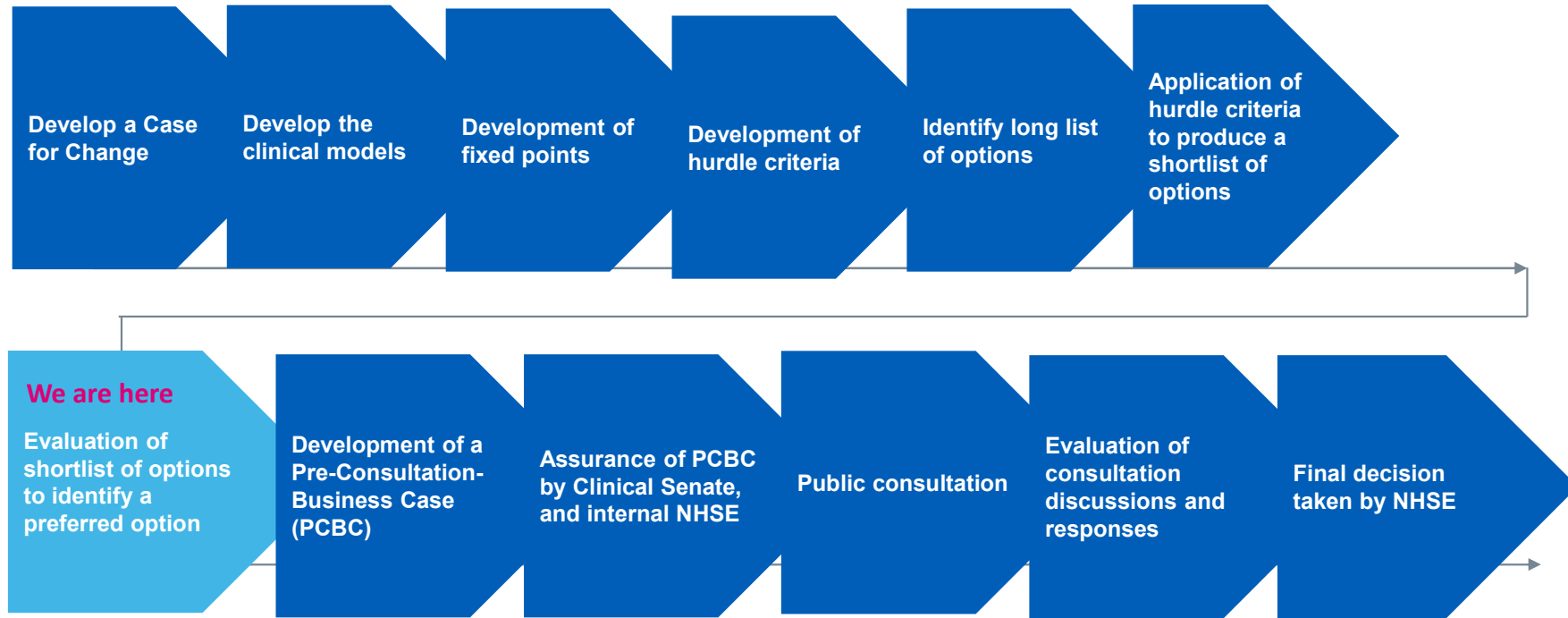
Supporting communications and engagement planning

- Informing frequently asked questions.
- Designing and agreeing the Association for Young People's Healthy survey (AYHP) questions to ensure they were accessible.
- The stakeholder group recommended wider engagement with current service users, which has been undertaken by providers and fed into the options appraisal process.

Options development

- Feedback from the stakeholder group and AYHP survey provided feedback on current patient experience and what was important, from their perspective, in terms of the service.
- As a result of feedback, several changes and additions were made to the patient experience domain criteria.
- Current service users on wards were surveyed to understand what good looks like in several areas of the sub-criteria.

Where we are in the formal reconfiguration process



Programme timeline/ expected milestones

January - June

- Options appraisal concluded
- Planning for consultation
- Development of Pre Consultation Business Case
- Development of Equalities Impact Assessment
- Meeting with Clinical Senate
- **Meeting with OSCs/JOSCs**
- Commissioning of expert organisation(s) to support engagement
- Preparing consultation materials and questions

June - September

- **Expect to launch and conduct consultation**
- Equalities Impact Assessment updated
- Conduct mid-point review

September - December

- Consultation feedback analysed and outcome report prepared
- Programme Board considers feedback ahead of decision making
- Decision Making Business Case Prepared
- Decision confirmed and communicated – consultation respondents notified
- Begin planning to implement decision

Working with you going forwards

In November, we started a cycle of early conversations with OSC Chairs from all areas to brief them on the programme and discuss how we best work together. We understand that guidance suggests forming a JOSC in these circumstances, but that this requires significant time and energy – especially as this programme involves inner and outer London OSCs (Kent and Medway, Surrey, Sussex and south east and south west London).

We would want to engage with you **at several key points** in the process, including at least one meeting before, during and after consultation to:

- Brief all members about the programme and impact in their area
- Present and discuss plans for consultation and seek feedback
- Share key documents like the pre-consultation business case and consultation materials
- Share the outcome of the consultation and the decision
- Share plans for implementation and the impact this may have on each area

Our proposed approach to engage with you

We will be engaging with each of the affected OSCs/ JOSCs to understand if they believe the changes are substantial for their residents. If more than one committee agrees the changes are substantial, then there will need to be a Joint HOSC. We would like to explore whether there is the opportunity for regional JHOSCs to scrutinise the consultation outcomes and form a view as to whether to recommend referral to the Secretary of State.

We believe this will enable:

- Early engagement with OSCs to happen so that members are briefed and can be involved in conversations about planned activities in their local area
- Understanding of whether individual areas feel the change is substantial and how they would like to be involved/ engaged throughout the process
- Enable enough time for the practicalities of a JOSC to be worked through so that a group could be properly constituted
- A balance between understanding local concerns and preferences and having a shared conversation
- Everyone to have an equal voice

Discussion and next steps

Discussion questions:

- Do you, as a committee, view this change as **substantial**?
- If you do not think it is substantial, how would you like us to engage with you moving forward?
- If you think it is substantial, what further information would be helpful at this time?

Should more than one overview and scrutiny committee call the proposal substantial, we will work with the relevant Committee chairs and officers to determine the most practical way of coordinating a Joint HOSC.

Next steps:

- Agreeing arrangements for engagement and working together moving forward
- Meetings with other OSCs involved to understand their views
- Background work with democratic services teams to take forward feedback from today's session