

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

**Evaluation Criteria**





# Introduction

Guy's and St Thomas' NHS Foundation Trust, which runs Evelina London, and St George's University Hospitals NHS Foundation Trust, which runs St George's Hospital, each put in proposals to be the site of the future Principal Treatment Centre.

In these proposals, they set out responses to questions about their expertise, experience, skills and plans for the future Principal Treatment Centre.

Their responses to these questions were assessed and scored by four expert panels, one for each of four key areas for the future service. The proposals were tested across all four key areas, because the Programme Board overseeing this work had been told by stakeholders that this was a complex decision and needed to incorporate a number of factors.

The evaluation considered the proposals from a range of perspectives to help us assess the two options in more detail before going out to consultation. The four areas were:

- 1) clinical services,
- 2) patient and carer experience,
- 3) enabling (non-clinical) factors,
- 4) research.

To undertake the assessment and scoring, the panels used evaluation criteria which had been developed with involvement from many different experts.

Each panel received the section of the evaluation criteria pack relevant to their domain, and this is what was used to guide their scoring of the two proposals.

Slide four onwards of this pack sets out the evaluation criteria shared with panels in November 2022.

# Evaluation Criteria



# Evaluation criteria

This pack sets out the evaluation criteria and scoring framework for each criterion and sub-criterion to support quantifiable and consistent scoring of domains. Scoring is currently set as swing scores between 0-10.

The criteria are intended to be as objective as possible, with evidence assigned to scores based on:

- the requirements of the service specification
- evidence of current delivery of CYP oncology services or equivalent experience delivering complex specialised CYP services, applying best practice standards where documented (see appendix)
- publicly available data (where published)
- data from the data lake or separate provider submissions (i.e., workforce)

The criteria were developed in line with the service specification published in November 2021 and through a wide process of engagement informed by stakeholder, clinical and managerial inputs. This pack details the final set of evaluation criteria to be used in the option appraisal process.

# Clinical Domain

# Clinical Domain – Scoring Framework 1: Interdependencies

Evaluation Criteria	Interdependent Service	Yes – 1 point per positive	No - 0 point											
<p><b>1.1 Interdependencies<sup>^</sup></b> (see appendix 1 for service specification excerpt)</p> <p><b>Purpose:</b> This was an important part of the required transformation, to ensure that children and young people have access to the greatest density of specialty skill through the co-location of services.</p> <p>Assessing % of patients able to readily access services ensures that these benefits are available to the highest number of patients.</p>	<p>The services that are listed in the service specification as a must will be assessed via the hurdle criteria, so this evaluation criteria looks at those services listed as not required to necessarily be delivered on site but PTCs will need to ensure the services are readily available with a preference given to where the services are on site.</p> <table border="1" data-bbox="479 505 1243 1293"> <tr><td>Paediatric Radiotherapy services</td></tr> <tr><td>Paediatric Endocrinology services</td></tr> <tr><td>Paediatric Nephrology services</td></tr> <tr><td>Paediatric Neurosurgery</td></tr> <tr><td>Paediatric Ophthalmology</td></tr> <tr><td>Paediatric Gastro-enterology service</td></tr> <tr><td>Paediatric Cardiology services</td></tr> <tr><td>Specialist Paediatric surgery (other than management of emergencies, central lines and biopsy services)</td></tr> <tr><td>Paediatric pathology</td></tr> <tr><td>Paediatric Infectious Disease</td></tr> <tr><td>Paediatric Palliative care</td></tr> </table>	Paediatric Radiotherapy services	Paediatric Endocrinology services	Paediatric Nephrology services	Paediatric Neurosurgery	Paediatric Ophthalmology	Paediatric Gastro-enterology service	Paediatric Cardiology services	Specialist Paediatric surgery (other than management of emergencies, central lines and biopsy services)	Paediatric pathology	Paediatric Infectious Disease	Paediatric Palliative care	<p>Does the provider currently have bed-based provision for each of the interdependencies on site? Bed-based provision is defined as physically on-site consultant programmed activities (PAs) for 7 days a week and robust 24/7 cover for all services specifically for paediatrics (in line with Keogh requirements).</p>	
Paediatric Radiotherapy services														
Paediatric Endocrinology services														
Paediatric Nephrology services														
Paediatric Neurosurgery														
Paediatric Ophthalmology														
Paediatric Gastro-enterology service														
Paediatric Cardiology services														
Specialist Paediatric surgery (other than management of emergencies, central lines and biopsy services)														
Paediatric pathology														
Paediatric Infectious Disease														
Paediatric Palliative care														

<sup>^</sup> It is recognised that there is a national review of radiotherapy services following the introduction of Proton Beam Therapy. Responses should indicate the current position and any known changes. [Genomic testing; - it was agreed by Clinical Advisory Panel (CAP) that Genomic testing did not need to be available onsite within 30 minutes, so is excluded from the evaluation criteria.] Neurology is not included in the specification at this time and therefore not included in this criteria.

# Clinical Domain – Scoring Framework 2: Transition

Evaluation Criteria	Low Swing 0 points	2 points	4 points	6 points	8 points	High Swing 10 points
<p><b>1.2 Transition</b></p> <p><i>(see appendices 2a, 2b &amp; 2c for further information on draft specification requirements and best practice to support scoring)</i></p>	No response given; or does not meet the requirements in any way; or provides no evidence that the proposed service will be delivered in accordance with the specification.	No confidence provided by the response with limited reference to the requirements in the service specification and/or limited examples of transition support in line with best practice.	Limited confidence provided by a response that covers most requirements in the specification, but one or more areas lack detail/ evidence giving rise to some minor concerns.	Confidence provided by a response that meets the service specification requirements and best practice, with evidence of the proposed service achieving compliance in full against 1-2 of the NICE Transition Quality Standards for children with cancer and partial compliance against the other standards.	High level of confidence provided by a strong response that addresses the service specification requirements and is in line with best practice, with evidence of the proposed service achieving compliance in full against 3-4 of the NICE Transition Quality Standards for children with cancer and partial compliance against the other standards.	Exceptional level of confidence provided by a very strong description of transition services that exceeds the requirements of the service specification, best practice and evidence of the proposed service achieving compliance in full with all NICE Transition Quality Standards for children with cancer.
<p><b>Purpose:</b> Whilst the scope of the service reconfiguration relates to children up to the age of 16, there is an important externality for teenage and young adult patients. This is therefore assessed to understand how transition to other services is supported given the relation to clinical outcomes.</p> <p><i>Experience of delivering care for children with cancer, which may include CYP oncology services will support confidence in the responses provided</i></p>						

# Clinical Domain – Scoring Framework 3: Treatment Transfers

Evaluation Criteria	Low Swing 0 points	2 points	4 points	6 points	8 points	High Swing 10 points
<p><b>1.3 Treatment Transfers</b></p> <p>Refer to appendix 3 for analysis of treatment transfers</p>	There is no evidence of pathway management that would give confidence that relevant treatment transfers would be minimised.	No confidence provided by the response, with minimal evidence of pathway management that would suggest that relevant treatment transfers would be minimised.	Limited confidence provided by a response that evidences some description of pathway management that would suggest that relevant treatment transfers would be minimised.	Confidence provided by a response that evidences clear pathway management that would suggest that relevant treatment transfers would be minimised.	High level of confidence that relevant treatment transfers would be minimised, provided by a strong response with evidence of active and routine pathway management.	Exceptional level of confidence that relevant treatment transfers would be minimised, provided by a very strong response with very strong evidence of active and routine pathway management.
<p><b>Purpose:</b> <i>There was a particular concern within the Professor Sir Mike Richards review on 'shuttling' of children between sites. This criterion focuses on the small group of treatment transfers which are potentially avoidable, and where a transfer would adversely impact on patient experience and safety.</i></p>						



# Clinical Domain – Scoring Framework 4: Network Effectiveness and System Benefits

Evaluation Criteria	Low Swing 0 points	2 points	4 points	6 points	8 points	High Swing 10 points
<p><b>1.4 Network Effectiveness &amp; System Benefits</b></p> <p><i>(see appendices 4a &amp; 4b for specification requirements and further information on the network maturity assessment framework to support scoring)</i></p> <div style="border: 2px dashed blue; border-radius: 15px; padding: 10px; margin-top: 10px;"> <p><b>Purpose:</b> As well as the fixed clinical metrics above, the Clinical Advisory Panel (CAP) felt that a further criteria around demonstrating how their particular approach to leading networks would allow the unique opportunities of each option to be demonstrated.</p> <p><i>Experience of delivering care for children with cancer, which may include CYP oncology services will support confidence in the responses provided</i></p> </div>	No response given; or does not meet the requirements in any way; or provides no evidence that the service will be delivered in accordance with the specification.	No confidence provided by a response which does not meet all requirements in the service specification around clinical networks, and/or provide examples of clinical network delivery in line with best practice. There is no resolution of the risks of mobilising the proposal within the wider network.	Limited confidence provided as does not address all of the service specification requirements, with limited examples of best practice. One or a few areas lack detail/evidence giving rise to some minor concerns, and there is minimal resolution of the risks of mobilising the proposal within the wider network.	Confidence provided by a response that addresses the service specification requirements with some evidence of best practice included. Leadership of comparable clinical networks described with evidence of effectiveness in line with 2 or more elements of the network maturity assessment framework as best practice. There is some understanding of risks relating to mobilising the proposal, and some confidence in the proposed mitigations.	High level of confidence provided by a strong description of leadership in comparable clinical networks in line with the service specification requirements and best practice, with evidence of effectiveness in line with 4 or more elements of the network maturity assessment framework. Good evidence of positive impact on clinical outcomes for patients. There is a good understanding of risks relating to mobilising the proposal within the network and there is a high level of confidence in the proposed mitigations.	Exceptional level of confidence provided by a very strong response that meets all the requirements of the service specification and best practice, and evidences effectiveness in line with all elements network maturity assessment framework. Very strong description of the leadership of clinical networks to deliver excellent clinical outcomes for patients, with excellent evidence. Risks relating to mobilising the proposal within the network are fully understood and there is exceptional confidence in proposed mitigations.

# Enabling Domain



# Enabling Domain – Scoring Framework 1: Impact on Staff

Evaluation Criteria	Criteria components	Low Swing 0 points		High Swing Composite score (see below)
<b>2.1 Impact on Staff</b>	Scoring percentage for this criterion based on equally weighted cumulative score of 3 component parts.			
<p><i><b>Purpose:</b> There is consensus that the transition to the new PTC model must not have an unnecessary or significantly negative impact on the workforce who deliver the service.</i></p>				
<p>This criterion applies to staff of all grades working directly in the paediatric cancer service for more than 50% of their time, excluding those staff due to retire within the next 2.5-year transition period to the new service model. The final list of staff included in this definition to be agreed with NHSE</p>	Benefits to staff* (see appendix 5)	Option does not meet the current level of benefits available (scores 0 marks)	Proportional linear allocation of points based on number of marks scored out of 14 against appendix 5	Option delivers benefits in line with the current level available and offers further benefits. (scores 14 marks)
	Impact on training programmes* (see appendix 6)	Significant adverse impact on training programme provision (scores 0 marks)	Proportional linear allocation of points based on number of marks scored out of 4 against appendix 6	Current level of training programme provision maintained with further additional benefits identified. (scores 4 marks)
	Increased staff travel times by public transport at 7am Monday (will be applied to all staff within the service)	≥ 90% staff have over 15-minute journey time increase.	Proportional linear allocation of points available based on the calculated score for travel time impact between 90% (0 points) and 10% (4 points).	≤10% staff have over 15-minute journey time increase.

\* Equivalent benefits and training programmes are acceptable and does not have to be a direct replication for the purposes of assessment as long as the core training needs or benefits are met.

# Enabling Domain – Scoring Framework 2: Support for Staff

Evaluation Criteria	Criteria components	Low Swing 0 points	1 point	High Swing 2 points
<b>2.2 Organisational Support for Staff</b> <i>(see appendix 7 on staff survey scoring)</i>	Scoring based on cumulative score of 5 component parts (the baseline comparator dataset is drawn from the teaching trust subsets of national all-staff data returns).			
<div style="border: 2px dashed blue; border-radius: 15px; padding: 5px;"> <p><b>Purpose:</b> The change to the new model involves leading staff who have established roles through a period of change, and sustaining the care model through this process. Need to demonstrate the host organisation will support staff.</p> </div>	Vacancy Rates	Within upper quartile range	Within inter-quartile range	Within lower quartile range
	Turnover Rates (measured via stability rates)	Lower quartile	Inter-quartile range	Upper quartile
	Sickness rates	Upper quartile	Inter-quartile range	Lower quartile
	Staff Survey	Lower quartile	Inter-quartile range	Upper quartile
	CQC Well led domain <sup>^</sup>	Inadequate or Requires Improvement rating	Good rating	Outstanding rating

*~It is recognised that how organisations group their staff will differ, so using Paediatric service level information will include slightly different groups of staff within each organisation, but for ease it is proposed that this difference is accepted.*

*^ CQC ratings will be based on the trust definition of paediatrics and will be on different timeframes depending on when the last inspection was undertaken.*

# Enabling Domain – Scoring Framework 3: Resilience

Evaluation Criteria	Low Swing 0 points	2 points	4 points	6 points	8 points	High Swing 10 points
<p><b>2.3 Resilience</b></p> <p>(See appendices 8a - business continuity and 8b - Key EPRR Core Standards)</p> <div style="border: 2px dashed blue; border-radius: 15px; padding: 10px; margin-top: 20px;"> <p><i><b>Purpose:</b> Significant numbers of patients use the service, and it is important that they are able to access care when required, including when services may be disrupted. There also needs to be sufficient theatre capacity to meet surgical (and other) demands within reasonable timescales.</i></p> </div>	No response given; or does not meet the requirements in any way; or provides no evidence that the service will be delivered in a resilient manner.	No confidence provided by a response which provides no evidence of a robust business continuity plan.	Limited confidence provided by a response where one or a few areas lack detail/ evidence of a robust business continuity plan giving rise to some minor concerns.	Confidence provided by a response that provides evidence of a sufficiently robust business continuity plan.	High level of confidence provided by a strong response that provides strong evidence of a robust business continuity plan that exceeds expectations in multiple EPRR core standards.	Exceptional level of confidence provided by a very strong response that provides comprehensive evidence of a robust business continuity plan that exceeds all expected EPRR core standards.

# Enabling Domain – Scoring Framework 4: Capacity

Evaluation Criteria	Low Swing 0 points	2 points	4 points	6 points	8 points	High Swing 10 points
<p><b>2.4 Capacity</b></p> <p>(see appendix 9 for more information on capacity)</p> <div style="border: 1px dashed blue; border-radius: 15px; padding: 10px; margin-top: 20px;"> <p><b>Purpose:</b> Ensuring that sufficient capacity is in place to treat children from a wide geography for a condition that requires speedy access is a key requirement of the reconfiguration programme.</p> <p><i>This includes pathways and processes that support the delivery of care.</i></p> </div>	No response given; or does not meet the requirements in any way.	No confidence provided by a response which provides no evidence of sufficient capacity demonstrated.	Limited confidence provided in a response where one or a few areas lack detail/ evidence and a clear description the capacity to deliver the service will be created including processes, and support services, for good care delivery including for BMT.	Confidence provided by a response that provides evidence of a sufficiently robust description of the capacity to deliver the service including processes, and support services, for good care delivery including BMT.	High level of confidence provided by a strong response that provides strong evidence of the capacity to deliver the service, setting out how the processes, and support services, including BMT will be delivered, with strong evidence of why the proposer thinks this is the case.	Exceptional level of confidence provided by a very strong response that provides comprehensive evidence the capacity to deliver the service, setting out how the processes, and support services including BMT will be delivered, with very strong evidence of why the proposer thinks this is the case.

# Research Domain

# Research Domain – Scoring Framework 1: People

Criteria: People		Scope of information requested by template related to People				
<p><i><b>Purpose:</b> Research will need to be delivered across the PTC and ensure that all patients within a PTC have the same access to clinical trials and research is supported.</i></p>		Research workforce, including description of the research workforce, and income supporting research staffing, alongside delivery of a development programme for staff.				
		Research networks, including how the PTC will foster improved networking and collaboration for research, and previous impact on mobilising collaboration to advance international health policy.				
Evaluation Criteria	Low Swing 0 points	2 points	4 points	6 points	8 points	High Swing 10 points
3.1 People	Not submitted	Unclassified Evidence provided is insufficient to meet the one-star standard.	Nationally recognised (1*). Some evidence of ability to deliver a research workforce and research networks with potential within research for the care of children with cancer to <ul style="list-style-type: none"> <li>• Have <b>minor</b> influence</li> <li>• make an identifiable contribution to understanding, but without advancing thinking, practices, paradigms, and policies</li> </ul>	Internationally recognised (2*) Strong evidence of ability to deliver a research workforce and research networks with potential within research for the care of children with cancer to <ul style="list-style-type: none"> <li>• be a recognised point of reference</li> <li>• have <b>some</b> influence</li> <li>• be <b>incremental or cumulative</b> in advancing thinking, practices, paradigms, and policies,</li> </ul>	Internationally excellent (3*) Very strong evidence of ability to deliver a research workforce and research networks with potential within research for the care of children with cancer to <ul style="list-style-type: none"> <li>• be an <b>important</b> point of reference</li> <li>• have <b>considerable</b> influence</li> <li>• be a <b>catalyst for, or an important contribution to,</b> developing new thinking, practices, paradigms, and policies,</li> <li>• be capable of work that is <b>significantly</b> novel and innovative</li> </ul>	World-class leader (4*). Compelling evidence of ability to deliver a research workforce and research networks with potential within research for the care of children with cancer to <ul style="list-style-type: none"> <li>• be a <b>primary or essential</b> point of reference</li> <li>• have a <b>profound</b> influence</li> <li>• be <b>instrumental</b> in developing new thinking, practices, paradigms, and policies,</li> <li>• be capable of work that is <b>outstandingly</b> novel and innovative</li> </ul>

Scoring of this domain is being undertaken by an independent expert panel comprised of both clinical and scientific leads to ensure coverage of the broad range of research currently undertaken. The panel will score based on assessment of quantitative and qualitative information received. Levels have been set using the REF Main Panel D supplementary criteria interpretation, adapted from generic level definitions as described in the 2019 panel criteria and working methods paper. Note 'expanding the range' has not been used recognising the existing significant breadth of contribution within the existing provider.



# Research Domain – Scoring Framework 2: Place

Criteria: Place		Scope				
<p><i><b>Purpose:</b> Research will need to be delivered across the PTC and ensure that all patients within a PTC have the same access to clinical trials and research is supported.</i></p>		Research current capacity and excellence – proposed improvements in research capacity and capability for research for children and young people, including those with cancer, including but not limited to Phase 1, 2 and 3 trials, physical access including patient access for trials and research, patient and public involvement, tumour banking and cell banking, clinical and non-clinical infrastructure and interdependencies				
		Developing research potential - future plans to improve on existing provision through the proposed model, including scalable future capacity to accommodate researchers, patients, and necessary infrastructure including ICT and essential equipment.				
Evaluation Criteria	Low Swing 0 points	2 points	4 points	6 points	8 points	High Swing 10 points
3.2 Place	Not submitted	Unclassified Evidence provided is insufficient to meet the one-star standard.	Nationally recognised (1*). Some evidence of ability to deliver capacity and facilities with potential to enable research for the care of children with cancer which would <ul style="list-style-type: none"> <li>• Have <b>minor</b> influence</li> <li>• make an identifiable contribution to understanding, but without advancing thinking, practices, paradigms, and policies</li> </ul>	Internationally recognised (2*) Strong evidence of ability to deliver capacity and facilities with potential to enable research for the care of children with cancer which would <ul style="list-style-type: none"> <li>• would be a recognised point of reference</li> <li>• have <b>some</b> influence</li> <li>• be <b>incremental or cumulative</b> in advancing thinking, practices, paradigms, and policies,</li> </ul>	Internationally excellent (3*) Very strong evidence of ability to deliver capacity and facilities with potential to enable research for the care of children with cancer which would <ul style="list-style-type: none"> <li>• be an <b>important</b> point of reference</li> <li>• have <b>considerable</b> influence</li> <li>• be a <b>catalyst for, or an important contribution to,</b> developing new thinking, practices, paradigms, and policies,</li> <li>• be capable of work that is <b>significantly</b> novel and innovative</li> </ul>	World-class leader (4*). Compelling evidence of ability to deliver capacity and facilities with potential to enable research for the care of children with cancer which would <ul style="list-style-type: none"> <li>• be a <b>primary or essential</b> point of reference</li> <li>• have a <b>profound</b> influence</li> <li>• be <b>instrumental</b> in developing new thinking, practices, paradigms, and policies,</li> <li>• be capable of work that is <b>outstandingly</b> novel and innovative</li> </ul>

Scoring of this domain is being undertaken by an independent expert panel comprised of both clinical and scientific leads to ensure coverage of the broad range of research currently undertaken. The panel will score based on assessment of quantitative and qualitative information received.

# Research Domain – Scoring Framework 3: Performance & Capability



Criteria: Performance and Capability Criteria		Scope				
<p><i><b>Purpose:</b> Research will need to be delivered across the PTC and ensure that all patients within a PTC have the same access to clinical trials and research is supported.</i></p>		Current and future research performance and capability – research metrics and future vision for research and innovation				
		Potential risks to clinical and academic/translational research and mitigations- how the proposed model will minimise risks to research, including changes from the existing research model provision and the transition period to a new model.				
Evaluation Criteria	Low Swing 0 points	2 points	4 points	6 points	8 points	High Swing 10 points
<b>3.3 Performance and Capability Criteria</b>	Not submitted	Unclassified Evidence provided is insufficient to meet the one-star standard.	Nationally recognised (1*). Some evidence of a track record in research performance and capability, with potential to enable research for the care of children with cancer which would <ul style="list-style-type: none"> <li>• Have <b>minor</b> influence</li> <li>• make an identifiable contribution to understanding, but without advancing thinking, practices, paradigms, and policies</li> </ul>	Internationally recognised (2*) Strong evidence of a track record in research performance and capability, with potential to enable research for the care of children with cancer which would <ul style="list-style-type: none"> <li>• would be a recognised point of reference</li> <li>• have <b>some</b> influence</li> <li>• be <b>incremental or cumulative</b> in advancing thinking, practices, paradigms, and policies,</li> </ul>	Internationally excellent (3*) Very strong evidence of a track record in research performance and capability, with potential to enable research for the care of children with cancer which would <ul style="list-style-type: none"> <li>• be an <b>important</b> point of reference</li> <li>• have <b>considerable</b> influence</li> <li>• be a <b>catalyst for, or an important contribution to,</b> developing new thinking, practices, paradigms, and policies,</li> <li>• be capable of work that is <b>significantly</b> novel and innovative</li> </ul>	World-class leader (4*). Compelling evidence of a track record in research performance and capability, with potential to enable for the care of children with cancer which would <ul style="list-style-type: none"> <li>• be a <b>primary or essential</b> point of reference</li> <li>• have a <b>profound</b> influence</li> <li>• be <b>instrumental</b> in developing new thinking, practices, paradigms, and policies,</li> <li>• be capable of work that is <b>outstandingly</b> novel and innovative</li> </ul>

Scoring of this domain is being undertaken by an independent expert panel comprised of both clinical and scientific leads to ensure coverage of the broad range of research currently undertaken. The panel will score based on assessment of quantitative and qualitative information received.

# Patient and Carer Domain

# Patient & Carer Experience – Scoring Framework 1: Service Accessibility

Evaluation Criteria	Low Swing 0 points	2 points	4 points	6 points	8 points	High Swing 10 points
<p><b>4.1 Service Accessibility</b></p> <p><i><b>Purpose:</b> The relocation of services to a different site impacts on accessibility of the service. This is particularly significant for those who are most impacted by inequalities, and therefore less able to choose flexible travel arrangements.</i></p>	<p>&gt;75% have &gt;15 min increase against baseline in travel time by:</p> <ul style="list-style-type: none"> <li>- Private car</li> <li>- Public transport</li> </ul> <p>based on the median travel times for current cohort.</p>	<p>Proportional allocation of the 10 points available based on the calculated score for travel time impact.</p> <p>50% of the score will be allocated to public transport impact 50% of the score will be allocated to the private car transport impact</p> <p>For both the public transport and private car transport scores will themselves be split 50/50 between the impact on those in the most deprived quintile and the other 4 quintiles of deprivation.</p>				<p>&lt;5% have &gt;15 min increase against baseline in travel time by:</p> <ul style="list-style-type: none"> <li>- Private car</li> <li>- Public transport</li> </ul> <p>based on the median of travel times for current cohort.</p>

# Patient & Carer Experience – Scoring Framework 2: Quality of Facilities

Evaluation Criteria	Criteria components	Low Swing 0 points	1 point	High Swing 2 points
<p><b>4.2 Quality of facilities</b></p> <p><i>Purpose: Patient environments are an important contributor to the holistic experience of care.</i></p> <p><i>Experience of delivering care for children with cancer, which may include CYP oncology services will support confidence in the responses provided</i></p>	Scoring based on cumulative score of currently 5 component parts. <i>Section 2 of the service specification sets out the workforce and facility requirements, with key sections on quality of facilities shown in appendix 10.</i>			
	Age-appropriate environments (inpatient and outpatient) for infants, children and young people	Minimal or inadequate description of how the environments for the service are adapted to be age appropriate.	Description of environments adapted to meet the needs of some but not all ages	Full and well evidenced description of environments for the service are adapted to be age appropriate for all ages in line with the service specification (section 2.3.7).
	Play facilitation	Minimal or inadequate description of play facilitation model.	Play facilitation noted as available but not well described as to how this is embedded into the service.	Play facilitation model described and well evidenced, fully embedded into delivery model.
	Patient privacy and dignity	Minimal or inadequate description how privacy and dignity will be maintained for all ages of patient.	Privacy and dignity maintenance evidenced for some ages of patient but not the differing needs of different ages of patient.	Privacy and dignity maintenance well evidenced for all ages of patient.
	Space for parents/ carers to remain with the child	No or limited space for parents and carers to remain with the child.	Space for parents and carers to remain with the child in some but not all settings.	Space for parents and carers to remain with the child in the full range of settings, e.g. ward/ critical care.
	Education Model for children & young people	Minimal or inadequate description of education model in place for children and young people.	Education model described for some but not all ages of children.	Education model in place and well evidenced for the full range of children and young people.

# Patient & Carer Experience – Scoring Framework 3: Engagement and Collaboration

Evaluation Criteria	Low Swing 0 points	2 points	4 points	6 points	8 points	High Swing 10 points
<p><b>4.3 Engagement and Collaboration</b></p> <p><i>(Further guidance on what constitutes good engagement and collaboration has been collected from stakeholders and is shown in appendix 11).</i></p> <div style="border: 2px dashed blue; border-radius: 15px; padding: 10px; margin-top: 10px;"> <p><b>Purpose:</b> Organisations that successfully engage patients and carers are likely to be most successful in delivering a responsive service that meets the needs of those the NHS serves.</p> <p><i>Experience of delivering care for children with cancer, which may include CYP oncology services will support confidence in the responses provided</i></p> </div>	There is no evidence of collaboration or engagement with patients and carers as part of the routine business of the organisation.	No confidence provided by the response, with minimal evidence of collaboration or engagement with patients and carers as part of the routine business of the organisation.	Limited confidence provided by a response that evidences some engagement with patients and carers, but one or a few areas lack detail/evidence giving rise to some minor concerns.	Confidence provided by a response that evidences engagement with patients and carers, with some evidence on reasonable collaboration to co-design solutions and at least 2 methods of good engagement identified by parents.	High level of confidence provided by a strong response with evidence of active and routine collaboration with patients and carers, including evidence of reasonable co-design of this proposal. All of the top 3 methods of good engagement identified by parents evidenced.	Exceptional level of confidence provided by a very strong response with very strong evidence of active and routine collaboration with patients and carers, including evidence of reasonable co-design of this proposal. All of the top 3 methods of good engagement and most of the other areas of good practice evidenced.

# Patient & Carer Experience – Scoring Framework 4: Patient Navigation

Evaluation Criteria	Low Swing 0 points	2 points	4 points	6 points	8 points	High Swing 10 points
<p><b>4.4 Patient Navigation</b></p> <p><i>(info from service specification can be seen in appendix 12 to support scoring)</i></p> <p><b>Purpose:</b> <i>Patients and families want a positive, and connected experience of being guided through a complex set of treatments as a joined-up period of care, reassured by the quality of the service provided.</i></p> <p><i>Experience of delivering care for children with cancer, which may include CYP oncology services will support confidence in the responses provided</i></p>	<p>There is no reassurance that there will be a coordinated pathway of care within the option, and no evidence that there will be support and reassurance through the clinical journey.</p>	<p>There is information on care plans and proposed coordination of care with POSCUs, but the response does not fully meet the service specification requirements set out in section 2.3.2 and 2.3.5 (see appendix 12).</p>	<p>Response provides limited confidence as two or more areas below lack detail:</p> <ul style="list-style-type: none"> <li>- Continuity of Care, including a named care coordinator</li> <li>- Shared care arrangements</li> <li>- Support through clinical pathways*</li> <li>- Inter-operability of IT systems to join up patient records.</li> </ul>	<p>Confidence provided by a response that addresses areas below, but evidence lacking in one or more areas:</p> <ul style="list-style-type: none"> <li>- Continuity of Care, including a named care coordinator</li> <li>- Shared care arrangements</li> <li>- Support through clinical pathways*</li> <li>- Inter-operability of IT systems to join up patient records.</li> </ul>	<p>High level of confidence provided by a detailed response with supporting evidence provided for one or more areas however supporting evidence lacking in some areas:</p> <ul style="list-style-type: none"> <li>- Continuity of Care, including a named care coordinator</li> <li>- Shared care arrangements</li> <li>- Support through clinical pathways*</li> <li>- Inter-operability of IT systems to join up patient records.</li> </ul>	<p>All four key areas addressed in detail with evidence demonstrated to provide an exceptional level of confidence that there is a clear, seamless pathway of care that wraps around the needs of the patient and their carers, and a named care coordinator which provides reassurance and support across the care journey.</p>

\*This includes provision of information about the site where the child is receiving care and signposting to specialist charities that can provide additional support

# Patient Experience – Scoring Framework 5: Family Support

Evaluation Criteria	Low Swing 0 points	2 points	4 points	6 points	8 points	High Swing 10 points
<p><b>4.5 Family support during periods of extreme difficulty, including acute and rapidly evolving situations.</b></p> <p><i>(Further guidance on what constitutes good family support during periods of difficulty has been collected from stakeholders and is included in appendix 13).</i></p> <div style="border: 1px dashed blue; border-radius: 15px; padding: 10px; margin-top: 10px;"> <p><b>Purpose:</b> Patient families and carers have differing support needs depending on the phase of care the patient is going through. There is a particular need to consider the support and wrap around care available to families/ carers during periods of extreme difficulty.</p> <p>Experience of delivering care for children with cancer, which may include CYP oncology services will support confidence in the responses provided</p> </div>	No response given; or there is no consideration of the support needs of families and carers during periods of extreme difficulty.	No confidence provided by a response which does not provide detail around family support during periods of extreme difficulty, and / or no relevant evidence provided.	Limited confidence provided by a response, with family support during periods of extreme difficulty referenced, but one or a few areas lack detail/evidence giving rise to some minor concerns.	Confidence provided by a response that describes family support during periods of extreme difficulty described with some evidence of supporting the needs of families/carers. At least 2 of the areas identified as good practice by parents is evidenced.	High level of confidence provided by a strong response that describes family support during periods of extreme difficulty, including strong evidence of supporting the needs of families/carers. All of the top 3 areas identified as good practice by parents are evidenced.	Exceptional level of confidence provided by a very strong response that describes the family support during periods of extreme difficulty, with comprehensive evidence of supporting the needs of families/carers and individualised support available. All of the top 3 areas and most of the other areas identified as good practice are evidenced.



# Appendices

# Appendix 1: Clinical Domain – Interdependencies

## 2.4 Interdependencies with Other Services ([Children's PTC Specification](#))

PTCs have a range of critical co-dependencies with other clinical services. The following clinical services must be delivered on-site at every PTC:

- Paediatric oncology services;
- Paediatric cancer pharmacy services;
- Paediatric haematology services;
- Paediatric radiology services;
- Paediatric critical care (Level 3);
- Paediatric surgery, to include management of emergencies, central lines and biopsy services (where these are not provided by interventional radiology or anaesthetics);
- Paediatric anaesthetics and pain management; and
- Therapy services (such as psychology, physiotherapy).

See [service specification](#) on pages 16 and 17 for list of:

- Clinical services which do not necessarily need to be delivered on -site but PTCs need to ensure the services are readily available at all times
- Services where PTCs should ensure there are clear referral and management pathways in place, and
- Other related co-dependent services

# Appendix 2a: Clinical Domain – Transition Best Practice

Transition from children's to adult services is recognised as a key pathway where patients and their families need to have the right level of support to ensure ongoing engagement of young people in their healthcare and achievement of the best outcomes for the patient.

It is also covered in the [service specification](#) on pages 7 (cryopreservation & contraception) and pages 10, 12 (long term planning and transition):

There is a range of guidance and best practice examples available. Key best practice themes from across these are:

- Ensuring transition support is developmentally appropriate for the young person
- Planning should start early but be flexible to meet the needs of the patient without being rigid about the age transition starts and finishes
- A named worker should be identified to coordinate transition care and support
- There must be organisational support for transition to support cross team working and flexibility around the needs of the patient
- Support should continue for a period after transition to ensure ongoing engagement in health services
- Support should be holistic and consider the broader biopsychosocial needs of a patient
- Parent and carers should be involved, but their level of involvement should be guided by the young person

Teenage and Young Adult (TYA) services have developed to help address the themes above and provide an integrated approach to care for this cohort of patients. It will be important that these services are not destabilised due to any changes to the PTC provision.

# Appendix 2b: Clinical Domain – Transition Service

## Specification Requirements

### 2.3.4 Transition to TYA and Adult Services ([Children’s PTC Specification](#))

Transitional care is essential to ensure seamless provision of care from paediatric to TYA and then onto adult cancer / late effects services and should be defined for each tumour specific pathway within the Network. The PTC should ensure that transition to TYA or adult services is:

- Pre-planned and pro-active so that patients know what to expect and when transition is required;
- Occurs at a time of stability in the patient’s disease and treatment and may be effectively achieved during therapy and after completion of treatment; and
- Involves close liaison between the referring and receiving teams to ensure that the transition process is seen as a positive step and to minimise the anxiety that patients and families may feel (e.g. by having joint transition appointments).

### 2.5 Transitional Care ([Teenage & Young Adult PTC Specification](#))

Transitional care applies to those patients who had completed their cancer treatment as children, teenagers or young adults and/or due to relapse, development of a second malignancy, or as part of their ongoing treatment or aftercare plan, they now require transition to a different team due to their maturity.

The transition plan should begin well in advance of transition and be pro-active so that each patient knows what to expect. Transition should occur at a time of stability in the patient’s disease and treatment and may be effectively achieved during therapy or after completion of treatment. The referring and receiving teams should liaise carefully to ensure that the transition process is seen as a positive step and to minimise the anxiety that patients and families may feel (e.g., by having joint transition appointments).

# Appendix 2c: Clinical Domain – Transition

## NICE Quality Standards, Best Practice & Guidance

- **NICE Quality Standards** [Transition from children's to adults' services \(nice.org.uk\)](https://www.nice.org.uk/guidance/qs133)
- Quality Statements:
  - Planning Transition
  - Annual Meeting
  - Named Worker
  - Introduction to Adults' Services
  - Missed first appointments after transfer to adults' services
- A tool to support measurement against the standards is available here <https://www.nice.org.uk/standards-and-indicators/how-to-use-quality-standards>
- **Guidance**
- RCPCH – Facing the Future: Standards for ongoing health needs (2018) <https://www.rcpch.ac.uk/resources/facing-future-standards-ongoing-health-needs>
- NICE Guideline NG43 (<https://www.nice.org.uk/guidance/ng43>) and BMJ summary of this (<https://www.bmj.com/content/353/bmj.i2225>)
- Social Care Institute for Excellence – Care Act: Transition from childhood to adulthood <https://www.scie.org.uk/care-act-2014/transition-from-childhood-to-adulthood/>
- CQC – From the pond into the sea (2014) [https://www.cqc.org.uk/sites/default/files/CQC\\_Transition%20Report.pdf](https://www.cqc.org.uk/sites/default/files/CQC_Transition%20Report.pdf)
- **Examples of best practice**
- RCPCH – <https://www.rcpch.ac.uk/resources/best-practice-examples-health-transition>
- Developmentally Appropriate Healthcare Toolkit (Northumbria Healthcare NHS FT working with the Association of Young People's Health) <https://www.northumbria.nhs.uk/quality-and-safety/clinical-trials/for-healthcare-professionals/>
- Ready, Steady, Go (Southampton Children's Hospital) <https://www.readysteadygo.net/>
- 10 step transition programme provides a generic and simple transition pathway (Alder Hey Children's NHS Foundation Trust) <https://alderhey.nhs.uk/services/transition-adult-services>

# Appendix 3: Clinical Domain – Treatment Transfers

Patient Transfers from/to the Royal Marsden in 2019/20 – 0-15 year olds excluding Critical Care and St George's POSCU

The data lake includes a flag to indicate whether St George's consider the activity they undertook to relate to being a PTC or as a POSCU. This analysis excludes transfers to St George's which are part of their POSCU provision and any transfers which included critical care (as all options would provide critical care on site).

The data suggests there are four major types of inpatient transfer taking place:

- Haematology (primarily to King's)
- Cardiology (to GSTT)
- Neurosurgery (to King's)
- Paediatric Surgery (to St George's)

The data of inpatient spells within one day of an RMH spell shows that almost half of these were non-elective spells – the majority of which were for haematology at King's.

Spells with a transfer to/from RMH within 1 day	Day Case	Elective - Inpatient	Non-Elective - Inpatient	Total
<b>GOSH</b>		3	1	4
<i>Clinical Haematology</i>		2		2
<i>Paediatrics</i>			1	1
<i>Urology</i>		1		1
<b>GSTT</b>	13			13
<i>Paediatric Cardiology</i>	13			13
<b>KING'S</b>	6	10	30	46
<i>Neurosurgery</i>		2	4	6
<i>Paediatric Clinical Haematology</i>	4	8	22	34
<i>Paediatric Gastroenterology</i>	1		1	2
<i>Paediatrics</i>	1		3	4
<b>ST GEORGE'S</b>	2	9	6	17
<i>Paediatric Surgery</i>	1	9	3	13
<i>Paediatrics</i>	1		3	4
<b>TOTAL*</b>	21	22	37	80

Transfer Activity - Provider and Consultant Specialty Code	Patients	Spells	Transfers
<b>GOSH</b>	8	12	12
<i>Outpatient</i>	4	8	8
<i>Clinical Haematology</i>	2	2	2
<i>Paediatrics</i>	1	1	1
<i>Urology</i>	1	1	1
<b>GSTT</b>	15	19	21
<i>Outpatient</i>	5	6	6
<i>Paediatric Cardiology</i>	11	13	15
<b>KING'S</b>	37	81	113
<i>Outpatient</i>	18	35	37
<i>Neurosurgery</i>	6	6	8
<i>Paediatric Clinical Haematology</i>	16	34	62
<i>Paediatric Gastroenterology</i>	2	2	2
<i>Paediatrics</i>	4	4	4
<b>ST GEORGE'S</b>	30	38	49
<i>Outpatient</i>	16	21	27
<i>Paediatric Surgery</i>	13	13	16
<i>Paediatrics</i>	4	4	6
<b>Grand Total*</b>	83	150	195

\*The total number of patients is likely to be lower than the total you would get from adding up rows as an individual patient can be in more than one row



# Appendix 4a: Clinical Domain – Network Effectiveness & System Benefits, Specification Requirements

The [service specification](#) sets out a range of responsibilities for networks, including:

- Delivery of training programmes
- Leading on network governance arrangements
- Working with POSCUs across the network, including shared care arrangements
- Working with other related clinical networks
- Development of pan-network operational policies and pathways, including with community services
- Delivery of network quality arrangements including mortality and morbidity reviews, peer review, engaging in national quality initiatives etc.
- Management of research across the network (covered in Research domain)
- Monitor and report on network performance

# Appendix 4b: Clinical Domain – Network Effectiveness & System Benefits, Network Maturity Assessment Framework

- Clinical Networks provide a vehicle that supports collaboration across services in a given network to improve services and meet the needs of the population using the service.
- Effective networks are successful in a number of areas, including\*:
  - Establishing the strategic direction of the service and getting engagement from across the network in this.
  - Demonstrating effective, inclusive governance structures.
  - Leading by a strong team who are trusted and able to develop relationships across and outside the network to achieve the aims of the network.
  - Facilitating sharing of best practice and learning from across the network as part of the ongoing improvement of services across the network.
  - Demonstrating measurable impact and innovation that deliver system wide benefits, with stakeholder promotion of this.
  - Communication via a range of channels with a range of stakeholders to ensure there is constant engagement and influence over the strategic direction of related services.



# Appendix 5: Enabling Domain - Benefits to staff

The option should ensure that existing benefits or broadly equivalent benefits to staff identified below continue to be available, with scoring available where additional benefits in these areas are identified.

Existing Staff Benefit	Quantifiable Aspects	1 Mark	2 Marks
Nursery Provision	Ofsted rating	Good	Outstanding
	Access (currently a day nursery is available on site M-F 07:30-18:00)	Extended Hours (early morning & early evening)/ Offsite	Extended Hours (early morning & early evening)/ Onsite
Education Benefits	Access to enhanced levels of study leave (currently staff can access 10 days/ year or 30 days over 3 years)	Current RMH provision maintained	Enhanced provision
	Access to study budgets to support CPD (currently up to £3500 a year for nursing study budget and £1000 study expenses budget for locally employed doctors)	Current provision maintained	Enhanced provision
Staff Wellbeing	Access to MSK support (physiotherapy, osteopathy, massage etc.) at free/ discounted rates (currently osteopathy is offered at £25 for 45 mins. Other services are typically available at approximately 50% below private rates.)	Discounted RMH rates	Free
	Comprehensive wellbeing programme including but not limited to workshops, chaplaincy service, psychological and pastoral care for staff, with access to counselling services and bespoke provision for staff groups working in challenging environments	General offer available to all staff	Bespoke packages implemented
	Facilities to support breaks including outside space, kitchen facilities and access to food & drink out of hours	Access to kitchen and outside space for breaks	Access to out of hours provision to hot food & drink
<b>Total (max = 14 marks)</b>			

# Appendix 6: Enabling Domain – Training Programmes

- Further information on existing training programmes across all professional groups linked to the service at RMH and SGH is outlined below.
- Scoring based on ensuring current provision is maintained and scoring available to support where additional benefits are identified.

Training Programmes	Current Provision	Equivalent current provision maintained	Significant additional benefits
Professional Programmes	<ul style="list-style-type: none"> <li>•Preceptorship programmes, nurse development programmes (all levels), care certification and diploma for support workers, student nursing programmes with Kingston and City Universities.</li> <li>•Access for all staff to Oncology courses, accredited Supportive Care Course, Chemotherapy Administration &amp; BMT courses.</li> <li>•Access for all staff to accredited training programmes such as BSc, MSc, PhD, Advanced Clinical Practice.</li> </ul>	1 mark	1 further mark
CPD	<ul style="list-style-type: none"> <li>•Supportive training available to all staff to support them working in challenging environments, e.g. effective communications, coping strategies, managing emotional fatigue.</li> <li>•Supported access to conferences.</li> <li>•Access to a wide range of external organisations such as charities and higher education providers to support specialist education and training opportunities for all staff.</li> <li>•Access to ILM accredited coaches.</li> <li>•Access to leadership development programmes at all levels, including access to bespoke programmes arranged via the Kings Fund.</li> </ul>	1 mark	1 further mark
	<b>Total</b> (max = 4 points)		

# Appendix 7: Enabling Domain – Staff Survey Scoring

- It has been agreed at the Options Appraisal Working Group (OAWG) that it would be more appropriate to measure the sub-criteria components at a Paediatric rather than Trust level given the focus of this service.
- It is recognised however that individual organisations will group their staffing differently, and therefore the staffing within a paediatric division/ directorate in one organisation will not necessarily match that at another organisation.

Staff Survey Domain	Lower quartile	Interquartile range	Upper quartile
We are compassionate and inclusive	0	0.11	0.22
We are recognised and rewarded	0	0.11	0.22
We each have a voice that counts	0	0.11	0.22
We are safe and healthy	0	0.11	0.22
We are always learning	0	0.11	0.22
We work flexibly	0	0.11	0.22
We are a team	0	0.11	0.22
Staff Engagement	0	0.11	0.22
Morale	0	0.11	0.22
<b>Total (max = 2 points)</b>			

# Appendix 8a: Enabling Domain – Resilience: Business Continuity

## Business Continuity

- Business continuity is defined\* as the “ability of a service to detect, prevent, handle (i.e. to maintain their business prioritised activities) and recover from disruptive challenges”.
- Providers will need to provide details of their business continuity/ business impact assessment plans at a paediatric or relevant service level to demonstrate they are able to maintain business continuity across similar services. A template is available to guide these ([BIA NHSE template](#)).
- These will be considered against the NHSE EPRR Core Standards as a guide, with assessment against the following core standards.

# Appendix 8b: Enabling Domain – Resilience: Key EPRR Core Standards

## **EPRR Core Standard 51 (business continuity plan)**

The organisation has established business continuity plans for the management of incidents. Detailing how it will respond, recover and manage its services during disruptions to:

- People
- Information and data
- Premises
- Suppliers and contractors
- IT and infrastructure

## **EPRR Core Standard number 42 (mutual aid)**

- The organisation has agreed mutual aid arrangements in place outlining the process for requesting, coordinating and maintaining mutual aid resources. These arrangements may include staff, equipment, services and supplies. These arrangements may be formal and should include the process for requesting Military Aid to Civil Authorities (MACA) via NHS England.

## **EPRR Core Standard number 49 (business impact assessment)**

- The organisation annually assesses and documents the impact of disruption to its services through Business Impact Analysis(s).



## Appendix 9: Enabling Domain – Capacity


- Activity Profiles will demonstrate the level of bed days required for ward and paediatric critical care, the level of diagnostic procedures and the number of theatre hours that will be required to deliver the additional activity that will be incurred under the model proposed in each option.
- Assessments of capacity will need to be based on the information provided on:
  - Workforce (including how any gaps will be addressed where current staff may not TUPE across to a new provider and the ability to meet recognised staffing ratios in given areas)
  - Estates work requirements (including the timescales to deliver these)
  - Ability to accommodate additional activity into current service capacity
- Sufficient capacity is available for specific services such as BMT with questions set in the template associated to compliance for that service specification, including JACIE accreditation.

# Appendix 10: Patient & Carer Experience Domain – Quality of Facilities

## 2.3.7 PTC Facilities ([Children's PTC Specification](#))

Treatment for children with cancer is complex and intensive, and children can often become acutely ill during treatment, requiring a high level of medical support. As a result, care for children with cancer is mainly provided on an inpatient basis. The Service must be delivered in an age-appropriate setting, which means that the PTC must:

- Ensure there are dedicated facilities for children with cancer including:
  - Named wards for inpatient chemotherapy. These must be documented in a written policy and patients must be admitted to these wards in preference to other wards;
  - An agreed number of single rooms (not one room only) for inpatient isolation, each with an en-suite toilet and washing facilities;
  - Separate day care facilities for children with waiting and play areas;
  - Access to dedicated day care recovery beds (i.e., a ward or room(s)). These must be documented in a written policy and on the days that the PTC's day care facility is being used, the rooms must only be used for patients who are resting after day care treatments or after invasive investigation, or for other outpatients who have had clean day care procedures. Paediatric resuscitation equipment must be in all rooms where day care treatment takes place and this equipment should be checked at least weekly or line with the PTC's protocols; and
  - Regular children's outpatient clinics which are exclusive to patients under the care of PTC and are identified as a contact point for referral in the primary care referral guidelines.
  - Facilities for parents (e.g. overnight bed alongside the patient).



# Appendix 11: Patient & Carer Experience Domain – Guidance on Good Engagement and Collaboration

**Feedback from parents highlighted the following as key areas that demonstrate good engagement and collaboration:**

**Top 3:**

- Working with local and national charities who support children and young people with cancer
- Taking to patient groups/ panels made up of these with direct experiences of services
- Using children and young people friendly activities to seek feedback

**Others:**

- Involving service users and parent/ carers in key decision-making meetings/ boards
- Showing how feedback has made a difference (i.e. you said we did reports/ feedback walls)
- Using local and national survey feedback (like the Friends and Family Test) to improve
- Ability to carry out surveys electronically on wards
- Working with staff to understand concerns or issues raised
- Directly emailing families




# Appendix 12: Patient & Carer Experience Domain – Patient Navigation

## 2.3.2 Diagnosis, Treatment and Management of Cancer ([Children’s PTC Specification](#))

- Develop and agree treatment plans according to the following, as appropriate: (i) appropriate current UK Clinical Research Network (UKCRN) Portfolio protocol; (ii) Children’s Cancer and Leukaemia Group (CCLG) guideline; (iii) other guidelines as determined by individual cancer type (e.g., sarcoma); or (iv) in the case of a teenager, clear evidence of better outcomes on an adult guideline or protocol. In exceptional circumstances, children may be treated in line with a locally approved off protocol therapy; and Communicate care plans with their relevant POSCUs using a secure electronic system.

## 2.3.5 Information and Consent ([Children’s PTC Specification](#))

- Patient and Carer Information must be provided which covers generic and tumour specific information for children with cancer. Each provider and health care practitioner must comply with the relevant legislative framework and relevant guidance governing consent. Accordingly, each provider and health care practitioner must ensure that all children and young people who use services are:
  - Fully informed about their care, treatment and support and information must be age-appropriate;
  - Able to take part in decision making to the fullest extent that is possible; and
  - Asked if they agree for their parents or guardians to be involved in decisions they need to make.
- It is important that patients, parents and carers receive clear written guidance when consenting to treatment, this must include the following:
  - Treatment intent;
  - Prognosis and potential complications associated with their treatment;
  - Clear instructions who to contact if they need advice outside working hours including phone numbers for 24/7 advice lines (either at the PTC or POSCU);
  - How to proceed in the event of a medical emergency, in particular following SACT; and
  - Information on how to manage and care for a central line (where appropriate).



# Appendix 13: Patient & Carer Experience Domain – Guidance on Family Support Needs During Periods of Extreme Difficulty

**Feedback from parents highlighted the following as key areas where families can be supported during times of extreme difficulty (e.g. if patients require intensive care support or receive unexpected news about their condition):**

## **Top 3:**

- Direct access to counselling services
- Direct access to children and young people friendly activities to support with coping/ processing
- Signposting to local and national charities who support children and young people with cancer (joint 3<sup>rd</sup>)
- Named clinical lead to communicate with (joint 3<sup>rd</sup>)

## **Others:**

- Dedicated quiet space
- Support to make the journey home
- Written information/ leaflets
- Access on accommodation when the child is in intensive care (on or off site)
- Involving parents in the discussion around how/ if to break back news to a child