

# Engagement Report for *Paediatric Photon Radiotherapy (0-16<sup>th</sup> Birthday) Service Specification*

16 January 2022, Version 1

## Topic details

<b>Programme of Care</b>	<b>Cancer Programme of Care</b>
<b>Clinical Reference Group</b>	<b>Radiotherapy</b>
<b>Unique Reference Number (URN)</b>	<b>230601</b>

## 1. Summary

This report summarises the feedback NHS England received from engagement during the development of the Paediatric Photon Radiotherapy 0-16<sup>th</sup> Birthday service specification, and how this feedback has been considered. Eight responses were received from professional groups, organisations and charities involved in children's radiotherapy care. The feedback was positive with stakeholders registering their broad support for the service specification requirements and standards and noted its expected positive impact in driving improvements in quality and safety.

## 2. Background

In accordance with our normal processes, the Service Specification has been developed with the support of a working group (SWG), comprising representation from multi-professional children's cancer experts and patient and public voice representatives.

The SWG has extensive expert membership across different related professional groups across ten Trusts. .

The pattern of service provision for children requiring radiotherapy is changing, largely related to the opening of the UK Proton Beam Therapy Service (PBT), which is enabling more children to access proton therapy instead of conventional photon radiotherapy.

To help us understand the implications of this change and ensure that paediatric radiotherapy services continue to provide sustainable and high-quality care, a Case for Change was shared in March 2021, as part of a programme of stakeholder engagement and public involvement. The feedback we received about the Case for Change highlighted the importance of:

- Maintaining paediatric clinical oncology input to the multi-disciplinary teams supporting both Children's Cancer Services and the UK PBT Service;
- Minimising the burden of travel for children and their families;
- Ensuring local access to palliative and emergency radiotherapy where clinically safe and appropriate;
- Protecting wider service infrastructure, e.g. paediatric anaesthetics support; and
- Increasing service and workforce resilience – possibly through networked service arrangements.

Subsequent dialogue with NHS Trusts that deliver the services, coupled with the need to prepare for eventual delegation of the services to Integrated Care Systems, confirmed the need to develop a standalone service specification.

The Paediatric Photon Radiotherapy Service Specification covers the provision of external beam radiotherapy (radical, palliative and Total Body Irradiation [TBI]) in the treatment of children with cancer aged 0-15 years up to their 16<sup>th</sup> birthday in England and sets out the relationship between the Service and both the Children's Principal Treatment Centre (PTC) multidisciplinary team (MDT) and the Children's Haematopoietic Stem Cell Transplantation MDT.

The proposed service specification also supports provider plans to create partnerships between services, in order to meet the requirements. It is not expected to impact on children's radiotherapy services nor result in any material alteration to the configuration of services or to the role and function of the Principal Treatment Centre and the paediatric oncology MDTs and children's haematopoietic stem cell transplantation MDTs. However, it should be noted that two of the current twelve providers of paediatric photon radiotherapy have indicated that they intend to cease provision of the service – this is not related to the new service specification but is linked to the changing pattern of radiotherapy in this age range.

## 3. Engagement Results

### 3.1 Stakeholder Testing

NHS England has a duty under Section 13Q of the NHS Act 2006 (as amended) to 'make arrangements' to involve the public in commissioning. Full guidance is available in the Statement of Arrangements and Guidance on Patient and Public Participation in

Commissioning. In addition, NHS England has a legal duty to promote equality under the Equality Act (2010) and reduce health inequalities under the Health and Care Act (2022).

The service specification was sent for stakeholder testing for 2 weeks from 7<sup>th</sup> December 2022 to 21<sup>st</sup> December 2022. Prior to this, regional colleagues were offered the opportunity to provide feedback on the service specification.

Stakeholder comments have been discussed with the Chair of the Specification Working Group to enable full consideration of feedback and to support a decision on whether any changes to the specification might be recommended.

Respondents were asked the following questions:

- **Question 1 - Service Requirements**

A. Do you agree with the service requirements as described in the Children's Radiotherapy Service Specification, including the 'must do' elements?

- What impact do you think this will have on NHS Trusts?
- What impact do you think this will have on Service Users?

B. Do you support the emphasis on treatments being delivered in line with national quality metrics, utilising improvement approaches to implement best practice and participation in the audit of clinical and dosimetry practice.

- What impact do you think this will have on NHS Trusts?
- What impact do you think this will have on Service Users?

- **Question 2 - Do you agree that Children's Radiotherapy Services must operate in close alignment with and be located within the same geography (city) as a Children's Cancer Principal Treatment Centre (PTC) and provide the full range of conventional radiotherapy treatments (radical, palliative and TBI) so that appropriate specialist expertise and infrastructure can be sustained?**

- What impact do you think this will have on NHS Trusts?
- What impact do you think this will have on Service Users?

- **Question 3 - Do you agree that Children's Radiotherapy Services should be able to enter into networked or partnership arrangements with each other to secure service resilience?**

- What impact do you think this will have on NHS Trusts?
- What impact do you think this will have on Service Users?

- **Question 4 - Do you support the requirements of Consultant Paediatric Clinical Oncologists as described in the Service Specification?**

- What impact do you think this will have on NHS Trusts?
- What impact do you think this will have on Service Users?

- **Question 5 - Do you agree with the requirements set out within the Service Specification relating to the specialist paediatric radiotherapy team?**

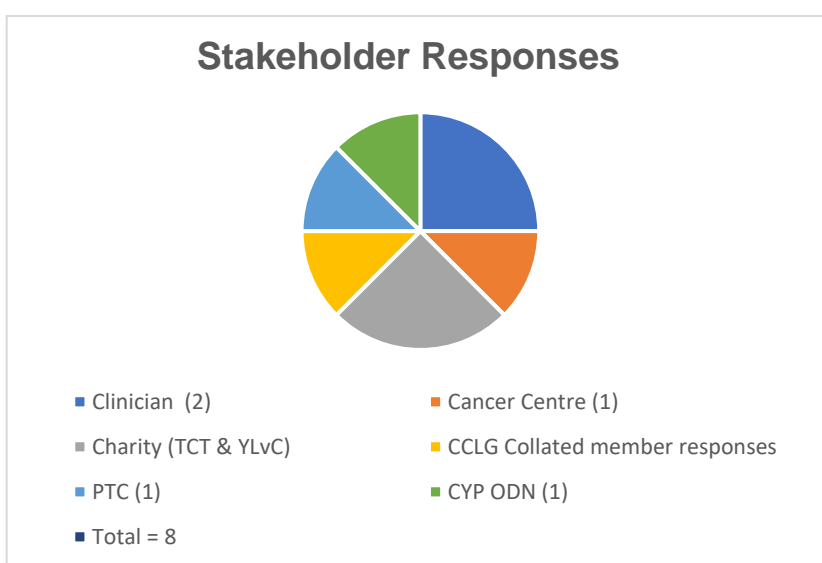
- What impact do you think this will have on NHS Trusts?
- What impact do you think this will have on Service Users?

- Any other comments on the proposed service specification changes?

## 3.2 Stakeholder testing results and summary of participants

Eight responses were received and a breakdown by stakeholder group is provided below. Feedback includes broad input from professional groups, organisations and charities involved in children's cancer care.

In general, the feedback is very positive with stakeholders registering their broad support for the service specification requirements and standards with some suggested drafting amendments. All respondents scored each of the questions as 4 (somewhat support) or 5 (strongly support). Some respondents described the expected positive impact of the service specification in driving quality and improving safety.



Commentary received has been collated into the appendix to this document. All comments have been reviewed by the Lead Clinician of the SWG.

A 13Q assessment has been completed following stakeholder testing.

The Cancer Programme of Care has decided that the service specification and proposed amendments does not constitute material changes to the way in which services are delivered or the range of services available and therefore further public consultation was not required. This decision has been assured by the Patient Public Voice Advisory Group.

## 4 How has feedback been considered

Responses to engagement have been reviewed by the Specification Working Group and the Cancer PoC. The following themes were raised during engagement:

Engagement activity theme identified in stakeholder engagement	Key themes in feedback	NHS England Response
	<b>Relevant Evidence</b>	
Individual CCLG member	Scope of services should not include Total Body Irradiation (TBI). Statement. No evidence provided.	The scope of the service specification, including the service model, was recommended by the Expert Clinical and PPV Advisory Group and agreed by Specialised Commissioning Steering Group to ensure sustainability of the services into the future. <b>No Change</b>
Individual Clinician	Centres not able to meet the service specification requirements may cease providing the service.  No evidence provided	<b>No change</b>
Individual Clinician	Many paediatric radiotherapy services will have to close as they will not be able to deliver this service – mainly due to lack of staff.	Trusts have confirmed their plans. The specification describes the relevant standards and requirements and describes the option for working in partnership. <b>No change</b>
Individual	Clear set of standards which must be delivered successfully to maintain quality. Some centres will choose not to adopt the standards in favour of patients being treated elsewhere. No evidence provided	Trusts have already confirmed their plans. The specification describes the relevant standards and requirements and describes the option for working in partnership. <b>No change</b>
Individual	PTCs to supply and distribute information for service users about their local services in advance of referrals.	Outside the scope of the specification. <b>No Change</b>
Individual	Allied health professionals should be detailed in the 'Essential Staff' groups	Already listed in the specification in section 7.4. <b>No change</b>
CCLG member	Naming 'Advanced Paediatric Radiographer'	Naming convention as per RCR Good Practice Guidelines. <b>No change</b>
Cancer Centre	All consultants to be members of the Children's Cancer and Leukaemia Group.	Membership recommended only as CCLG is a charity not a professional body. <b>No change.</b>

Cancer Centre	Use of descriptor 'Advanced Paediatric Radiographer'	References are in accordance with RCR's Good Practice Guide. <b>No Change</b>
<b>Impact Assessment</b>		
Cancer Centre	Not Applicable' to Pregnancy and Maternity, Pregnancy status is relevant from age 12 onwards.	<b>EHIA amended.</b>
<b>Current Patient Pathway</b>		
All respondents	Some will have to travel further. Impact on families	The service specification does include the provision of accommodation within the service aims section – at present, accommodation is not part of the commissioned service but is sometimes available through facilities such as Ronald MacDonald House and other provider or charity provision. Separate to the development of the specification, the Programme of Care is developing a proposal to secure support for making accommodation available, in line with that currently offered as part of the UK PBT service. Travel reimbursement is currently only available through government schemes. <b>No Change.</b>
	Travel and accommodation costs should be considered.	
CCLG Member	The requirement for highly individualised assessments and plans especially those with additional needs for children travelling to a remote service.	The service specification states: ...the paediatric oncology MDTs and the children's haematopoietic stem cell transplantation MDT (for TBI), involving a wide range of specialists responsible for determining and delivering whole pathway care plans for all children with cancer.  <b>No Change</b>
Cancer Centre	CRT centres able to comply with on-site Paediatric resuscitation.	This is already listed as an essential safety requirement in the service specification. <b>No Change</b>
Cancer Centre	ENT should be an integrated service co-located (in the same city)	This is already included as it forms part of the paediatric surgery specification.
<b>Potential impact on equality and health inequalities</b>		
Individual Costs	Seek assurance that families can access this treatment adequately and that lack of finances do not mean that some cannot adhere to treatment protocols.	Please see earlier response in relation to accommodation and travel. <b>No change</b>
<b>Changes/addition to Service Specification</b>		

	Adequate job-planned time to support partnerships and peer review	Amended
	The 'Job Planning' process and peer review	Amended to include a reference to peer review
	Provision of information- distribute information for service users	Amended
Cancer Centre	There is no mention of children's radiotherapy CNS	Amended
CCLG	Inclusion of occupational therapists	Amended
Cancer Centre	Paediatric anaesthesia, same town/city rather than co-located	Amended
Teenage Cancer Trust	Lack of references for consideration of adolescents.	The service specification has been amended to include references to adolescents.
Cancer Centre	Pregnancy status is asked at consent from the age of 12 onwards.	Service Specification amended to include consent and pregnancy.

## **5 Has anything changed in the service specification as a result of the stakeholder testing and consultation?**

The following change(s) based on the engagement responses has (have) been made to the service specification:

- Nine amendments have been made to the service specification as listed above.
- Amendment to the Pregnancy and Maternity section EHIA.

## **6 Are there any remaining concerns outstanding following the consultation that have not been resolved in the final service specification?**

None

## **7 What are the next steps including how interested stakeholders will be kept informed of progress?**

A summary of the feedback from stakeholder engagement will be made available to the relevant charities.