

## Consultation Report

### Topic details

<b>Title of policy or policy statement:</b>	Proton Beam Therapy for Children, Teenagers and Young Adults in the treatment of malignant and non-malignant tumours
<b>Programme of Care:</b>	Cancer
<b>Clinical Reference Group:</b>	Radiotherapy
<b>URN:</b>	1783

### 1. Summary

This report summarises the outcome of a public consultation that was undertaken to test the policy proposition.

### 2. Background

Cancer in children, teenagers and young adults is rare, however it is one the leading causes of death in this age group. External beam radiotherapy, also referred to as conventional radiotherapy, is a key treatment option for some children, teenagers and young people with cancer. Although treatment with conventional radiotherapy can result in cure, children, teenagers and young people with cancer can suffer from significant long-term effects as result of the treatment.

Proton beam therapy (PBT) is a type of radiotherapy. There is extensive literature describing the advantages of PBT compared to conventional radiotherapy, which leads to less irradiation of normal surrounding tissue. As a result, it is thought the treatment reduces the long-term side effects of conventional radiotherapy.

Some children, teenagers and young people have been able to access PBT services through NHS England's Overseas Programme. This policy proposition has been developed to support the development and ramp-up of the NHS PBT service.

The policy proposition has been subject to stakeholder testing and public consultation in line with NHS England's standard processes.

### 3. Publication of consultation

The policy proposition was published and sign-posted on NHS England's website and was open to consultation feedback for a period of 6 weeks from 23rd July 2019 to 5th September 2019. Consultation comments have then been shared with the Policy Working Group (PWG) to enable full consideration of feedback and to support a decision on whether any changes to the policy might be recommended.

Respondents were asked the following consultation questions:

- Has all the relevant evidence been taken into account?
- Does the impact assessment fairly reflect the likely activity, budget and service impact? If not, what is inaccurate?
- Does the policy proposition accurately describe the current patient pathway that patients experience? If not, what is different?
- Please provide any comments that you may have about the potential impact on equality and health inequalities which might arise as a result of the proposed changes that have been described?
- Are there any changes or additions you think need to be made to this document, and why?

#### **4. Results of consultation**

There were 23 responses to public consultation. These were from a range of individuals and organisations including clinicians, charities, individuals with a personal interest, professional groups and associations and one private provider.

Of the 23 responses received, four respondents fully supported the policy proposition and had no additional comments on the draft documentation. The remaining 19 respondents, although supportive of the policy proposition, raised the following points:

- Respondents raised concerns regarding the funding of travel for patients and their families. Furthermore, one respondent queried the use of the word 'funding' in Section 8 of the policy proposition and asked for clarification as to whether this included the costs of travel.
- Respondents raised that implementation of the policy, which widens access to PBT services, would have a significant impact on conventional paediatric radiotherapy services and queried how this would be dealt with.
- Respondents queried how centres treating these patients would deliver a number of other co-dependent services for children, teenagers and young people, including (i) paediatric anaesthetic services; (ii) paediatric chemotherapy services; and (iii) access to wider support services (such as therapies) required for these cancer services.
- Respondents commented on the available capacity within the NHS PBT service and queried whether this was sufficient to treat all eligible patients.
- One respondent noted that the policy proposition referenced parents of children, teenagers and young adults, but suggested that this be expanded to cover carers.
- One respondent felt that the shared decision-making tool included as an appendix in the policy required amending to reflect the potential of increased radionecrosis as a result of treatment with PBT.

## **5. How have consultation responses been considered?**

Responses have been carefully considered and noted in line with the following categories:

- Level 1: Incorporated into draft document immediately to improve accuracy or clarity
- Level 2: Issue has already been considered by the CRG in its development and therefore draft document requires no further change
- Level 3: Could result in a more substantial change, requiring further consideration by the CRG in its work programme and as part of the next iteration of the document
- Level 4: Falls outside of the scope of the specification and NHS England's direct commissioning responsibility.

## **6. Has anything been changed in the policy as a result of the consultation?**

All feedback from public consultation has been reviewed by the PWG. The following three responses were graded as Level 1 and these changes have been incorporated into the policy:

- Carers are now referenced in the policy proposition, along with parents.
- The decision-making tool has been amended to reflect the potential for increased radionecrosis as a result of treatment with PBT.
- 'Section 8' of the policy proposition has been amended to clarify that this section refers to the routine commissioning of PBT treatment only.

All other responses were graded as Level 2 or Level 4 responses and therefore no additional changes have been made to the policy as a result of public consultation feedback. PWG feedback is as follows:

- The PWG acknowledge and appreciate the impact of travel on patient and family lives. In relation to the cost of travel, at present it is possible to be reimbursed under the Healthcare travel Costs Scheme (HTCS), which forms part of the NHS Low Income Scheme, and is designed to provide financial assistance to patients who do not have a medical need for hospital or ambulance transport, but who require assistance with their travel costs. Under the Scheme, patients on low incomes, or in receipt of specific qualifying benefits or allowances, are reimbursed in part or in full for costs incurred while travelling to receive non-primary medical and non-primary dental services, where their journey meets certain criteria. Where a child under 16 attends an appointment, support may include the travel costs of a parent or guardian escorting the child to its appointment. Extending the remit of the HTCS is considered to be outside the scope of the policy development process because such a decision would require discussion with other parties, including the Department for Health and Social Care, and may also have wider implications for other healthcare services and patient groups which would

need to be considered. Grading: Level 4 response.

- It is recognised that once the NHS PBT service is as at full capacity, there will be an increased impact on the number of patients, particularly children, undergoing treatment with conventional radiotherapy. This issue is being considered separately by NHS England, in collaboration with a range of stakeholders, and is expected to conclude in 2021. As such, the consultation responses were considered to be outside of the scope of the policy proposition, as they relate to children's radiotherapy services rather than PBT. Grading: Level 4 response.
- The service requirements for PBT centres are clearly set-out in the relevant Service Specification (NHS England Reference 170071S), including the requirements for clinical co-dependent services such as anaesthesia, paediatric oncology provision and access to therapies. Both PBT centres will be expected to be compliant with this Service Specification. For this reason, these responses were considered to be outside of the scope of the policy proposition. Grading: Level 4 response.
- NHS England are confident that when both NHS PBT Centres are open, there will be sufficient capacity to treat all eligible patients. Grading: Level 2 response.

**7. Are there any remaining concerns outstanding following the consultation that have not been resolved in the final policy proposal?**

None.