

## Consultation Report

<b>Title of Standard Operating Procedure:</b>	Process for applying for Proton Beam Therapy and subsequent treatment centre allocation for eligible patients
<b>Programme of Care:</b>	Cancer
<b>Programme:</b>	National Proton Beam Therapy Programme

### 1. Summary

This report summarises the outcome of a public consultation that was undertaken to test the standard operating procedure (SOP) for the process for applying for Proton Beam Therapy and subsequent treatment centre allocation for eligible patients.

### 2. Background

NHS England has been referring patients eligible for proton beam therapy (PBT) overseas for treatment since 2008. The routine commissioned providers of this service are University of Florida Health Proton Institute, Jacksonville, USA and Westdeutsches Protontherapiezentrum (WPE) Essen, Germany. Both centres have been through a full NHS England procurement or quality assurance process and both are fully compliant with the NHS England service specification for overseas PBT providers which can be found at: <https://www.england.nhs.uk/publication/service-specifications-proton-beam-therapy-service-adults-and-children/>

On occasion, some adult patients may be treated at the Paul Scherrer Institut, Villigen, Switzerland. This will particularly be for those patients unable to travel to the United States for either clinical or other personal issues such as visa restrictions

The first NHS PBT centre at The Christie NHS Foundation Trust Manchester commenced treating patients in December 2018. The second NHS PBT centre will open in 2020 at University College London Hospitals NHS Foundation Trust.

The NHS PBT centres will go through a period of clinical and capacity ramp-up during which time the clinical indications and number of patients able to be treated within these centres will increase based on capacity and safety plus ability to meet critical pathways of treatment starting times, to a point at which it will no longer be necessary to refer any NHS patients overseas for treatment. It is anticipated this will be by March 2022.

In July 2018, NHS England held a co-production workshop attended by 39 individuals including representatives from the Brain Tumour Trust, Brain Tumour Support, The Brain Tumour Charity, Cancer Research UK, CLIC Sargent, Patient/carers (Brain Tumour Research), Public & Patient Voice (NHS England), Royal College of Radiologists, University Hospital Birmingham NHS Foundation Trust, University Hospital Bristol NHS Foundation

Trust, The Christie NHS Foundation Trust, University College London Hospitals NHS Foundation Trust and NHS England.

The purpose of the workshop was to develop a Standard Operating Procedure (SOP) to address how all patients eligible for PBT treatment should be allocated/referred to the NHS England commissioned PBT providers set out above in line with the capacity available; recognising that some patients would still need to be treated overseas until the NHS based service was up to full capacity.

The workshop was well received particularly by charity organisations and patient/carer representatives.

Following the workshop, a draft of the SOP was sent to attendees and those invited who were unable to attend the workshop. 4 responses were received and the SOP amended where appropriate. The amended version of the SOP was then issued for public consultation.

### **3. Publication of consultation**

The SOP was published and sign-posted on NHS England's website and was open to consultation feedback for a period of 6 weeks from 8th November 2018 to 20<sup>th</sup> December 2018.

Respondents were asked the following consultation questions:

- Do you support the proposals within the SOP?
- Do you support the framework that has been developed to allocate patients to a treatment centre?
- Do you have any specific comments on the treatment centre allocation process as set out within the SOP?
- With reference to paragraph 5.4 are there any other criteria that you feel should be taken into consideration when making a decision?
- Do you have any further comments?

Consultation comments were shared with the national PBT Programme Commissioning meeting to enable full consideration of feedback and to support a decision on whether any changes to the SOP would need to be recommended.

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

Five responses were received. One was supportive of the SOP with no further comment. This was from the Royal College of Physicians. Four were not supportive.

All four of the non-supportive responses were either from or advocating for The Rutherford Cancer Centre in South Wales. This is a private PBT provider not commissioned by NHS England. The main theme of the responses was to question why The Rutherford Cancer Centre was not considered as a provider of PBT for NHS England patients, particularly in light of a recent decision by NHS Wales to commission PBT service from The Rutherford Cancer Centre for a small number of non-complex adult patients.

## 5. How have consultation responses been considered?

Responses were 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 in the SOP's development and therefore draft document requires no further change
- Level 3: Could result in a more substantial change, requiring further consideration by the programme as part of the next iteration of the document
- Level 4: Falls outside of the scope of the SOP

The main theme of all of the non-supportive responses was that The Rutherford Cancer Centre was a potential alternative provider of PBT services, commissioned by NHS Wales and should therefore be considered. These responses have been categorised as either Level 2 or 4 as they related to the commissioning decisions taken by NHS England and not the SOP itself.

However, for clarity the following points should be noted:

- NHS England is responsible for commissioning services for the population of England. Similarly, Wales, Scotland and Northern Ireland are responsible for commissioning services for their populations. Commissioning decisions taken by NHS England and the devolved administrations are independent unless a specific agreement is in place. In this case the commissioning decision taken by NHS Wales is independent of that of NHS England.
- NHS Wales have taken their commissioning decision based on a different service specification.
- In late 2017 NHS England undertook a full and open procurement process for a PBT Provider for services to children and young people for an interim period until the NHS PBT Service was fully up and running. The procurement was based on the published NHS England service specification for the Proton Overseas Programme. A bid was received from The Rutherford Centre at Newport, South Wales, along with two other bids. All bidding centres were visited by a team from NHS England consisting of clinicians and managers. The Rutherford Centre was found not to meet the acceptable standard set by NHS England in many of the areas examined, the majority of which were in relation to clinical standards and pathways. The Rutherford Centre was therefore, excluded from the process.
- Since the procurement, NHS England has publicly consulted on and published a service specification for the NHS PBT service. This includes the key criteria that the PBT centres must be hospital based, integrated within a cancer centre and have a minimum of two proton treatment rooms. It is NHS England's understanding that The Rutherford Centres are not able to meet these criteria.
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## 6. Has anything been changed in the policy as a result of the consultation?

No

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

No