Proton beam therapy

Understanding the pathway



When does proton beam therapy happen?

Proton beam therapy (PBT), just like all other cancer treatments, takes place once a diagnosis has been confirmed by the multidisciplinary team. In the case of proton beam therapy, after diagnosis, each case is reviewed by both the PBT National Clinical Panel, who commission the treatment on behalf of NHS England, and the proton beam therapy centre multidisciplinary team, either in Manchester or London. This is to ensure that proton beam therapy is indeed the most effective treatment for the patient. For more information, read the 'Understanding the decision process' booklet.

As with other forms of radiotherapy, proton beam therapy may be given in addition to other forms of cancer treatment, such as surgery and chemotherapy. If surgery is appropriate, this may be done to perform a biopsy, partial removal or maximum removal of the tumour. Whether the surgery is emergency or planned, in the majority of cases, it takes place prior to radiotherapy. Scans are then taken after surgery in order to inform the course of treatment for proton beam therapy. Regardless of whether the patient receives proton beam therapy alone or with other treatments, the schedule of treatment will be discussed with the patient, along with any changes that are made along the way. In terms of timescale, the treatment should start as soon as possible after a diagnosis, with a period of no more than 62 days from urgent referral to treatment, and 31 days between diagnosis and first

definitive treatment. If surgery is appropriate, this is likely to constitute the first definitive treatment.

Preparing for proton beam therapy

Preparation for proton beam therapy is very similar to the preparation for complex X-ray radiotherapy patients. Before proton beam therapy takes place, the patient travels to the proton beam therapy centre, either in Manchester or London, for an assessment visit. This assessment takes place in a single visit (overnight accommodation will be provided if required) and includes:

- a clinical oncology review
- any other relevant medical reviews, such as paediatric oncology or anaesthesia
- giving consent for treatment
- planning scans
- making a special mask if the tumour is located in the brain
- meeting with key workers
- any pre-treatment investigations or assessments.²

During this assessment day, the patient meets the team who will be delivering the treatment. A radiation oncologist (a doctor who specialises in radiotherapy) oversees the treatment, and they will review medical records, perform a physical exam and recommend any tests during the assessment day. This doctor provides all the information

¹ NHS England (2013).

² NHS England (2018).

needed, and there will be plenty of opportunity to ask questions about proton beam therapy.

As part of the proton beam therapy care pathway, the patient is given a named key worker who is part of the multidisciplinary team looking after them at the proton beam therapy centre. This person is the patient's main point of contact during treatment, so if the patient has any questions or concerns, this is the person to talk to. Also in the proton beam therapy multidisciplinary team are:

- clinical oncologists
- therapy radiographers
- medical physicists
- anaesthetists
- health play specialists (for paediatric patients)
- medical engineers
- dosimetrists
- administrative support
- specialist nurses
- allied healthcare professionals (as required)
 - occupational therapists
 - physiotherapists
 - psychologists.3

This multidisciplinary team will be in place to recognise and evaluate the whole patient pathway, not just the delivery of protons.

 $^{^{3}}$ NHS England (2018).

In order to determine the best position for the patient during treatment, there will be a radiation simulation. This is a rehearsal where the team helps the patient to find a comfortable position on a table that will be used during treatment. This is essential because the patient needs to lie still so that the protons can deliver the radiation to an exact position. The table used in proton beam therapy is an advanced 'robotic couch' that allows very precise positioning. The couch enables corrections along all three dimensions in space, as well as in rotational axes. Cushions and straps will be used to help the patient stay still, and the radiotherapy team will use a marker to mark on the patient's body where the radiation will go. They may also use permanent tattoo markings. For head and neck radiotherapy, it is likely that the patient will need to wear a special mask that is moulded to the face and head of each patient. The patient will be able to breathe and see normally with this mask on, and it will be attached to the table to hold the head still throughout the few minutes of treatment. This mask will be made during the assessment visit. Another important aspect of preparation will be scans of the area for treatment. These may be magnetic resonance imaging (MRI) or computerised tomography (CT) scans. The radiotherapy team uses these scans to determine the precise location for treatment and the best way for the protons to reach this location.

Once the assessments are done, the proton beam therapy will commence and will take place over a course of six to eight weeks. Accommodation will be provided if required.

What happens after proton beam therapy?

After treatment, the patient enters a stage of care known as follow-up. This involves ongoing monitoring and support to ensure that the treatment remains effective. Follow-up care takes place locally, as close to home as possible, and will take the form of regular clinical reviews. MRI scans may be used as part of these clinical reviews, but reviews will also assess changes to physical, psychological and cognitive well-being. The patient will also be given access to allied health professional assessment and rehabilitation services.

If at any point the patient experiences new or changing symptoms, or they are concerned that the cancer might be returning, they will receive an urgent re-referral and appropriate imaging. Clear information on who to contact if this happens will be provided.

The standard of care given throughout this pathway is the same for all complex radiotherapy treatments, regardless of the type of radiotherapy being given. This pathway is not specific to proton beam therapy but is the same for all complex radiotherapy patients.

References

American Society of Clinical Oncology (2022) What to expect when having radiation therapy, Cancer.Net. Available at: https://www.cancer.net/navigating-cancer-care/how-cancer-treated/radiation-therapy/what-expect-when-having-radiation-therapy (Accessed: 4 February 2024).

Burnet, N.G. *et al.* (2020) 'Proton beam therapy: Perspectives on the National Health Service England clinical service and research programme', *The British Journal of Radiology*, 93(1107), p. 20190873. doi:10.1259/bjr.20190873.

NHS England (2013) '2013/14 NHS Standard Contract for Radiotherapy (All Ages)'. London: NHS England. Available at: https://www.england.nhs.uk/wp-content/uploads/2018/08/Radiotherapy-all-ages.pdf (Accessed: 4 February 2024).

NHS England (2018) 'Proton Beam Therapy Service (All Ages)'. London: NHS England. Available at: https://www.england.nhs.uk/wp-content/uploads/2018/07/service-spec-proton-beam-therapy-service-all-ages.pdf (Accessed: 4 February 2024).

Funded (in part) from EPSRC EP/N027167/1 Grand Challenge Network+ in Proton Therapy.

brainstrust would like to acknowledge the invaluable input of the patient, caregiver and clinical communities who have given their time to ensure that the information in this guide is as relevant and useful as possible.



Registered charitable trust – *brainstrust* is a registered charity in England and Wales (1114634), and Scotland (SCO44642).

Published February 2024.

Due for review February 2027.

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