

# Proton beam therapy

## Frequently asked questions



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# Proton beam therapy: Frequently asked questions

These are the questions that are most frequently asked by patients. The availability of proton beam therapy continues to evolve in the UK, and services are currently provided by the NHS at The Christie, in Manchester, and University College London Hospitals. Rutherford Health plc was a private provider but went into administration in June 2022.

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# 1. General interest

## How do protons work?

Proton beam therapy (PBT) is a form of radiotherapy treatment delivered by a beam of subatomic particles rather than high-energy X-rays. However, unlike conventional radiotherapy using X-rays, which deliver radiation throughout their journey through the body, protons deposit their radiation within the tumour site, which spares more of the surrounding healthy tissue from damage.

## Is my condition treatable with proton beam therapy?

It is a clinical decision that determines whether a patient's condition is suitable for proton beam therapy. Based on a referring oncologist's recommendation, an NHS patient will be referred to the PBT National Clinical Panel to determine their suitability and eligibility for treatment. These criteria are based on particular tumour diagnoses and age limits.

## Is proton beam therapy suitable for recurrent brain tumours?

For brain tumours that have recurred following prior radiotherapy, sometimes radiotherapy can be repeated if the interval between the first and second courses is at least one year. Proton beam therapy may offer a safer means of delivering repeat radiotherapy than conventional radiotherapy. However, whether proton

beam therapy can be used for treating a recurrence will need careful consideration by your oncologist.

## **Is proton beam therapy suitable for terminal cancer?**

Proton beam therapy is unlikely to be effective. An oncologist is likely to offer care that is designed to support quality of life. This is called best supportive care.

## **Are proton beam therapy patients admitted as inpatients?**

No. Proton beam therapy is delivered in an outpatient environment, just like conventional radiotherapy. Treatment is likely to be given daily over a period of several weeks, and accommodation is arranged if patients live too far from the centre to travel daily.

## **Is proton beam therapy available for children?**

Proton beam therapy is particularly effective in the treatment of some childhood cancers, in order to minimise or avoid the late side effects of radiotherapy treatment.

## **Why is the NHS still sending some patients abroad?**

Clinical need usually determines the best referral pathway for the patient. While the NHS continues to develop its proton beam therapy services, it will continue to need additional capacity until it reaches full capacity of treating around 1,500 patients per year.

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## 2. The decision process

### **Is proton beam therapy available on the NHS?**

It is available at The Christie, in Manchester, and University College London Hospitals, for patients who meet the NHS criteria.

### **Can I access proton beam therapy privately?**

If it is an appropriate treatment for you, then you should be able to access proton beam therapy on the NHS.

### **How can I find out what the decision-making criteria are?**

For NHS patients, the decision-making criteria are available on the NHS England website: **[www.england.nhs.uk/commissioning/spec-services/highly-spec-services/pbt](http://www.england.nhs.uk/commissioning/spec-services/highly-spec-services/pbt)**.

### **Who holds the budgets and the decision-making power?**

NHS budgets and decision-making powers for proton beam therapy are held by NHS England and each of the devolved administrations in Wales, Scotland and Northern Ireland.

### **Will I find out why it wasn't offered if my case is discussed?**

Yes. NHS patients will be advised of the outcome of the PBT National Clinical Panel's decision and the reason for the treatment not being made available.

## **Can patients self-refer?**

NHS patients will be referred by their oncology consultant to the PBT National Clinical Panel for a decision on whether they are eligible for proton beam therapy according to agreed criteria.

## **How much will proton beam therapy cost me?**

For patients not eligible to use the NHS – so self-pay and insured patients – the total cost of treatment is unique to the patient's individual needs, according to tumour site and the length of treatment. There is no one-size-fits-all pricing bracket. Instead, a personalised cancer treatment plan will be designed for each patient.

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## 3. Where to have proton beam therapy

### Where are the NHS proton beam therapy centres?

They are at The Christie, in Manchester, and University College London Hospitals, for patients who meet the NHS criteria.

### What are the advantages of having proton beam therapy on the NHS?

There are several. Many people believe that with our overpressed NHS system, using private healthcare is better. However, when dealing with illnesses such as cancer, the NHS offers aspects of care that the private system is unable to.

### What does the NHS offer?

**Data.** Having your treatment on the NHS means that your data will be added to a prospective outcomes study. This data is collected with the correct safeguards and ethical approvals needed, and it feeds into the world's largest single database of people living with cancer. This dataset is transforming cancer service delivery, as we are developing a better understanding of how each subtype of cancer responds to treatment. This is helping doctors to target genetic mutations with a new generation of treatments designed to work effectively on relatively small numbers of patients.

**Service delivery.** Patients who benefit from proton beam therapy tend to have rare or less common cancers. Their cases can be very complex, and so support and treatment may be needed from a huge number of people. Having proton beam therapy on the NHS means that the patient's treatment will be viewed in the context of the wider range of other services that might be needed at the same time. All these services need to work together for the benefit of the patient. For example, a patient may need access to occupational therapy, psychology or play therapy (in the case of a child).

**Quality control.** Treatment at an NHS proton beam therapy centre comes with gold-standard quality controls and monitoring. The service standards are stringent and rigorous and are reviewed each year. There are technical standards too, such as exposure to radiation, safeguarding children and vulnerable adults, ensuring that radiotherapy is delivered according to national and international standards, and meeting the requirements of the Cancer Reform Strategy Commitment to Achieving World-Class Outcomes,<sup>1</sup> the NHS Long Term Plan<sup>2</sup> and the NHS England Vision for Radiotherapy 2014–2024.<sup>3</sup>

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<sup>1</sup> NHS England (2016).

<sup>2</sup> NHS England (2019).

<sup>3</sup> Samuel and Boon (2014).



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## 4. Financial questions

### **Do eligible NHS patients incur any costs for proton beam therapy treatment?**

No. The cost of treatment and accommodation for the patient and a caregiver is covered for treatment in the UK.

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## 5. Regulation and patient outcomes

### **Is it safe? Has it been tested? What is the evidence?**

Proton beam therapy has been in use since the 1950s, particularly in the United States and some centres in Germany and Switzerland. There is clinical evidence available of its safety, and strong clinical consensus about its efficacy for a range of tumour sites, but not all. The targeted nature of proton beam therapy can reduce the side effects of treatment and in some cases lead to a higher chance of cure.

### **Are there many different types of proton beam therapy machine, and is any one better than the others?**

There are just a few international suppliers of proton beam therapy equipment in the world. Their equipment is slightly different, but they all deliver the same treatment. The most modern machines deliver what is referred to as pencil beam scanning (PBS), as compared to the older double scattering technique. The facilities at The Christie and University College London Hospitals have the most up-to-date proton beam therapy equipment.

### **Are the proton beam therapy machines susceptible to breakdowns?**

The protons used in the machines are produced by cyclotrons, which are highly complex pieces of equipment that require ongoing maintenance to ensure

their continued operational performance. There may be an occasion when a machine is not available for a short time, and should this happen, a radiographer will advise you on how your treatment will be handled.

## **What happens if the cyclotron is not available during a course of treatment?**

The treating radiographer will advise on how the treatment will proceed. For example, some fractions may be replanned to be delivered over a weekend. In accordance with guidelines from the Royal College of Radiologists, there is also scope to deliver the treatment over a slightly longer timescale without detriment to the clinical outcome.

## **What are the success rates for proton beam therapy?**

Patients meeting the optimal criteria for treatment via proton beam therapy respond well to treatment. However, it is not possible to give a measured success rate, as success can be defined in many ways, depending on the stage and nature of the individual cancer.

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## 6. The treatment pathway

### **What are the benefits of proton beam therapy compared to conventional radiotherapy?**

Proton beam therapy utilises cutting-edge technology to concentrate the radiotherapy dose delivered to the cancer itself, reducing the amount of radiation delivered to the surrounding healthy tissue. Research indicates that patients experience reduced side effects when treated with proton beam therapy.<sup>4</sup>

### **Is proton beam therapy an alternative to surgery?**

As with conventional radiotherapy, depending on the patient's circumstances, the tailored treatment plan may include proton beam therapy delivered as the main treatment or alongside other treatments, including surgery.

### **Is it an alternative to radiotherapy?**

Proton beam therapy is one of several precision radiotherapies that might be offered to a patient, according to their tumour site and type.

### **Can you have proton beam therapy after conventional radiotherapy?**

Proton beam therapy may be suitable for treating a recurrent tumour, where conventional radiotherapy has been unsuccessful.

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<sup>4</sup> Baumann, B.C. *et al.* (2020).

## **Can you have proton beam therapy more than once? Is there a clinical limit?**

In some circumstances, it may be possible to receive a repeat course of proton beam therapy, but this is a complex decision that would need full discussion with a clinical oncologist.

## **Can I opt out and have conventional radiotherapy or no radiotherapy?**

In many cases, conventional radiotherapy can be given instead of proton beam therapy, but it is likely that this would increase the side effects of treatment. In some cases, proton beam therapy is better than conventional radiotherapy for treating the tumour. A comparison of the benefits and side effects of conventional radiotherapy and proton beam therapy depends on the individual features of the tumour and would need discussion with a clinical oncologist.

## **What are the long-term side effects?**

These will be discussed with you by your clinical oncologist. The long-term side effects of radiotherapy for brain tumours can include difficulties with short-term memory. One of the aims of proton beam therapy is to reduce the risk and severity of effects on memory following treatment.

## **What does follow-up for a patient look like?**

After treatment has finished, regular follow-up appointments are arranged by the treatment team, including the oncologist. These can take place in the clinics and sometimes on the telephone if that is more convenient for you. For some tumour types, scans and tests are carried out to monitor your response to treatment. The follow-up appointments are usually more frequent in the first year following treatment and may be less frequent during subsequent years, but direct access to the treatment team is always available if you have any concerns.

## **How does it work with the rest of my cancer treatment?**

In the same way as conventional radiotherapy, proton beam therapy is sometimes given in combination with surgery, chemotherapy and/or immunotherapy.

## **Do my caregivers or family get support?**

Caregivers and family are given access to all the holistic support offered to patients.

## **Are there support services available for children too?**

A broad package of care is available for children, which includes play therapy, a holistic needs assessment for the patient and their family, and support from a dedicated anaesthetics team (if required for very young children).

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