

Proton beam therapy:

Frequently asked questions



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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 both the NHS and Rutherford Health plc. Answering these questions should help you to exercise choice between the service providers, according to the sources of funding available.

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, which uses X-rays that pass through the tumour and out of the body (exit dose), protons deposit their energy within the tumour site. This 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 your condition is suitable for PBT. Based on a referring oncologist's recommendation, an NHS patient will be referred to the Proton Panel to determine their suitability and eligibility for treatment. These criteria are based on particular tumour diagnoses and age limits.

Rutherford Health is able to offer PBT for a wider range of tumours, as it is not restricted by NHS eligibility criteria.

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. PBT may offer a safer means of delivering repeat radiotherapy than conventional radiotherapy. However, whether PBT can be used for treating a recurrence will need careful consideration by your oncologist.

Is proton beam therapy suitable for terminal cancer?

PBT is unlikely to be effective. An oncologist is likely to offer care that is designed to support your quality of life. *brainstrust* can signpost patients to supportive care services.

Are proton beam therapy patients admitted as inpatients?

No. PBT 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 can be arranged if you wish to avoid travelling.

Is proton beam therapy available for children?

PBT is particularly effective in the treatment of some childhood cancers, in order to minimise or avoid the late side effects of radiotherapy treatment. The NHS currently specialises in treating children at The Christie NHS Foundation Trust, in Manchester, or refers them abroad.

Why is the NHS still sending some patients abroad?

Clinical need usually determines the best referral pathway for you. While the NHS continues to develop its proton beam therapy services, with the opening of a new centre at University College London Hospitals in the next few years, it will continue to need additional capacity. However, the Rutherford Cancer Centres do present an alternative option to avoid travelling overseas or excessive travel in the UK.

2. The decision process

Is proton beam therapy available on the NHS?

It is available at The Christie NHS Foundation Trust, in Manchester, for patients who meet the NHS criteria. It is available at the Rutherford Cancer Centre South Wales for adult patients from Wales.

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.

Who holds the budgets and the decision-making powers?

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. If you are an NHS patient, you will be advised of the outcome of the Proton 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 NHS Proton Panel for a decision on whether they are eligible for proton beam therapy according to agreed criteria.

Any patient may refer themselves to Rutherford Health plc via the enquiries helpline for an initial consultation and a potential referral to the Rutherford Proton Panel for a decision. Treatment would be funded by the patient or the patient's insurer: rutherfordhealth.com.

How much will proton beam therapy cost me?

For self-pay and insured patients, the total cost of treatment is unique to your 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 you.

3. Where to have PBT

Where are the NHS proton beam therapy centres?

PBT is currently available at The Christie NHS Foundation Trust, in Manchester, for patients who meet the NHS criteria. A proton centre is due to open at University College London Hospitals NHS Foundation Trust during 2020.

Where are the proton beam therapy centres in the independent sector?

Currently, proton beam therapy is available at:

- (i) Rutherford Cancer Centre South Wales, near Newport
- (ii) Rutherford Cancer Centre North East, in Bomersund, Northumberland
- (iii) Rutherford Cancer Centre Thames Valley, in Reading.

Rutherford Cancer Centre North West, in Liverpool, will open during 2020 and begin treating with proton beam therapy in 2021.

Can I get proton beam therapy at Rutherford Cancer Centres as an NHS patient?

At this time, only adults in Wales can be referred by the NHS for high-energy proton beam therapy at Rutherford Cancer Centres.

How does the relationship work between the NHS and Rutherford? We know that the NHS refers to Rutherford. Does it work the other way around?

NHS Wales directly commissions Rutherford Cancer Centre South Wales to treat Welsh adult patients. All of the Rutherford Cancer Centres work with NHS clinicians to deliver NHS and private patient care pathways.

Do the Rutherford Cancer Centres treat children?

The Rutherford Cancer Centres are currently treating adults at all of their centres and have started treating children privately in Newport. They are planning to expand the service to all of their centres, with a paediatric patient pathway for selected patients who have adequate paediatric oncology support, in due course. The NHS currently specialises in treating children at The Christie NHS Foundation Trust, in Manchester, or refers them abroad.

If I am in an independent centre, will I still have access to any clinical trials?

Potentially, yes, if the centre is participating in a relevant clinical trial.

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. If you are referred abroad, some travel costs are also covered. You may need to make your own arrangements to cover subsistence while staying abroad.

How much does PBT cost in the independent sector?

Proton beam therapy treatments are planned according to your needs and the number of treatments required. Everyone is different, and consequently, the price of each care package will vary. Self-funding patients can expect a package of care to cost between £50K and £90K.

What does a package of care include?

A package of care includes initial consultation, patient assessment, treatment planning, treatment, follow-up and support services. Accommodation is offered as an optional extra for self-funded patients being treated in the independent sector.

How does pricing in the independent sector compare to the NHS cost of treatment?

At full capacity, the NHS expects that patients will cost an average of £45K each, which is significantly less than the cost of sending patients overseas at an average cost of £112K (2017/18). Prices at the Rutherford Cancer Centres are likely to be between £50K and £90K.

Does the independent sector offer any financing packages to spread out the costs?

The Rutherford Cancer Centres can provide a link to a financial services provider who is aware of its services and can advise on options for personal loan services. Alternatively, Rutherford Direct is a membership scheme that covers the cost of cancer services, in accordance with its terms and conditions.

Does the independent sector offer free consultations?

The Rutherford Cancer Centres will undertake initial telephone or face-to-face assessments at no cost. If patients proceed to a full outpatient consultation, this is chargeable in the usual manner to the insurer or is self-funded by the patient.

5. Regulation and patient outcomes

Is proton beam therapy a regulated service at Rutherford Cancer Centres? The same as the NHS?

Yes. Rutherford Cancer Centres are registered with Health Inspectorate Wales and the Care Quality Commission to deliver proton beam therapy to the same standards of patient safety as the NHS.

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

PBT 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. Recent research from many centres concludes that PBT can be used to deliver effective treatment for many tumours. The targeted nature of PBT can reduce the side effects of treatment and, in some cases, lead to a higher chance of cure.

Are there many different types of PBT 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 treatments.

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 Rutherford Cancer Centres all have the most up-to-date PBS equipment.

Are the PBT machines prone to breakdowns?

The protons used in the machines are produced by cyclotrons. These are highly complex pieces of equipment that require ongoing maintenance to ensure their continued operational performance. There may be an occasion when it is not available for a short time. 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 affecting the clinical outcome.

Patients being treated at the Rutherford Cancer Centres can be treated at an alternative Rutherford Cancer Centre due to its unique IT networking, which enables patient treatment plans to be easily shared across its centres.

How do Rutherford Cancer Centre results compare to other centres?

Patients are reporting a good patient experience at all of the proton centres in the UK.

Is my data still collected by the National Cancer Registration and Analysis Service (NCRAS) if I have treatment at a Rutherford Cancer Centre?

Rutherford Cancer Centres are working to collaborate with the NCRAS on data collection.

What are the success rates for proton beam therapy?

Patients meeting the optimal criteria for treatment via proton beam therapy respond well to treatment. When treating brain tumours, PBT offers the same chance of tumour response as conventional radiotherapy but with fewer side effects. 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.

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.¹

Is proton beam therapy an alternative to surgery?

As with conventional radiotherapy, depending on the patient's circumstances, the tailored treatment plan may include PBT 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.

¹ Baumann et al. Abstract 6521. Presented at: ASCO Annual Meeting; May 31–June 4, 2019; Chicago.

Can you have it after conventional radiotherapy?

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

Can you have PBT after PBT? Is there a clinical limit?

In some circumstances, it may be possible to receive a repeat course of PBT, 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 PBT, but it is likely that this would increase the side effects of treatment. In some cases, PBT is better than conventional radiotherapy for treating the tumour. A comparison of the benefits and side effects of conventional radiotherapy and PBT depends on the individual features of the tumour and would need discussion with a clinical oncologist.

What are the long-term effects?

These will be discussed with you by your clinical oncologist. The long-term 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 or 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 clinic 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. Follow-up appointments are usually more frequent in the first year following treatment and may be less frequent during the 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, PBT is sometimes given in combination with surgery and/or chemotherapy/immunotherapy.

Do my caregivers or family get support?

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

Are there support services available for children too?

Proton centres provide a broad package of care 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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Notes





Registered charitable trust – *brainstrust* is a registered charity in England and Wales (1114634), and Scotland (SC044642).

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