

Where should I have proton beam therapy?

NHS or private



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Until very recently, this question would not have even been raised. But with the opening of both private and NHS proton beam therapy centres, this will be in the forefront of some people's minds. It's a confusing landscape.

Many people believe that with our over-pressed NHS system, using private healthcare is better. However, when dealing with illnesses such as cancer, the NHS offers aspects of care that the private healthcare system is unable to. The bottom line is that there are many advantages to being treated in one of the NHS proton beam therapy centres.

We know that there are many uncertainties around proton beam therapy (see 'Proton beam therapy clinical research – The current state of clinical research'). This is because:

- There are multiple potential indications for proton beam therapy.
- We need more studies to demonstrate the promised clinical benefits.
- The challenge is teasing out those studies that have a meaningful clinical benefit – we need to collect outcomes if we are to do this.
- There needs to be more clinical research into defining those patients who would benefit most.

By opting to be treated at an NHS proton beam therapy centre, patients will be helping to eliminate these uncertainties.

What the NHS offers¹

Data – the world’s largest single database of people living with cancer

This database was developed and established by Public Health England to harness the power of data to revolutionise care. NHS clinicians now have instant access to detailed clinical data, including the way tumours respond to different types of treatment. This will speed up work to deliver personalised cancer medicine to patients in the future.

It will eventually track how each subtype of cancer responds to treatment, helping doctors target genetic mutations with a new generation of drugs designed to work most effectively on relatively small numbers of patients.

Every aspect of the patient and their pathway is adding to population-level data. This data is collected with the correct safeguards and ethical approvals needed, and feeds into the National Cancer Registration and Analysis Service. All patients who are treated in an NHS proton beam therapy centre will be on a prospective outcomes study so that this data can add to the picture that will help all patients who need proton beam therapy now and in the future. A prospective study watches for outcomes, such as the development of a disease, during the study period and relates this to other factors such as suspected risk or protection factors. This means that all the data attached

¹ NHS England. (2018). *Proton Beam Therapy NHS Service (All Ages)*. [online] London: NHS England. Available at: www.england.nhs.uk/wp-content/uploads/2018/07/proton-beam-therapy-service-all-ages.pdf [Accessed 3 Sep. 2018].

to that patient will be collected along the pathway, from referral to long-term follow-up.

Service delivery

Patients who are going to benefit from proton beam therapy tend to have rarer or less common cancers. Their cases can be very complex and can need support and treatment from a huge number of different people. For example, every patient who is having proton beam therapy will have a named key worker, and all of these people, who have had training in proton beam therapy, will be involved on their pathway:

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

The provision of proton beam therapy treatment must be viewed in the context of the wider range of other services that a patient may need access to, often at the same time. The proton beam therapy service has to be hospital-based to ensure these services all work together for the benefit

of the patient, which includes managing appointments and not overwhelming the patient.

Quality control

Treatment at an NHS proton beam therapy centre also comes with the gold standard quality controls, and monitoring. The service standards are stringent and rigorous, and are reviewed every year. The proton beam therapy service has to meet the five NHS Outcomes Domains:

- Domain 1 - Preventing people from dying prematurely.
- Domain 2 - Enhancing quality of life for people with long-term conditions.
- Domain 3 - Helping people to recover from episodes of ill health or following injury.
- Domain 4 - Ensuring people have a positive experience of care.
- Domain 5 - Treating and caring for people in a safe environment and protecting them from avoidable harm.

Within this framework, the proton beam therapy service has many indicators, which include:

1. clinical outcomes (e.g. number of patients referred, survival outcomes, short- and long-term effects)
2. patient outcomes (e.g. patient-reported outcomes, number of patients given information, number who have a named key worker)
3. structure and process (e.g. staff training, quality management, risk management, treatment and follow-up pathways, interdisciplinary care, involvement in research and trials).

And there is more! There are Obligatory National Standards that the proton beam therapy centres and service must meet. These are the more technical standards, 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 Outcomes² and the NHS England Vision for Radiotherapy 2014–2024.³

Research

Research, too, is a key feature of NHS proton beam therapy centres. The UK has an excellent track record of developing clinical trials across many disease areas. The proton beam therapy research strategy is being driven by the NCRI CTRad PBT Clinical Trial Strategy Group. This group's role is to:

- set the scene
- track all proton beam therapy clinical trial development
- help to develop specific high-priority trials
- liaise with funders
- develop international links
- help with prioritisation – we can't do everything all at once.

² NHS England. (2016). *Cancer Strategy Implementation Plan*. [online] Available at: www.england.nhs.uk/cancer/strategy/ [Accessed 3 Sep. 2018].

³ Cancer Research UK. (2014). *Vision for Radiotherapy 2014–2020*. [online] London: Cancer Research UK. Available at: www.cancerresearchuk.org/sites/default/files/policy_feb2014_radiotherapy_vision2014-2024_final.pdf [Accessed 3 Sep].

This group, which has a broad membership and is made up of clinicians, patients and researchers, will:

- identify and prioritise the scientific and clinical questions
- develop the proton beam therapy clinical trial portfolio
- engage and form productive partnerships with consumers, the clinical oncology community, clinical study groups, funders and clinical trial units
- ensure trials are underpinned by multidisciplinary translational and pre-clinical research, including tissue and blood biobanking, imaging and quality-of-life data collection
- develop the infrastructure to ensure delivery of clinical trials
- coordinate the research portfolio and ensure it is effective and patient-centred.

Proton beam therapy is being introduced within an academic research framework and being integrated into major NHS cancer centres. This is essential due to the complex nature of the patients, many of whom will have less common cancers, and also the recognition that this is a technology that is developing fast but that still has uncertainties. Only the NHS is placed to deliver the research that is needed to address the questions that remain, and those that will no doubt emerge in the future, such as around late effects.

Proton beam therapy research also has its own quality assurance, delivered through the UK RTTQA (Radiotherapy Trials Quality Assurance) group. This is built on photon experience, is efficient and allows streamlining of quality assurance into international trials.

Summary

The NHS proton beam therapy centres have the most up-to-date equipment, are working within an academic setting with the right research infrastructure, and have the integrated, hospital-based model of multidisciplinary cancer treatment that is required for the safe and effective delivery of treatment for people who are living with complex cancer, including children.

Sources

Cancer Research UK. (2014). *Vision for Radiotherapy 2014-2020*. [online] London: Cancer Research UK. Available at: www.cancerresearchuk.org/sites/default/files/policy_feb2014_radiotherapy_vision2014-2024_final.pdf [Accessed 3 Sep. 2018].

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Mike, Tom, Rebecca, Charlie & Sophie