# Proton beam therapy myths

## Myths that need busting

## Why do we need to bust some myths?

With the NHS Proton Beam Therapy Centre due to treat its first patient at The Christie, Manchester, in 2018, interest in this treatment is high. It's therefore crucial that we have factual, independent information available about this treatment so that people can understand proton beam therapy in the context of other treatments, and make the right choices, with their clinical team, about what is right for them.

Given the significant amount of media attention proton beam therapy has had in the last three years, it's not surprising that the waters around this treatment are somewhat muddied.

## How did we identify the myths?

An audit of media coverage about proton beam therapy[1] showed that nearly 2,000 articles were published in the three years prior to March 2018. Two further face-to-face workshops were held to look at and further understand the evidence highlighted by the audit to ensure that certain aspects of proton beam therapy that were discussed by the media could be properly explained here.

[1] Jones, W., Flynn, E. and Bulbeck, H. (2018). *Proton Beam Therapy in the Media 2015–2017*. (Unpublished research.) Cowes: *brainstrust*.

# What are the myths?

## Protons can treat any cancer.

**Not true.** Proton beam therapy can't treat all cancers. It is just another form of radiotherapy, and not all cancers can be treated with radiotherapy. Radiotherapy is an essential cancer treatment that experts suggest contributes to 4 in 10 cases (40%) where cancer is cured.[2]

In England, access to radiotherapy varies from 25% to 49%, depending on the centre, with the average around 38%.[3] Comparative studies with other countries suggest that 52% of cancer patients should receive radiotherapy as part of their treatment.[4] Modelling in England suggests access should be around 40.6%.[5] So radiotherapy is not an appropriate treatment for just under 60% of people diagnosed with cancer. And where a cancer can be treated with radiotherapy, it doesn't always follow that proton beam therapy is the best option.

[2] Department of Health and Social Care. (2012). *Radiotherapy Services in England 2012*. [online] London: Department of Health and Social Care, p.12. Available at: assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/213151/Radiotherapy-Services-in-England-2012.pdf [Accessed 3 Sep. 2018].

[3] Cancer Research UK. (2009). Achieving a World-Class Radiotherapy Service across the UK. [online] London: Cancer Research UK, p.15. Available at: www.cancerresearchuk.org/sites/default/files/policy-achieving-a-world-class-radiotherapy-service-across-the-uk.pdf [Accessed 3 Sep 2018].

[4] Ibid.

[5] Round, C. E., Williams, M. V., Mee, T., Kirkby, N. F., Cooper, T., Hoskin, P. and Jena, R. (2013). Radiotherapy Demand and Activity in England 2006–2020. *Clinical Oncology*, 25(9), pp.522–30.

Proton beam therapy is useful in the following situations:

- Tumours that are near important parts of the body. For example, tumours near the eye, brain and spinal cord.
- Childhood cancers of the eye, brain and spinal cord. Proton beam therapy lessens the chance of harming healthy developing tissue.

It isn't an effective treatment for cancers that have spread (metastases).

For more information about which cancers can be treated with proton beam therapy, visit www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/10/b01-pc-prtn-bm-thrpy-teens-yng-oct15.pdf.

## BUSTED

### Proton beam therapy is more effective than conventional radiotherapy.

**We don't know.** It is still a relatively new form of treatment, and we need more evidence to be able to answer this. It's very complex because of:

- the large number of reasons for radiotherapy
- the degree of variation in patients and their cancers
- the limited experience of proton beam therapy in commoner cancers
- the small numbers of patients who have had proton beam therapy.

This makes it extremely difficult to evaluate the clinical effectiveness of proton beam therapy for every potential clinical condition. We also have more-advanced types of

radiotherapy that can be just as effective as proton beam therapy, such as intensity modulated radiotherapy (IMRT).

Some evidence from the USA has suggested that whilst proton beam therapy might be more effective for people diagnosed with prostate cancer, those that did have proton beam therapy experienced more side effects. For the study, investigators looked at data from nearly 13,000 men treated with radiation for non-metastatic prostate cancer (that is, cancer that had not spread beyond the prostate) between 2000 and 2009. The men had been treated with conventional radiation, IMRT or proton beam therapy.

The investigators found that IMRT was associated with fewer adverse gastrointestinal effects and fewer hip fractures than conventional radiation, but more erectile dysfunction. Overall, there was no significant difference between proton beam therapy and IMRT – with one major exception. Men treated with IMRT were 34% less likely than those who had proton beam therapy to develop gastrointestinal problems after their treatments.[6]

## BUSTED

[6] Sheets, N. C., Goldin, G.H., Meyer, A-M., et al. (2012). Intensity-Modulated Radiation Therapy, Proton Therapy, or Conformal Radiation Therapy and Morbidity and Disease Control in Localized Prostate Cancer. *Journal of the American Medical Association*, 307(15), pp.1611–1620.

## Protons can cure cancer that other treatments can't.

**Not true.** However, it is important to know that proton beam therapy is in its infancy. We cannot say that proton beam therapy is 'better' overall than conventional radiotherapy. At the moment, there isn't the research evidence to say whether proton beam therapy is a more effective treatment than conventional radiotherapy. Proton beam therapy may cause less damage to healthy tissue, or it may be better at destroying cancerous tissue, but this is not proven. It is still unclear whether it is as good at destroying cancerous tissue as conventional radiotherapy. At the same time, we have ample evidence that other, more advanced types of radiotherapy, such as IMRT, stereotactic radiosurgery (SRS) and stereotactic radiotherapy (SRT) also protect nearby healthy tissue. For more information about different types of radiotherapy, visit www.nhs.uk/conditions/radiotherapy/what-happens.

As proton beam therapy is usually reserved for very rare types of cancer, it is hard to gather systematic evidence about its effectiveness when compared to radiotherapy.

People who travel abroad from the UK to receive proton beam therapy usually respond well. But these people have specifically been selected for treatment, as they were seen as 'optimal candidates' who would benefit the most. Whether this benefit would apply to more people with cancer is unclear.

**BUSTED**

## Having proton beam therapy through a private provider is better than through the NHS.

**Not true.** It is a confusing landscape out there. Proton beam therapy has been available to UK patients since 2008 through the NHS-funded overseas programme, and The Clatterbridge Cancer Centre has treated patients with rare eye cancers with low-energy protons for many years.

From 2018, The Christie in Manchester will provide the first UK-based NHS high-energy proton beam therapy service, followed by University College London Hospital in London in 2020.

Care within an NHS setting is very different from care in a private setting. Whilst at times it may seem like the NHS is creaking, there is a level of wrap-around care that just isn't available privately. People who need proton beam therapy often have complex needs, and need to be part of a major cancer centre where they can access highly specialist surgery and cancer services. This is why having proton beam therapy within a major cancer centre, linked to an academic oncology and medical physics framework, is essential.

With the NHS comes:

- complex pathway management
- comprehensive support services
- acute care
- diagnostics
- patient support
- support for families
- an established research environment

- opportunity to access clinical trials
- comprehensive data collection, so that patient data feeds into population-level data
- insights that can only be gathered from treating more patients, particularly with rarer or less common cancers
- quality assurance of technology and care, as rigorous quality standards are essential
- proton beam therapy delivered in an established hospital, which is important, as proton beam therapy is less forgiving than radiotherapy if it goes wrong.

And, of course, by using the NHS, patients are adding to the bigger research picture by sharing their data. You're giving something back.

## BUSTED

### Decisions to be treated with proton beam therapy are based on money.

**Not true.** There are very clear criteria as to whether a person would be eligible for proton beam therapy. A National PBT Clinical Panel assesses all applications for proton beam therapy against the NHS clinical commissioning policy.[7] In addition, careful modelling of the population and looking at future trends ensures that there is enough funding in place to meet demand. Capacity has been commissioned to meet demand where there is current evidence.

## BUSTED

[7] 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].

## Other countries use proton beam therapy in most cases.

**Not true.** This myth was propagated by media coverage and came about with stories of people having to travel abroad for their treatment. It is true that the number of proton beam therapy centres is increasing. In 2014, 29 countries had a proton beam therapy facility (the USA had 13), with another 22 under construction and 9 planned.[8] However, each country that has access to a proton beam therapy centre applies the same rigorous criteria to patient selection and has developed national guidelines.[9]

**BUSTED**

## Most people should be treated with proton beam therapy.

**Not true.** This myth has already been busted. Just to recap:

- It is not appropriate for all cancers. For example, cancers that have spread to other parts of the body (metastatic cancer) or cancers that are not localised are not appropriate targets for proton beam therapy.
- There is some limited evidence to show that side effects can be worse after proton beam therapy, in prostate cancer.
- We don't have enough evidence to know whether proton beam therapy is any better than some of the more advanced radiotherapy treatments.

[8] Patel, S., Kostaras, X., Parliament, M., Olivotto, I. A., Nordal, R., Aronyk, K. and Hagen, N. (2014). Recommendations for the referral of patients for proton-beam therapy, an Alberta Health Services report: a model for Canada? *Current Oncology*, 21(5) pp.251–262.

[9] Ibid.

- Proton beam therapy is still in its infancy (the first hospital to treat patients with proton beam therapy opened in 1990), so we don't know what the late effects of proton beam therapy are.
- Access to this treatment is limited; not everyone wants to travel or spend time away, particularly when they aren't well.
- Not everyone wants to be treated.

The bottom line? Patients pass the first hurdle if:

- Proton beam therapy is considered to give a cure.
- The patient has a cancer 5-year survival of at least 40%.
- The patient has no other diseases that are likely to limit life expectancy to less than 5 years.
- The patient's quality of life is WHO performance status 0–1.[10]

**BUSTED**

## Sources

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[10] National Institute for Health and Care Excellence. (2007). Carmustine implants and temozolomide for the treatment of newly diagnosed high-grade glioma. [online] Available at: www.nice.org.uk/guidance/ta121/chapter/appendix-c-who-performance-status-classification [Accessed 3 Sep. 2018].

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**Mike, Tom, Rebecca, Charlie & Sophie**