

Proton beam therapy

What does it mean to you?

The wider narrative...

- To have independent, factual information available
- To ensure that people have the information they need
- To help people understand PBT in the context of other treatments
- To dispel myths and misunderstandings around PBT
- To build trust in PBT and clinical judgement
- To articulate the research challenges around PBT
- To create a best practice template

The muddy waters of:

- Insight
- Science
- Capacity
- Experience
- Emotion, perspectives and opinions
- Strategy
- Planning

The current narrative

The current narrative

- Fundraising is essential to secure PBT– NHS won't provide funding for treatment
- PBT is the most suitable/effective treatment for all cancers
- Other countries use this treatment in many/most cases
- Most people should be treated with PBT

2015 – 782 articles

NHS - Incompetency/inadequacy, death penalty, injustice

PBT - miracle cure, radical, life-saving

2016 – 886 articles

NHS – inadequate, not giving the best chance

PBT – only option, success stories

2017 – 223 articles

NHS – giving up too easily

PBT – suitable for everyone, best chance

Questions asked

What is PBT?

What are your perceptions? Where did they come from?

How are patients selected?

What would need to happen so that you're confident about the decision to treat, or not?

What information would you need as a patient/carer? And when?

What should you think about when choosing where to have the treatment?

Themes

- Myths
- Understanding the decision process
- Understanding the pathway
- Is it the right treatment for me?
- Where should I have it?
- What should I expect?
- How does it work?
- The need for research

It's a challenge

Research challenges

- Multiple indicators
- More RCTs needed
- Which patients?
- Collecting outcomes
- Rare and less common cancers
- Private v NHS
- Timing of research
- Range of technology
- Identifying the question

Thank you

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