Exploring patient experiences of proton beam therapy within the HIT-Meso trial: a qualitative sub-study

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HIT-Meso Clinical trial (Reg number: NCT05655078)

- Phase III RCT for patients with unilateral malignant pleural mesothelioma
- Eligible patients are randomised (1:1) to receive either
  - **Arm 1 (control):** active surveillance and deferral of systemic anti-cancer therapy (SACT) until clinical or radiological progression, or
  - **Arm 2 (interventional):** proton beam therapy (PBT)
- Recruiting at sites across the UK. PBT treatment given at the Christie Hospital, Manchester, or University College London Hospital. Patients have the option to stay at or near the hospital for the duration of the 5-week treatment.

Qualitative sub-study

Aim: to understand patient expectations, experiences of receiving PBT, perceptions of the trial process, and factors influencing decisions regarding participation and randomisation.

- Patients randomised to the PBT arm are invited to participate in the sub-study via separate consent
- Purposive sample of 8–10 participants
- Questionnaire prior to PBT and semi-structured interview three months post-PBT
- Quantitative data are analysed descriptively. Qualitative data are analysed using descriptive thematic analysis.

See our website for more information about this study and what we do at the Mesothelioma UK Research Centre

For more information about the wider HIT-Meso trial, see this website

Results: To date, six participants have completed the questionnaire and interview. Preliminary findings are summarised:

Motivations for participation

- Altruism: "*if it doesn't help me, it might help someone else"*
- Hope for improved survival
- Clinician recommendation
- Avoiding a "watch and wait" approach: *"Sitting and waiting and doing nothing is a very unattractive option"*

All participants expressed a preference for the intervention arm (PBT). One said they would have left the trial if allocated to the control group.

Receiving PBT

- Described as physically and mentally demanding.
- Participants emphasised the relentless daily schedule, likening it to *"a treadmill*".
- While one participant described it as *"totally painless",* five reported discomfort or pain due to staying in one position for prolonged periods.

"It was quite intense... you lie there, you have to be completely still. And that was quite a challenge."

Accommodation

- Three of six participants stayed in trial-provided accommodation and reported largely positive experiences.
- Accommodation was comfortable, had good nearby amenities, and enabled family visits. Some viewed it as an opportunity to explore the city.

"Everything was fine, the accommodation was great. I have not complaints at all"

- The only negative feedback related to distance from the hospital, particularly at night, which felt intimidating for one person who was unfamiliar with the city.

Travel

- Travel from home to the PBT centre was tiring. Some described anxiety regarding train delays and fear of being late.
- Travel from trial accommodation was generally manageable, though reliance on public transport caused stress for some. Daily journeys were described as tiring over time.

"It [journey from trial accommodation to hospital] probably doesn't sound a lot but when it's five days a week for five weeks, it certainly built up, and come the end of it, you want to get out, you know."

Communication and support from the trial team

Participants all reported high levels of support. They valued:

- the organisation of care: "*Everything happened exactly as it should have done"*
- access to multiple professionals*: "it wasn't just going in and having the treatment, you had your doctor, your dietitian, the mental side, your physio"*
- regular monitoring: *"Very well monitored. It is top drawer; I've got no complaints at all."*

Participants described the overall trial experience as highly professional, supportive and positive.

'"overall, it has been a really, really positive experience"

Conclusion: This qualitative sub-study provides valuable insights into patient experiences of PBT and clinical trial participation in mesothelioma. Findings highlight the importance of clear communication, flexible delivery, and comprehensive support when designing and implementing trials for people living with life-limiting conditions. These insights will inform patient-centred approaches to communication, support provision, and trial design in future research.

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