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## Background

In the United Kingdom, the management of soft tissue sarcoma (STS) is centralised at specialist centres, of which the Royal Marsden Hospital (RMH) is one. The primary treatment for localised STS is surgery [1]. Surgery for lower limb sarcoma is associated with poorer functional outcomes and a higher rehabilitation need than other anatomical sites [2]. The patient experience of current rehabilitation provision is unknown.

## Aim

To explore patient experience of rehabilitation in the surgical pathway for lower limb STS at the RMH.

## Objectives

To explore:

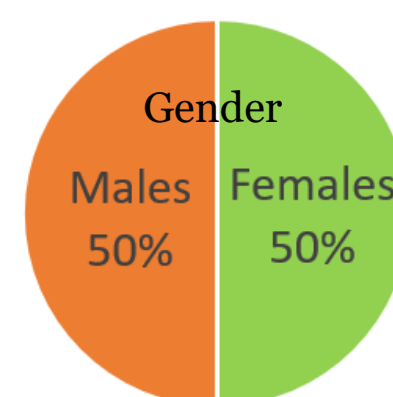
- whether rehabilitation met participants needs and supported a return to meaningful activities;
- whether recovery and rehabilitation matched prior expectations;
- experience of continuity of care between rehabilitation services; and
- experience of information provision.

## Method

- Qualitative, descriptive phenomenological study.
- Ethical approval granted by the RMH Service Evaluation Committee and the University of the West of England Research Ethics Committee.
- Data were collected through semi-structured interviews with patients who had undergone lower limb STS surgery at the RMH between six months and two years previously.
- Following a pilot interview, eligible participants were identified from clinic lists and purposively sampled according to age, gender and distance from the hospital.
- Data were analysed using thematic analysis for descriptive phenomenology [3].

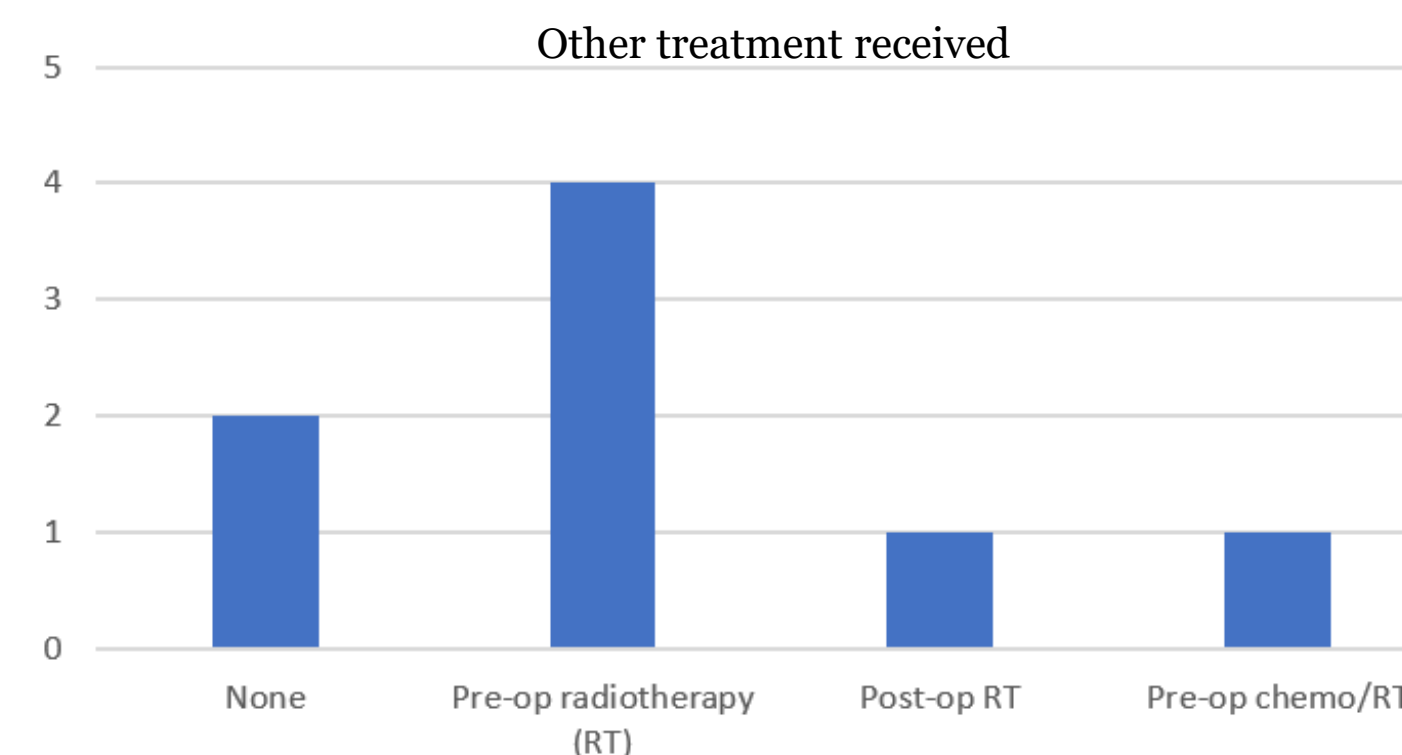
## Participants (n=8)

- Time since surgery (months): 6 – 23.5 (mean 12.3)
- Age at interview (years): 32 – 80 (mean 58.8)
- Distance from RMH (miles): 1 – 85 (mean 39.5)



### Key messages

- Prehabilitation could support preparation for lower limb soft tissue sarcoma surgery and inform expectations of recovery.
- Delays and difficulty accessing community rehabilitation services affected continuity of care and negatively impacted patient experience.
- Patients experienced difficulties returning to meaningful activities e.g. work, life roles, and physical activity.
- Multidisciplinary working across settings from diagnosis to deliver person-centred rehabilitation is needed.



## Results

Eight semi-structured interviews (45 – 60 minutes) were conducted between February and April 2023 (Face-to-face n=1; Online n=4; Telephone n=3). Three main themes (and seven subthemes) were identified (see fig 1).

Fig 1. Themes, subthemes and supporting quotes

Theme 1: Accessing the right services at the right time		
Timing and access to rehabilitation	Factors influencing timing and access	
<i>“The only thing that I was let down on was the community physiotherapy...they were very, very busy and there was only two instead of being five community physiotherapists.” (002)</i>		
Theme 2: “Communication is key” – providing knowledge and support to navigate uncertainty		
Managing expectations of recovery and rehabilitation	Navigating healthcare with a rare disease	
<i>“I got all this off the internet. Maybe there should be a sheet to say, some people take longer than others and don't get too upset if you haven't achieved it, because it knocks you back.” (004)</i>		
<i>“People don't know about sarcoma. Hospitals don't, wherever I go. The physio yesterday said ‘Oh, it's really interesting’. Of course it is, because it's not common and no one knows about sarcoma.”(007)</i>		
Theme 3: The importance of person-centred rehabilitation		
Restoring independence and getting back to the things that matter	Delivering tailored rehabilitation	Working together
<i>“My first goal was driving again. That was a big thing. It was definitely tailored working towards, right, what muscles do I need? What do I need to be able to do to get to that goal?” (001)</i>		
<i>“It makes you feel like they're just as invested in your health and your recovery as you are. So it makes you feel better, which then makes it feel more important to help prove them right.”(003)</i>		

## Conclusion

Despite timely inpatient rehabilitation post-operatively, gaps and delays at other timepoints led to missed opportunities to support preparation for, and recovery from, surgery. Multidisciplinary working across settings to deliver person-centred rehabilitation from diagnosis is needed to improve access, expectation management and continuity of care.

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[1] Dangoor A et al (2016) UK guidelines for the management of soft tissue sarcomas. Clin Sarcoma Res 6 (1):1-26. [2] Weschenfelder W et al (2020) Factors influencing quality of life, function, reintegration and participation after musculoskeletal tumour operations. BMC Cancer 20 (1):351-358. [3] Sundler AJ et al (2019) Qualitative thematic analysis based on descriptive phenomenology. Nurs Open 6 (3):733-739.