

Quality of Life update: SAM

Dr Lesley Storey on behalf of SAM research team

outline

- Development of Sarcoma Assessment Measure (SAM)
- What we found during data collection
- Where we are going next

Introduction

- ❑ Patient reported experience is central to evaluating quality of care in the NHS
- ❑ Incorporating a PROM into clinical practice improves processes, outcomes and satisfaction with care
- ❑ Current evidence inconclusive about the psychosocial impact of sarcoma (Storey et al. 2019 Sarcoma)
- ❑ Is this because current PROMs do not reflect the experiences of patients with sarcoma?

Aims

- Develop and validate a measure reflecting patient experience to guide clinical practice and consultation
- Explore if/how the Sarcoma Assessment Measure (SAM) can be used as an outcome measure

What do we know about patients experience of sarcoma?

- Literature search to December 2017
 - Qualitative studies describing experience
 - Quantitative studies measuring outcomes
- 118 studies are potentially eligible
 - Qualitative = 9
 - Quantitative = 109
- BT = 48%, STS = 14%, GIST = 6%, mixed = 30%

What do we know about patients experience of sarcoma?

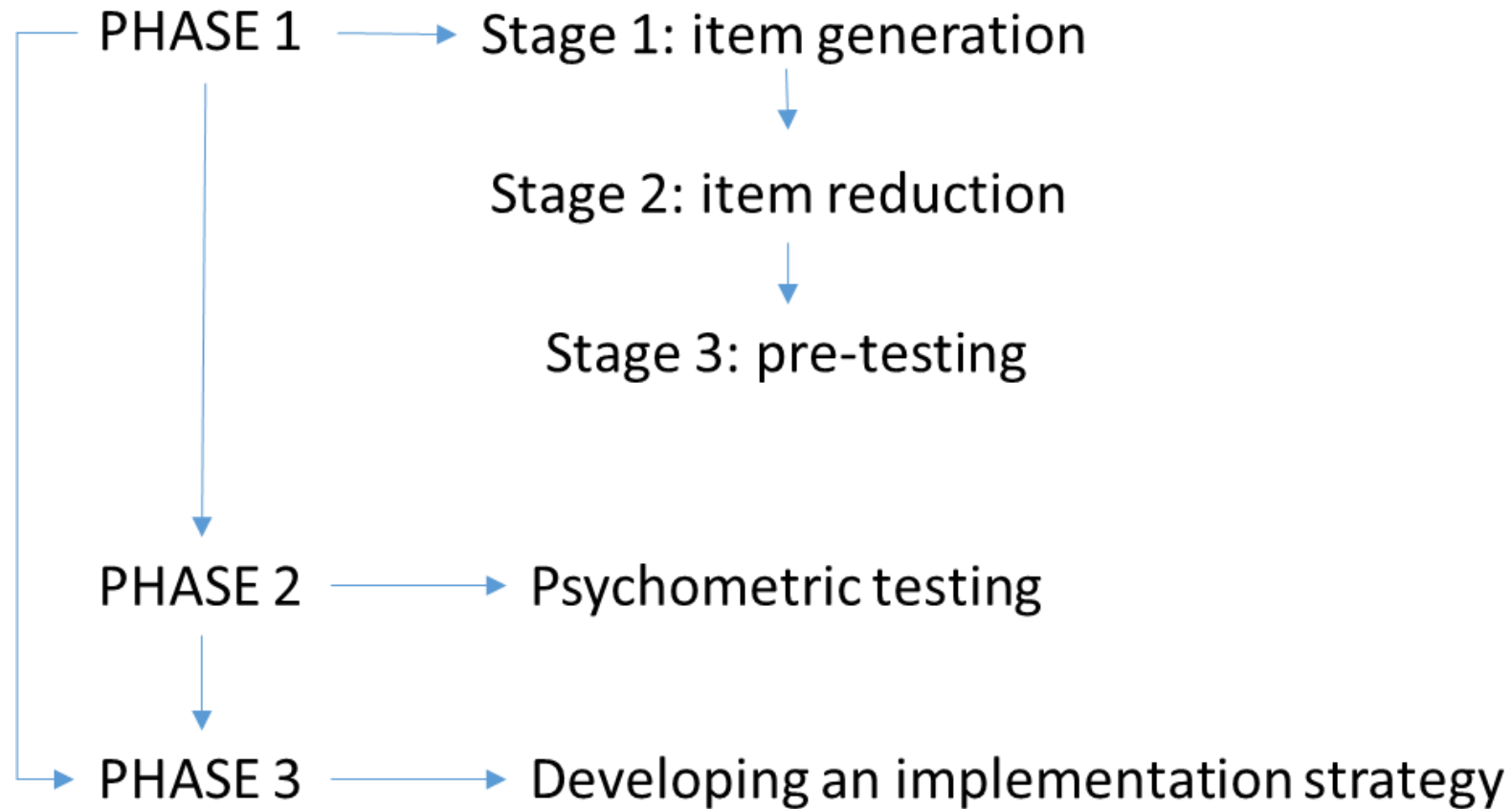
Not a lot!

- ❑ Different experience to those with other cancer types
- ❑ Unclear if there are different experience according to type of sarcoma

Review published in Sarcoma paper

- ❑ A Critical Review of the Impact of Sarcoma on Psychosocial Wellbeing (Storey et al, 2019)
- ❑ <https://doi.org/10.1155/2019/9730867>

Phases of development



Develop and pre-test SAM

- Content validity
 - Review by the multi-disciplinary team
 - Review by patients
- Establish comprehension
 - Interviews with patients
 - Can patients understand the items?
 - Can respondents answer the items?
 - Are questions too sensitive?

Stage 1: item generation

- Aim: to understand experiences of living with and beyond a sarcoma diagnosis
- Methods: semi-structured interviews
- Results: participants = 121, aged 13-82 years
 - 1,405 items (physical, emotional, social, financial wellbeing and sexuality)
 - Reviewed by SRT and reduced to 395 items

Stage 2: Item reduction

Patient review

- ❑ Item Reduction Questionnaire (n=395)
 - ❑ Two scales: importance and frequency
- ❑ Participants = 250 (aged 17-89 years)
- ❑ Calculated an impact score
- ❑ Subgroup analysis
 - ❑ Bone tumour
 - ❑ Amputation
 - ❑ Aged <40 years

Professional review

- ❑ 160 items
 - ❑ Compared to PROMs used previous in sarcoma (22 removed)
 - ❑ Review by the SRT
- ❑ 66 items retained
 - ❑ Included in the Content Validity Questionnaire (CVQ)

Stage 3: pre-testing

□ Content validity

- CVQ administered online to patients and healthcare professionals
- 33 patients, 24 healthcare professionals
- Discard items with a content validity ratio $<.31$
- 22 items retained

□ Establish comprehension

- Can patients understand and answer questions?
- Are any too sensitive
- 10 participants, minor changes to 4 questions

Implementation strategy

- ❑ How will SAM benefit patients?
- ❑ How can healthcare professionals use SAM?
- ❑ What are the organisational facilitators and barriers?
- ❑ Develop the strategy for implementing SAM into practice

SAM – a rich source of data

- ❑ What did we discover while developing the measure?
- ❑ Interaction with life stage is important for quality of life
- ❑ Rare cancer impacts on making sense of sarcoma experience
- ❑ Distinctive challenges for living with and beyond treatment

The loneliest cancer

- The expertise and experience of clinical teams restored patient's trust in the healthcare professionals, especially if their route to diagnosis had been long and complex
 - *“Well, because it was sarcoma, the doctor couldn't share anything else, because he had no experience of it. They'd never had a case like that in his career, or at that hospital”*
 - *“Purely because that is the centre of excellence, shall we say, where, you know, the condition I have is a rare sarcoma and I've been referred to [SPECIALIST SARCOMA HOSPITAL] for a reason (...) I want to see the specialists and have the opportunity to talk to someone”*

After the end of treatment

Quotes from interviews	ITEM used IRQ
<p>'It's always at the back of your mind whether it will come back, or whether it will be worse, or affect you in a worse way than it has this time, so that's always a worry, I think' P4</p>	<p>61. I worry that my cancer may return</p>
<p>'so it was a concern whether it will come back, or whether it will have spread to my lungs, but I feel like I'm dealing with it better than I did' P5</p>	
<p>'I think that feeling of 'what if?' comes back. I don't think it will ever go'</p>	
<p>'If it doesn't work, well, I don't know. It's a concern and distressing' p7</p>	

Phase 3: Utility of SAM

□ Aims:

- How could SAM benefit patients?
- How could healthcare professionals use SAM?
- What are the organisational barriers and facilitators?

□ Workshops:

- National Sarcoma Forum
- Sarcoma Support Groups
- A.N.Other(s)

Summary

□ Achieved to date:

- Collated existing knowledge
- Data on patient's experiences of sarcoma
- Developed the items that potentially include in SAM
- National engagement of patients and professionals

Ongoing work

- ❑ Secondary analysis of sub-populations - bone and STS are under review/in press
- ❑ PhD student completing analysis to develop a dynamic model of resilience in AYA
- ❑ Analysis of data looking at the role/importance of the clinical nurse specialist

Building on SAM

- ❑ New Sarcoma UK funded study
- ❑ Reassure_ME
- ❑ **Aim:** To explore the nature of the fear of recurrence (FoR) in patients with sarcoma in order to develop an intervention to help patients manage this.
- ❑ Mixed Methods
- ❑ Starts in April

SAM Research Team

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