

# Development of the Sarcoma Assessment Measure - SAM

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On behalf of the SAM Research Team

# Introduction

- ❑ Patient experience is central to evaluating quality of care in the NHS
- ❑ Currently, the only Patient Reported Outcome Measure (PROM) used nationally in sarcoma is the Cancer Patient Experience Survey
- ❑ Incorporating PROMs in clinical practice improves processes, outcome and satisfaction with care
- ❑ PRO reporting improves perception of care, enhances communication and reduces psychological distress

## *Cont.*

- ❑ Essential to choose appropriate PROM = true reflection of experience
- ❑ PROMs for sarcoma?
  - Bt-DUX (Bekkering et al. 2009)
- ❑ Are experiences the same across all cancer types, across all sarcomas?
  - If yes – Item bank
  - If no – Develop Sarcoma-specific PROM

# 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%

# Qualitative studies

“So, are you back to work yet?” Re-conceptualizing ‘work’ and ‘return to work’ in the context of primary bone cancer

Jane Aileen

Journal of Surgical Oncology 2010;101:447–450

*Sociology of Health & Illness* Vol. 37 No. 7 2015 ISSN 0141-9889, pp. 1055–1071  
doi: 10.1111/1467-9566.12281

Rup  
illne  
Cat

Research Article

Cured  
Study

ANTICANCER RESEARCH 35: 6081-6090 (2015)

Journal of Surgical Oncology 2016;113:229–234

Changes in the Body Image of Bone Sarcoma Survivors Following Surgical

ORIGINAL ARTICLE

WILEY European Journal of Cancer Care

**Sarcoma survivors’ perspectives on their body image and functional quality of life post-resection/limb salvage surgery**

Myra F. Taylor PhD, MPhil, MSoc Sc, BGE, Research Fellow<sup>1</sup> | Julie A. Pooley PhD, Professor<sup>2</sup>

# Quantitative studies



# What do we know about patients experience of sarcoma?

## Not a lot!

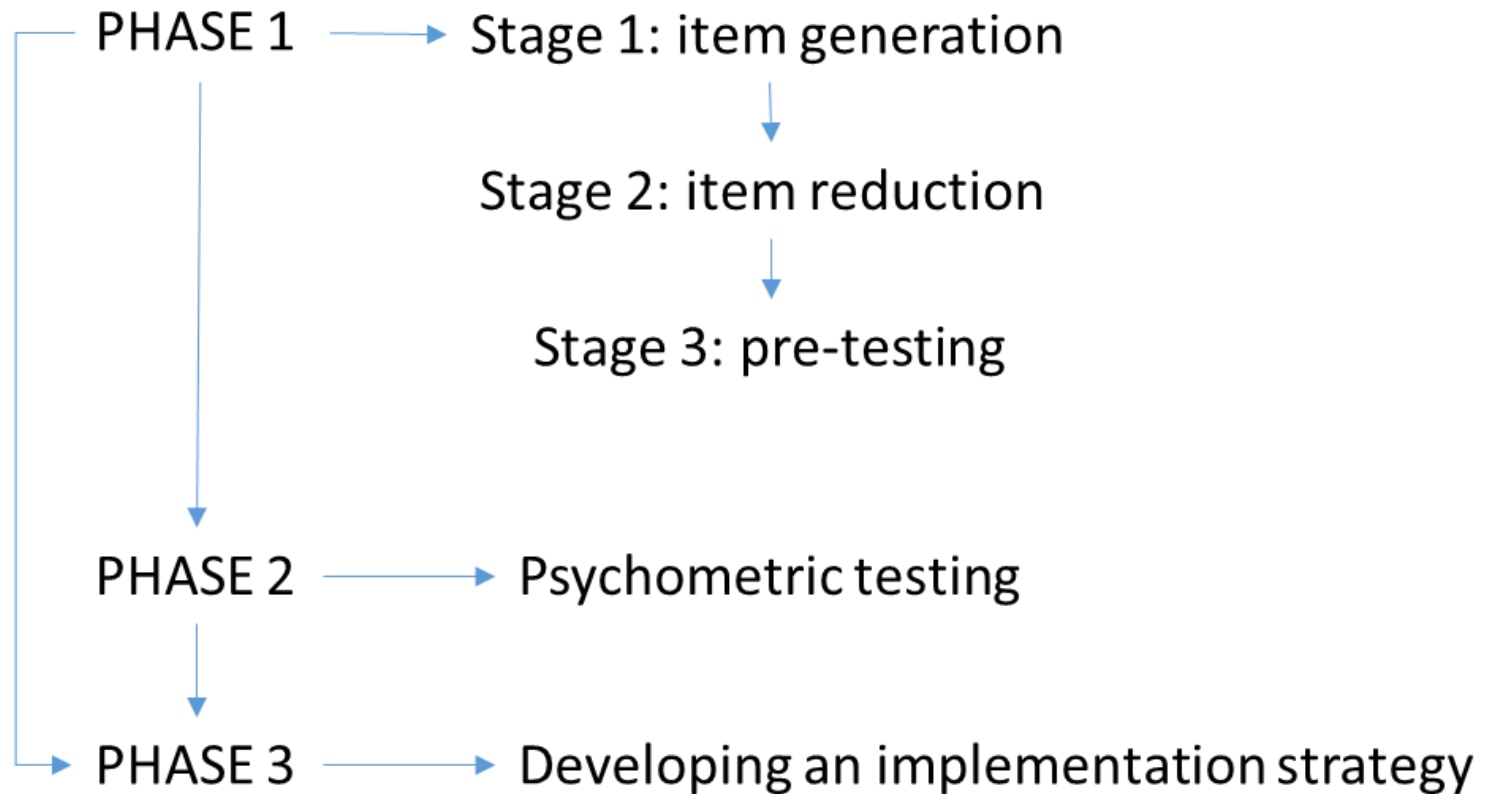
- Different experience to those with other cancer types
- Unclear if there are different experience according to type of sarcoma

# Aims

- ❑ Develop and validate the Sarcoma Assessment Measure (SAM)
- ❑ Develop a strategy for maximising utility in practice



# Phases of development

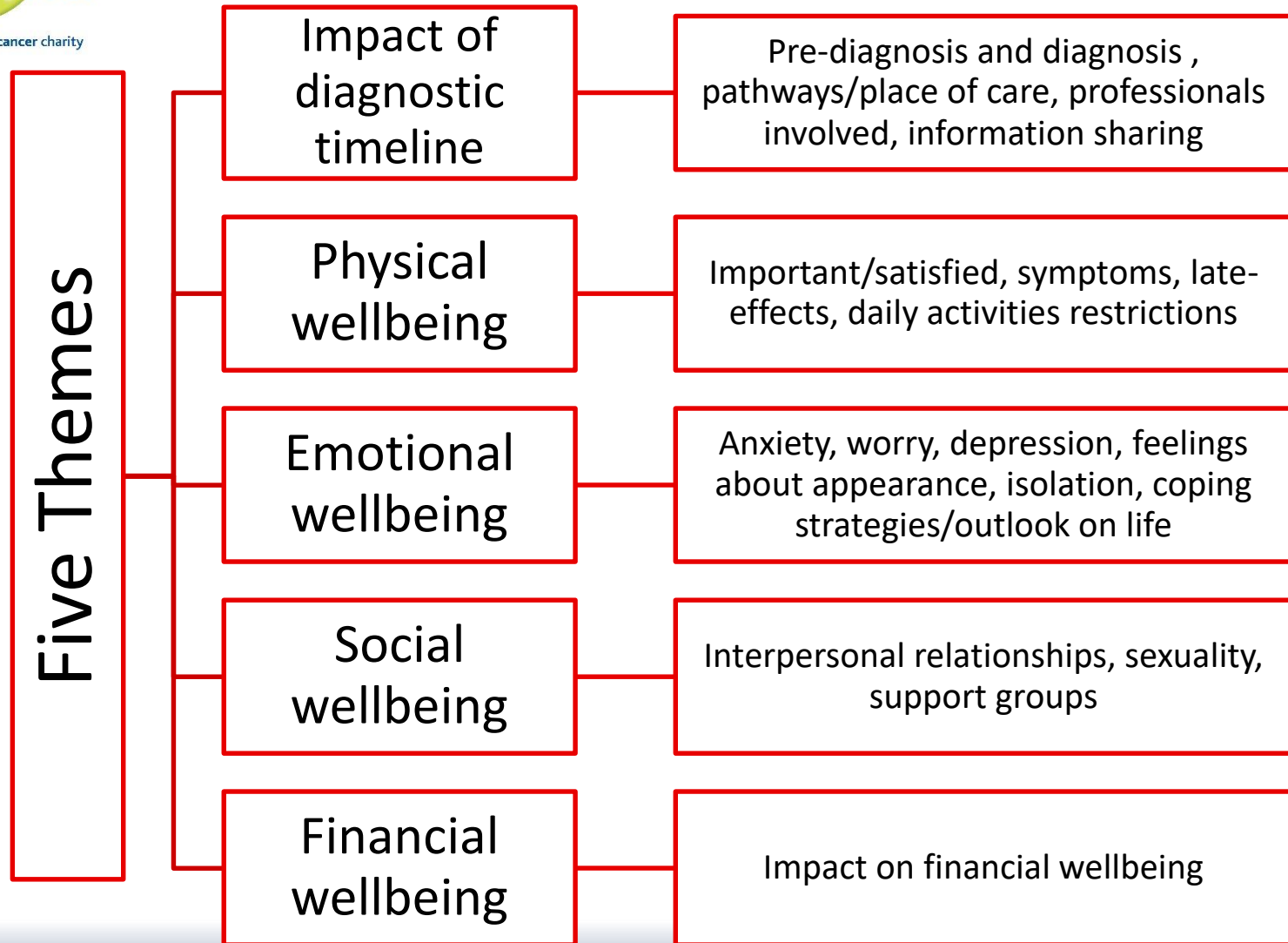


# Item generation

- Aim: understand experiences of living with and beyond a sarcoma diagnosis
- Methods: semi-structured interviews
- Participants:
  - n = 121
  - 50% male
  - Aged 13 - 82 years (M = 50.2 SD = 17.5)
  - STS = 62%, BT = 28%, GIST = 10%



# Results



# Structure of SAM

- Quality of life framework
- Content analysis
  - Physical wellbeing (n = 317)
  - Emotional wellbeing (n = 507)
  - Social wellbeing (n = 411)
  - Financial wellbeing (n = 104)
  - Sexuality (n = 64)

# Item reduction: Professional review

- All 1,403 items reviewed by 4 clinicians, 4 researchers and 2 patient representatives
- Remove redundant and repetition
- Reworded quotes to item 'language'
- Item Reduction Questionnaire (n = 393):
  - Physical wellbeing (n = 121)
  - Emotional wellbeing (n = 146)
  - Social wellbeing (n = 67)
  - Financial wellbeing (n = 33)
  - Sexuality (n = 26)

# Item reduction: Patient expert review

- Starting 1<sup>st</sup> March 2018
- Complete the Item reduction Questionnaire
  - How important is this item to you?
  - How often do you worry about this?
- Anticipated completion July 2018
- What is different to existing QOL measures?
- Differences according to heterogeneity?

# 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?

# Testing SAM

- Complete the final version of SAM
- + Established measure of QOL
- + A.N.Other PROM
- Analysis against a set of hypotheses



# 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

# 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

# SAM Research Team

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Dr Ana Martins  
Research Associate



The bone & soft tissue cancer charity

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Questions?

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