

# Quality of Life: Listening to the patients...

*Development of the Sarcoma Assessment Measure - SAM*

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On behalf of the SAM Research Team

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# The objective of this session is to:

- Briefly remind members of the objectives and nature of the project
- Describe the work undertaken in the last year
- Describe the work which will be undertaken in the coming year

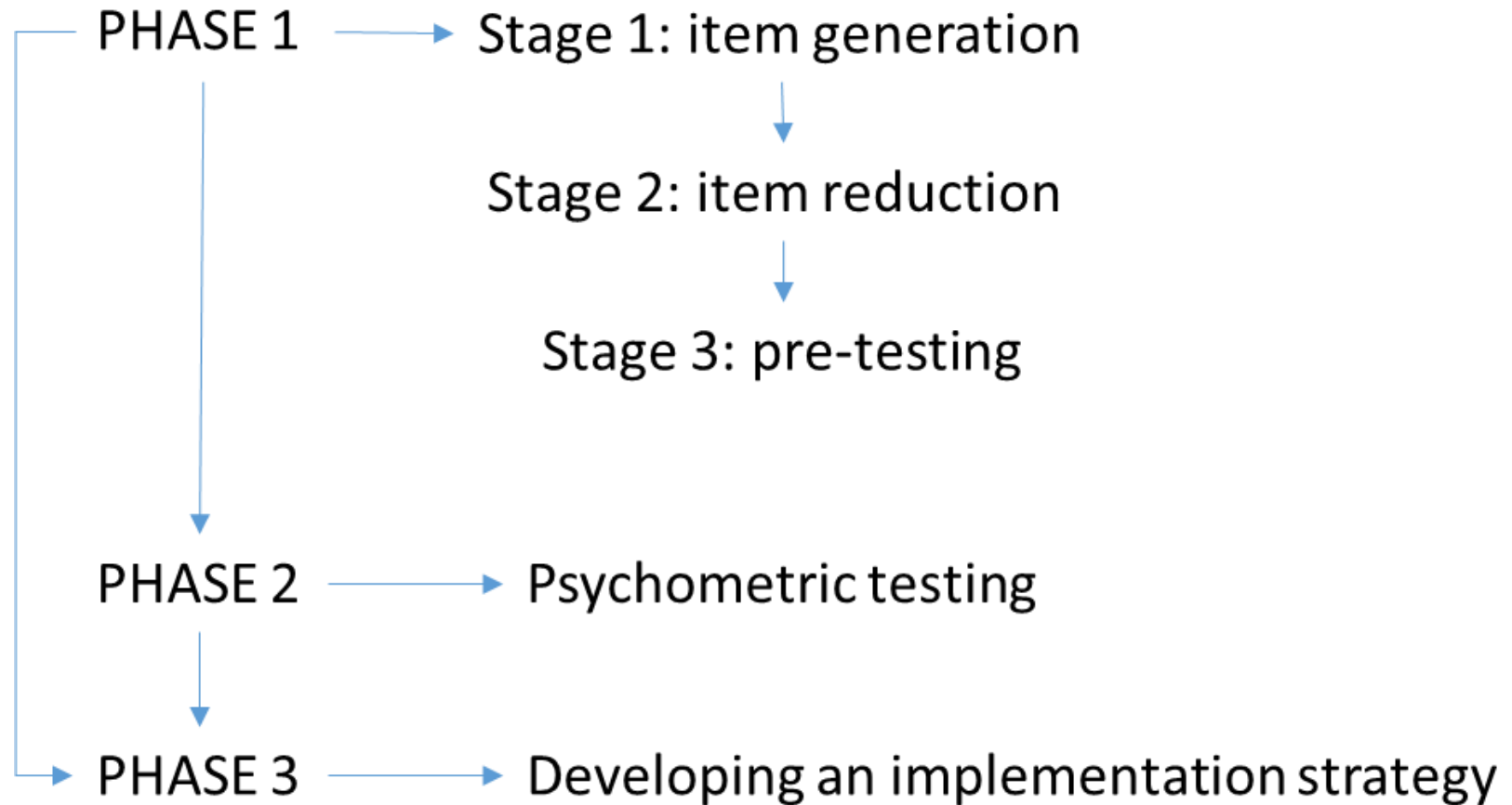
# Introduction

- ❑ Patient experience is central to evaluating quality of care in the NHS
- ❑ Incorporating PROMs in clinical practice improves processes, outcome and satisfaction with care
- ❑ What do we know about patients experience 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%



# Structure of SAM

- Quality of life framework
- Content analysis
  - Physical wellbeing
  - Emotional wellbeing
  - Social wellbeing
  - Financial wellbeing
  - Sexuality

# Item reduction: Professional review

- All **1,405** items reviewed by 4 clinicians, 4 researchers and 2 patient representatives
  
- Item Reduction Questionnaire (n = **395**):
  - Physical wellbeing (n = 121)
  - Emotional wellbeing (n = 146)
  - Social wellbeing (n = 67)
  - Financial wellbeing (n = 34)
  - Sexuality (n = 27)



# Example

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>	

# Item reduction: Patient expert review

- Participants:
  - n = 250
  - 51% male
  - Aged 17 - 89 years (M = 53.7 SD = 18.9)
  - STS = 59%, BT = 36%, GIST < 1%
- Impact score was calculated (importance + frequency)
- The top scoring items in each domain were reviewed and compared to those in subgroups (bone tumours, amputations, age <40 years)



# Item reduction

## Patient expert review

- This resulted in **160 items**
  - Physical wellbeing: 50 items
  - Emotional wellbeing: 57 items
  - Social wellbeing: 30 items
  - Financial wellbeing: 11 items
  - Sexuality: 12 items

## Professional review

- **160 items**
  - Compared against the content of the EORTC QLQ C30, SF36, PROMIS, FACT-G, WHOQOL-BREF and TESS questionnaires
  - Review by the research team and agreement through consensus discussion
- **66 items** were included in the Content Validity Questionnaire (CVQ)

# Develop and pre-test SAM: Content Validity

- ❑ Review by patients and by the multi-disciplinary team
- ❑ The CVQ was administered via an online survey
- ❑ Sent to 214 participants of previous stages (15% part)
  - N=33
  - Gender=58% female
  - Age=19-82 years old
  - STS=58%; BT=39%; GIST=3%
- ❑ 24 professionals participated
  - Nurse N=11
  - Oncologist N=9
  - Surgeon N=2
  - Occupational therapist N=1
  - Physiotherapist N=1

# Develop and pre-test SAM: Content Validity

- Following analysis, items with a content validity ratio score  $<.31$  were discarded
- 22 ITEMS identified
  - Physical wellbeing: 7 items
  - Emotional wellbeing: 10 items
  - Social wellbeing: 3 items
  - Financial wellbeing: 1 item
  - Sexuality: 1 item
- The wording of final set of items was reviewed and changed to fit the proposed response variable (strongly agree – strongly disagree)

## EMOTIONAL

- |       |                                                                               |
|-------|-------------------------------------------------------------------------------|
| 0.76  | <b>1. I worry that my cancer may return</b>                                   |
| 0.52  | 2. I feel anxious before my scan/appointment                                  |
| 0.27  | 3. I am struggling with the 'what ifs' and what could happen                  |
| 0.09  | 4. I find life emotionally challenging as a result of my sarcoma              |
| 0.45  | 5. Since my diagnosis I appreciate everyday things more                       |
| 0.21  | 6. I feel more positive mentally                                              |
| 0.52  | 7. I have accepted how sarcoma has changed my body                            |
| 0.64  | 8. I try to keep a sense of humour                                            |
| 0.52  | 9. I focus on what I can do rather than what I can't do                       |
| 0.45  | 10. I try and cope on my own                                                  |
| 0.39  | 11. I put fears about my sarcoma to the back of my mind                       |
| -0.09 | 12. I have difficulty planning for the future                                 |
| -0.03 | 13. I feel frustrated because I can't do everything I want to                 |
| -0.33 | 14. I am frightened as to how much I can live a normal live                   |
| 0.33  | 15. I have friends/family I talk to about things I worry about                |
| 0.15  | 16. I'm upset I caused pain to the people who supported me                    |
| 0.03  | 17. I am self-conscious of my physical appearance                             |
| 0.09  | 18. I'll never be the same again                                              |
| 0.03  | 19. I do not want to burden my family by sharing information about my sarcoma |
| -0.03 | 20. I want to protect my family, so I do not show how I am feeling            |

# Develop and pre-test SAM: Establish Comprehension

- Interviews with patients
  - Can patients understand the items?
  - Can patients answer the items?
  - Are questions too sensitive?
  
- Participants:
  - N=10
  - 6 females and 4 males
  - Aged 27-56 years old
  - STS=2, BT=7, GIST=1
  
- Minor changes were made to 4/22 items



### SECTION 1: SARCOMA ASSESSMENT MEASURE (SAM)

We are interested in your experience of being diagnosed and living with or beyond sarcoma. Thinking about your current situation please answer how much do you agree or disagree with the following statements by circling the number that best applies to you. If a statement does not apply to you, please circle N/A (Not Applicable).

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	N/A
1. I do whatever I can to keep healthy	1	2	3	4	5	0
2. I am more conscious of what I eat since I was diagnosed with sarcoma	1	2	3	4	5	0
3. I can do everything without help	1	2	3	4	5	0
4. My arm/leg is not as strong as it was before diagnosis	1	2	3	4	5	0
5. My prosthesis is heavy and uncomfortable	1					
6. My prosthesis fits well enough to do the things I want to	1					
7. My painkillers don't take all the pain away	1					
8. I worry about whether I will be able to have a family	1					
9. I worry that my sarcoma may return	1					
10. I feel anxious before my scan/appointment	1					
11. Since my diagnosis I appreciate everyday things more	1					
12. I have not accepted how sarcoma has changed my body	1					
13. I try to keep a sense of humour	1					
14. I focus on what I can do rather than what I can't do	1					
15. I try and cope emotionally on my own	1					
16. I put fears about my sarcoma to the back of my mind	1					
17. I have friends/family I talk to about things I worry about	1					
18. I am self-conscious of my physical appearance	1					
19. I have been able to go back to work/university/school	1					
20. My friends/family treat me normally	1					
21. I find the costs of travelling to and from the hospital difficult to meet	1					
22. My treatment for sarcoma has affected my intimacy with others	1					

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# Next Phases...

## PHASE 2 - Testing SAM

- Sarcoma Assessment Measure (SAM) Validity Questionnaire
  - Sarcoma Assessment Measure (SAM)
  - European Organization for Research and Treatment of Cancer Core Quality of Life Questionnaire (EORTC QLQ-C30)
  - Global Rating of Change Questionnaire (GRCQ)
  - Toronto Extremity Salvage Score (TESS)
- Analysis against a set of hypotheses

## PHASE 3 - 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
  - Developed final version of SAM
  - National engagement of patients and professionals



The bone & soft tissue cancer charity

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Questions?

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