

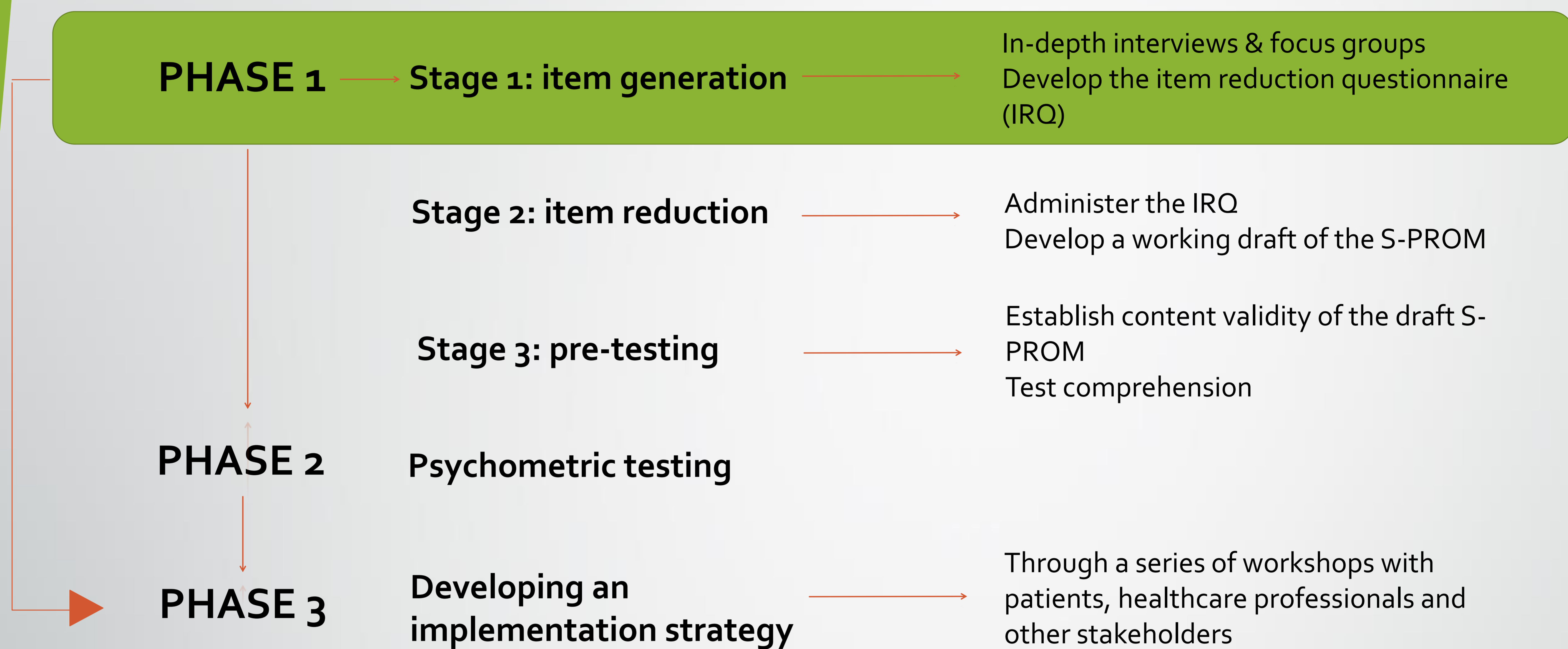
# A national collaboration to develop a sarcoma-specific patient reported outcome measure

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## Background

Introducing patient-reported outcome measures (PROM) into clinical practice is known to improve patient-clinician communication and patient experiences and outcomes<sup>1</sup>. While there are many generic cancer PROMs these may not capture issues that are important to patients with sarcoma. There is currently no sarcoma-specific PROM.

This new Sarcoma UK and Bone Cancer Research Trust funded study will develop and validate a sarcoma-specific PROM and develop a strategy for its incorporation into practice. This is a mixed methods study comprising three stages:



## Who can take part in the study?

### Inclusion criteria

Diagnosis of sarcoma  
Aged 13 onwards  
Able to communicate verbally or in writing in English

### Exclusion criteria:

Absence of consent

## Recruitment

- Recruitment through contact from sarcoma charities

- Recruitment through participating in a sarcoma support group

### - Recruitment by healthcare teams in participating Trusts:

1. Each participating Trust will be recommended to nominate a member of the multi-disciplinary team (MDT) to be the link for recruitment
2. The nominated healthcare professional will be responsible for liaising with the researcher to identify eligible patients

### How to get involved?

We want to involve as many centres in the project as possible so the outcome measure is relevant to patients' experiences across the UK

The support of clinical teams will be crucial in identifying participants. Patients will be identified by the study team working with the clinical team. In the first stage patients will be sent a letter giving them the opportunity to opt-out from further contact about the study. A contact list of patients who want to be contacted will then be passed to the research team who will invite the patients to take part in the study.

If you think you'd like to be part of the Sarcoma Outcome Measure Collaboration and would like more information, please contact Ana on 07415 557668 or [SarcomaResearch@uclh.nhs.uk](mailto:SarcomaResearch@uclh.nhs.uk)

## Expected outcomes

a detailed understanding of patients' experiences of sarcoma and outcomes that are most relevant and important to patients

a validated PROM

a strategy to incorporate the PROM into clinical practice