

## Background

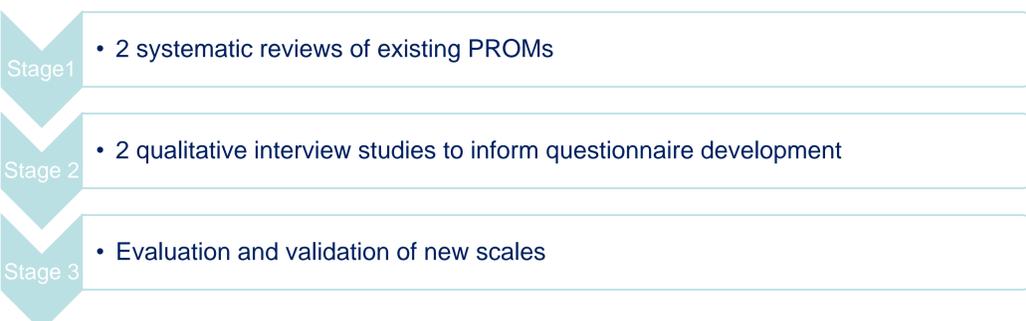
More patients are surviving longer with cancer. Although this is a cause for celebration, there are some negative associated consequences for patient and informal caregiver wellbeing.

Formal assessment capturing broader aspects of life that are affected by cancer and cancer treatments, e.g. the impact on roles and responsibilities is not normal practice. However looking after children, jobs and careers, finances, family relationships and future plans are all likely to be impacted by diagnosis and treatment.

Systematic review<sup>1</sup> revealed a need for rigorously developed, well-validated measures to assess these neglected topics.

## Aims

PROACT is a 3 stage project; the primary aim is the development and evaluation of two new scales measuring broad life impacts of cancer and cancer treatment for patients (to be administered alongside FACT-G) and informal caregivers (a standalone measure).



Here we present data from Stage 2 – questionnaire development.

## Methods

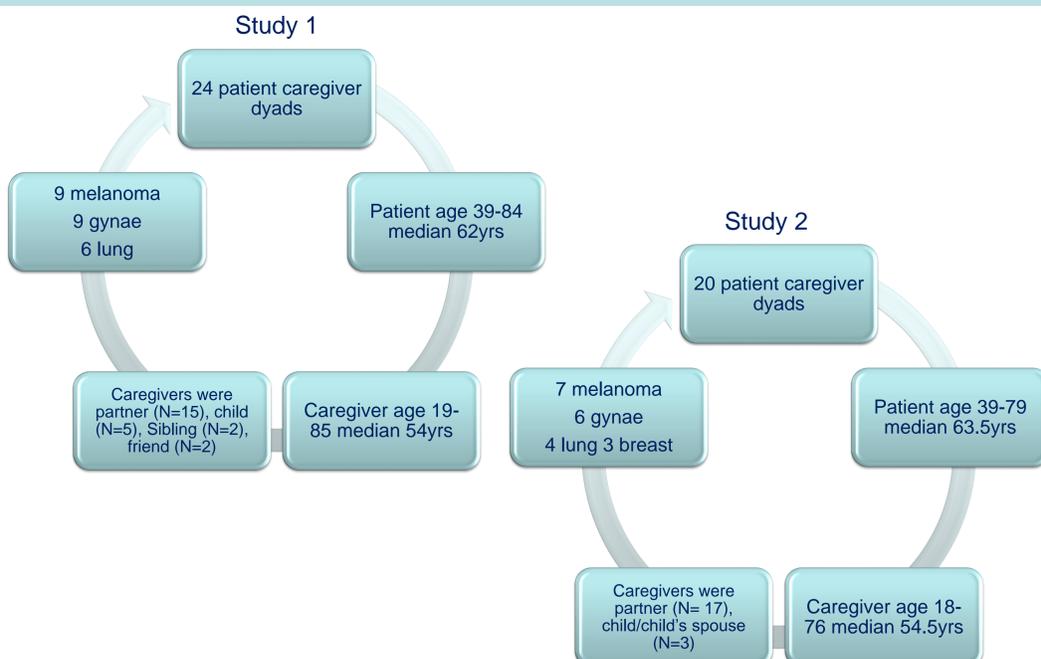
### Study 1:

- We conducted in depth qualitative interviews with patients with advanced cancer and their nominated informal caregivers about the impact of extended cancer survival on broader aspects of life and wellbeing.
- Topic guides were informed by our earlier systematic reviews and through discussion with advisors with lived experience of cancer or caring for people with cancer.
- Interviews were transcribed verbatim. A thematic framework was developed from an initial process of open coding and tested iteratively as new data were collected.
- Thematic analysis was used to generate the long lists of potential items for inclusion in the draft questionnaires.
- The long lists were reviewed by members of the team and the PPI panel before constructing draft questionnaires to use in study 2.

### Study 2:

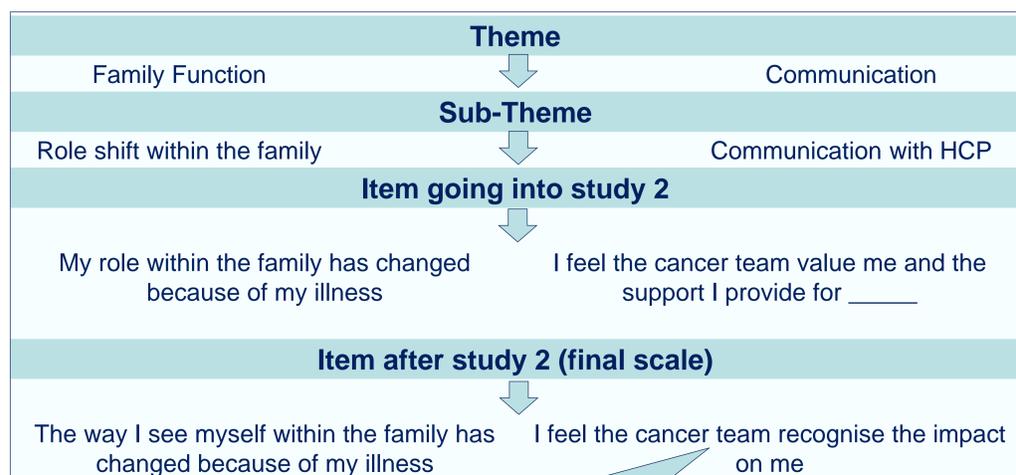
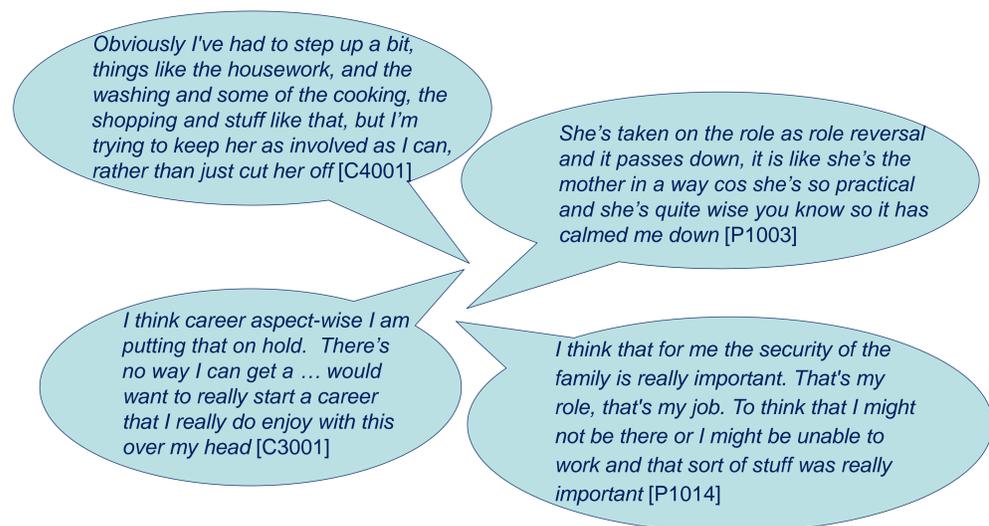
- We conducted cognitive interviews with a new cohort of patients with advanced cancer and their nominated informal caregivers to refine the scale content.
- We used a mixture of a 'think aloud' technique and specific probes around comprehension, retrieval, judgement and response to assess each of the potential questionnaire items.
- Questions were revised, added and removed in an iterative fashion through the course of the study.

## Results



- 20 major themes and 33 sub-themes around broader life impacts were identified including role shifts within the family and limitations on career and social opportunities.
- Lists of 44 (patients) and 51 (caregivers) questions were generated and reviewed by the research team and PPI panel for relevance, importance, acceptability and redundancy.
- Draft scales consisting of 30 patient items and 64 caregiver items were then assessed in cognitive interviews in study 2.

	Patients	Caregivers
Hours of recorded interview*	19hrs 12mins	19hrs 20mins
Thematic Framework	20 parent nodes 33 child nodes	
Initial item areas generated	179	182
Items reviewed by PPI panel and other team members	44	51
Items evaluated in Study 2	31	64
Final scale items	29	60



*And those things, they sound so small, but I think when your life is being nibbled at all year by the disease and things are being taken away, the really small things like the eye contact and the acknowledgement that actually the cancer's screwing up several lives, not just one, it helps [C1011]*

## Summary and Conclusions

- We have developed two new scales measuring the broader life impacts of living with cancer 1) as a patient and 2) as a caregiver.
- The scales focus on family roles and responsibilities, such as caring for children/grandchildren and financial and employment responsibilities.
- The scales were developed with patients with advanced cancer and their informal caregivers however are intended for more generic use with other stages of cancer and chronic health conditions.
- The finalised scales will undergo initial psychometric evaluation and validation in a multicentre longitudinal study involving 240 participants.
- Once validated these scales will be useful tools for clinicians and researchers enabling broader longer term evaluation of new treatments in clinical trials and to aid decision-making about treatment options and supportive interventions.

## Reference

Shilling, V. Matthews, L. Jenkins, V. Fallowfield, L. (2016) Patient-reported outcome measures for cancer caregivers: a systematic review. *Qual Life Res*, 25 (8): 1859-1876.