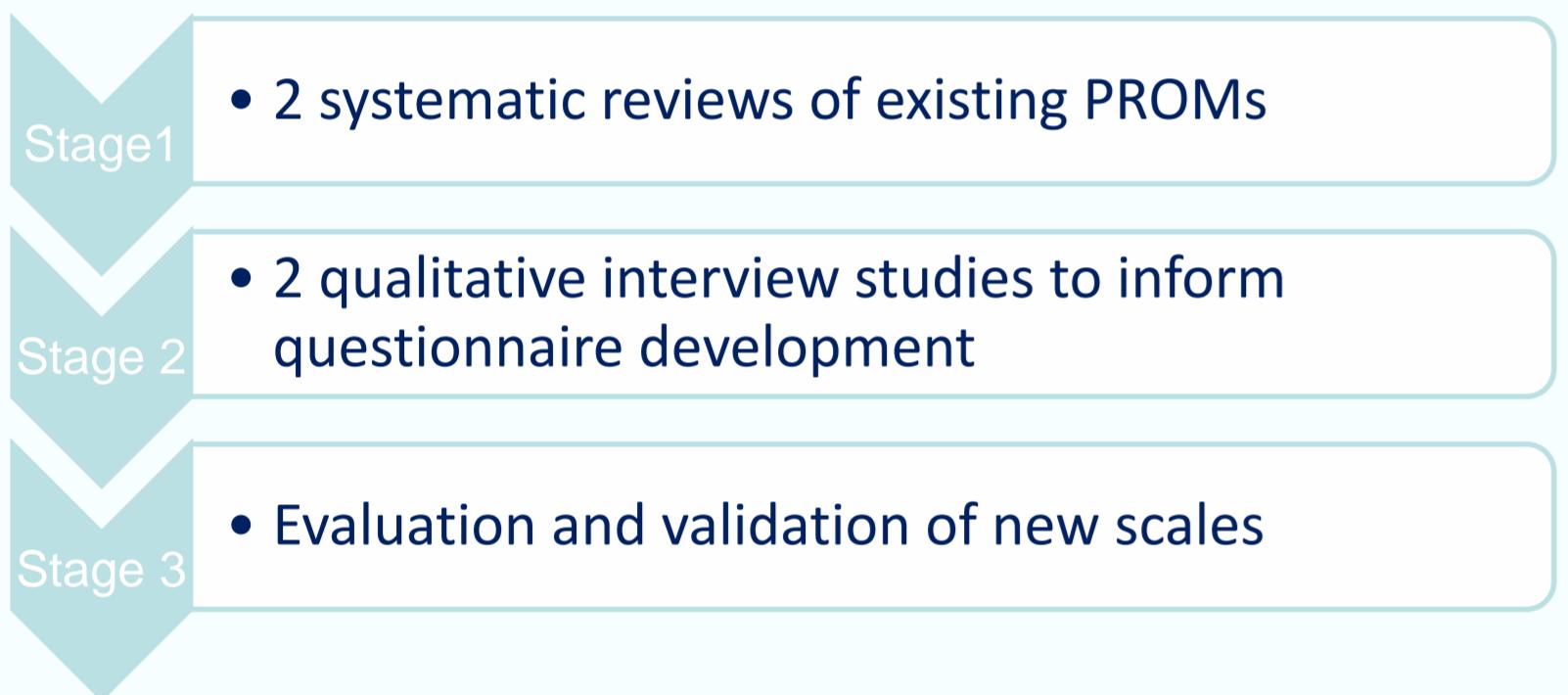


Background

- More patients are surviving longer with cancer; both patients and informal caregivers may struggle to adjust to some of the new challenges this brings.
- Being a cancer patient (Pt) or caregiver (Cg) does not make one less of a parent, child, employee or family provider yet formal assessment of the impact on roles and responsibilities is not normal practice.
- In the Patient Reported Outcomes impact of Age and Carer role demands associated with Treatment (PROACT) study we have developed two scales measuring wide-ranging life impacts of cancer and treatment for Pts and Cgs (see poster board K10 for a full description of the study).
- We focus on 1) Pts as caregivers themselves, to children or parents for example 2) Cgs with multiple caring roles.

Aims

PROACT is a 3 Stage study to develop and evaluate two new scales:



- 2 systematic reviews of existing PROMs

- 2 qualitative interview studies to inform questionnaire development

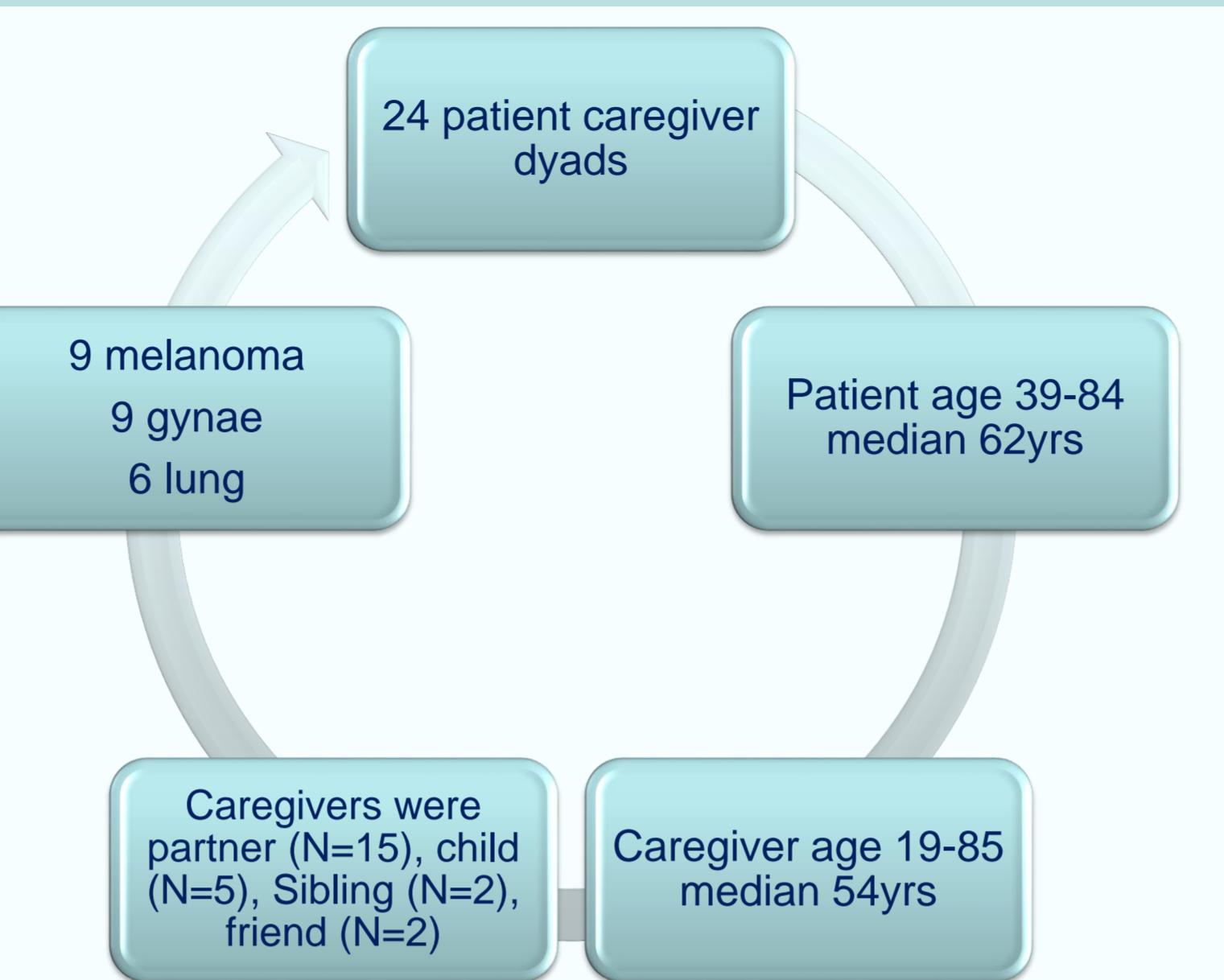
- Evaluation and validation of new scales

An overarching theme in the qualitative interviews was uncertainty about the future. Here we explore this specific topic, and contrast Pt and Cg experience.

Methods

- In depth qualitative interviews with Pts with advanced cancer and their nominated informal Cgs about the impact of extended cancer survival on broader aspects of life and wellbeing.
- Topic guides informed by our earlier systematic reviews and through discussion with advisors with a lived experience of cancer or who were supporting someone with cancer.
- Topics included, but were not limited to:
 - How the family is functioning and changes in role responsibilities within the family*
 - Impact on occupation and career aspirations/progression, including role responsibilities*
 - Finances including loss of income and out of pocket expenses*
 - Leisure and social activities*
- Interviews were transcribed verbatim. A thematic framework was developed from an initial process of open coding and tested iteratively as new data were collected.

Findings



- Analysis of over 38 hours of recorded interviews identified 20 major themes and 33 subthemes.
- A predominant theme for both Pts and Cgs was uncertainty for the future. This encompassed issues such as providing for one's family, employment and finances but also plans for retirement.
- For both Pts and Cgs the uncertainty of the disease trajectory was pervasive. They feel a lack of control and an inability to make plans that resulted in a sense that their lives could only be lived one day at a time.

"So it's living with uncertainty and how to manage it all" Cg1015

"As I say, I just live day-by-day but we don't plan on booking a holiday in advance" Pt1013

- Pts were particularly concerned with their family's future financial and emotional wellbeing.

"The security of the family is really important. That's my role, that's my job. To think that I might not be there or I might be unable to work and that sort of stuff was really important" Pt1014

"I just want them to be happy and safe and stable and at ease with everything. That's a big concern for me" Pt1016

- Cgs often felt a lack of control over their own future and a sense of life 'being on hold'.

"But I think it's just that uncertainty, do I stay here for like the next six years or five years or whatever or even a year and a half or something like that, or do I go and live my own life? Or are we just stuck in the same thing?" Cg3001

"I think until we get a good period of time of clear results, no operations and things, I think maybe then we might start to think about moving or a new car but I do feel like we're just stagnant at the moment" Cg1014

- Some felt it would be easier to have a definite time frame about death and were frustrated that no one could predict what would happen and when.
- For Cgs there was sometimes guilt associated with these feelings although they were recognised by some patients.

"It's like if you think the person's going to die, like with mum, it was easier because you were in the today world and it was the end. With [my sister] the whole year we're moving between, do we have tomorrow, do we not? And that's really very, very difficult" Cg1011

"I feel like sometimes they're putting their lives on hold waiting for me to die, but they don't quite know when that's going to be and since I don't know when it's going to be and nobody else seems to know when it's going to be it's a bit awkward" Pt3001

"It would be easier because you could then, even if it wasn't a definite, you would roughly have a rough idea and you knew what you were doing" Cg1016

- Age appeared to mediate some uncertainty. In younger participants there were practical concerns around employment, finances and family.
- Those around retirement age keenly felt the loss of the future they had worked hard to spend together.
- Older participants were less affected by practical concerns. There was also an absence of discussion of unfulfilled life goals interrupted by the cancer.
- Pts and cgs rarely discussed their concerns for the future with each other and more commonly described not talking openly as a means of preservation of self or the other person.

Summary and Conclusions

- Patients and their informal caregivers are challenged about coping with death but equally about coping with life and the lack of a defined trajectory.
- Uncertainty impacts many areas including employment, retirement and general planning for the future.
- The range and scale of the 'impact of uncertainty' varied however few people were unaffected by the discomfort of 'not knowing'.
- Dyads seldom discussed these concerns with each other so might benefit from professional help aimed at facilitating open discussion together.

Acknowledgement

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