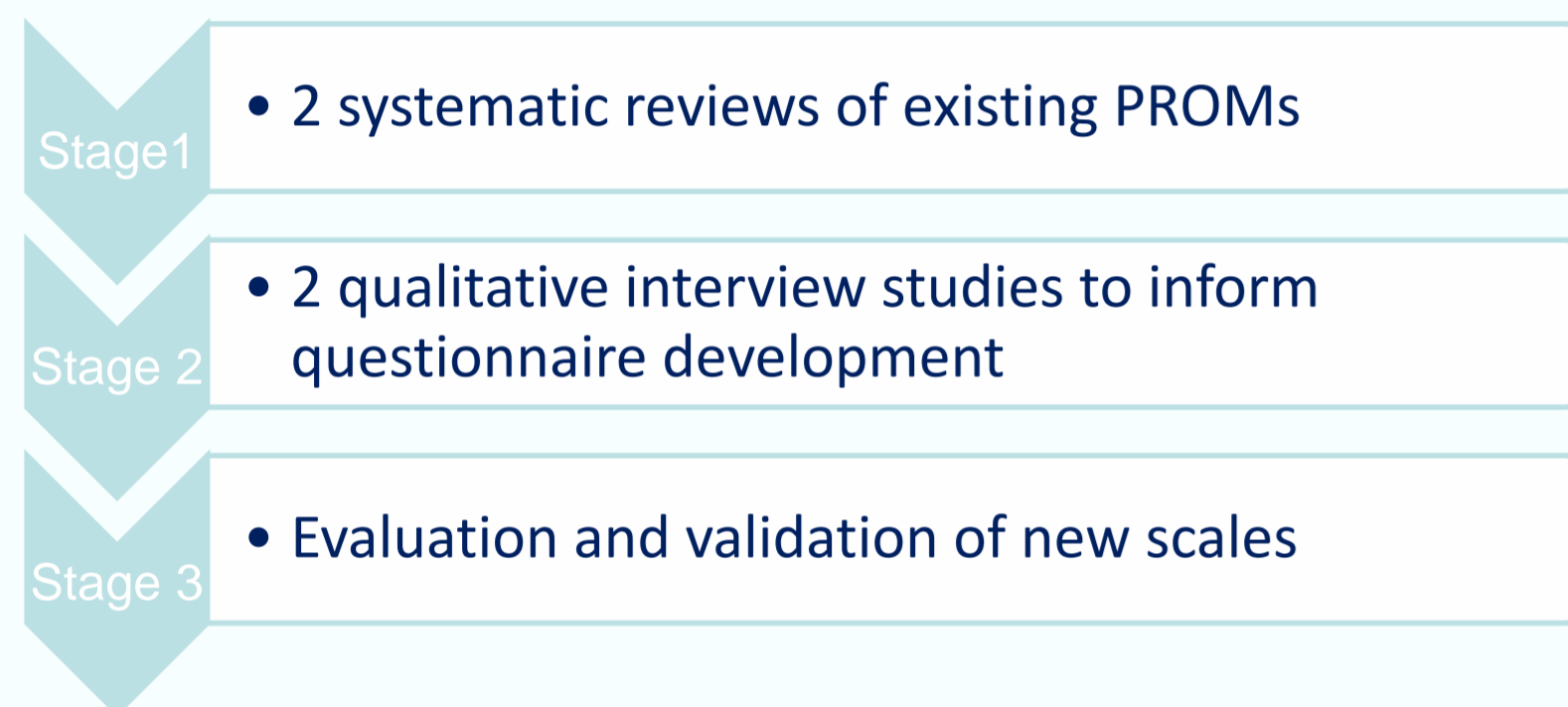


**Background**

- 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:

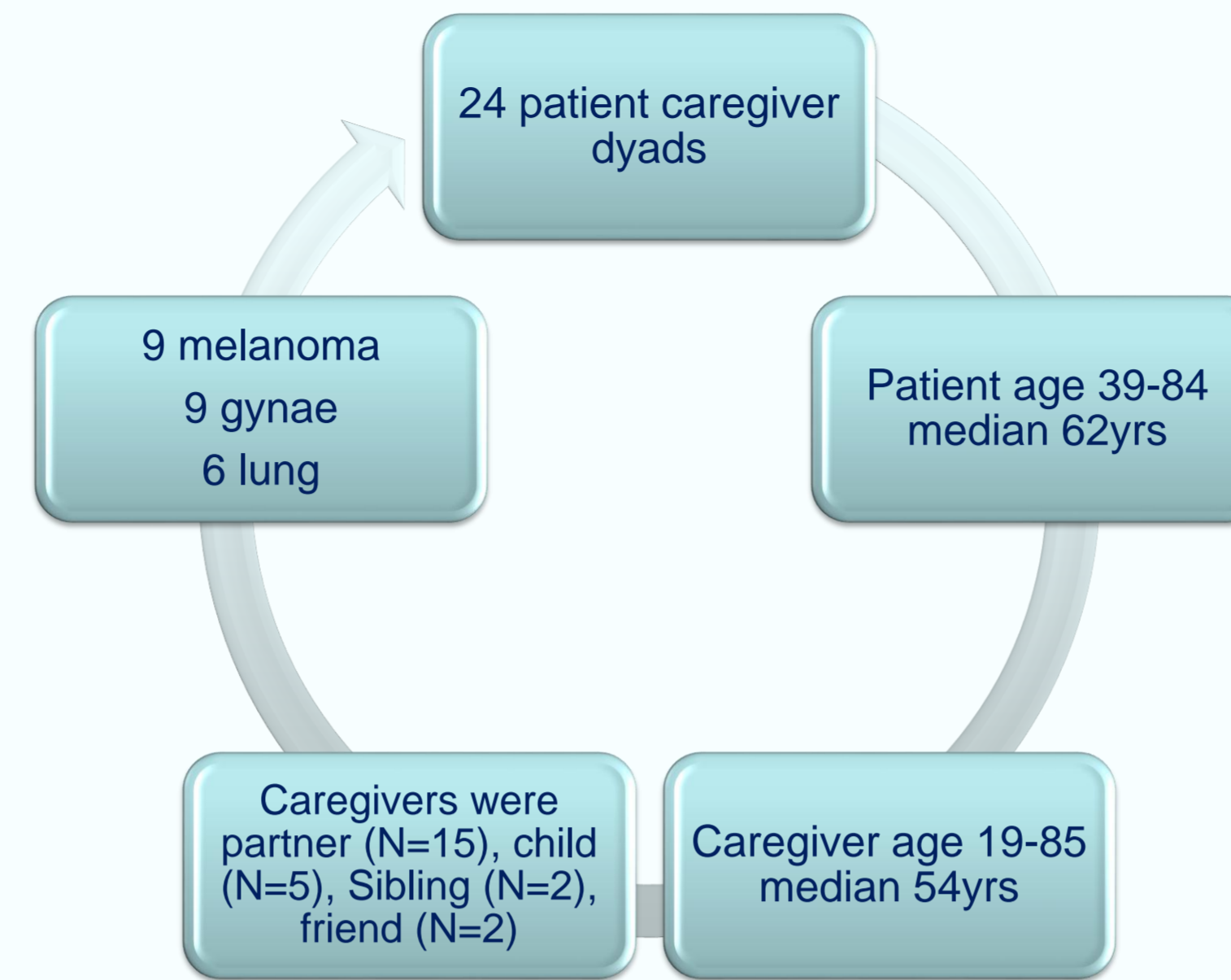


An overarching theme in the qualitative interviews was uncertainty about the future. Here we explore this specific topic, and contrast Pt and Cg experience.

**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 makes 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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