

# Supporting melanoma patients and their carers:

*A qualitative exploration of social interaction between patients, carers and healthcare professionals.*

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## BACKGROUND

Melanoma incidence continues to rise in Europe, the USA and Australia with mortality rates remaining relatively stable, meaning more patients undergoing surveillance. Treatments may include multiple surgeries, BRAF/MEK inhibitors and immune therapies. Clinical Nurse Specialists (CNS) provide support for melanoma patients and their carers in the UK but there is little evidence to guide interactions with limited resources available.

## AIMS / PURPOSE

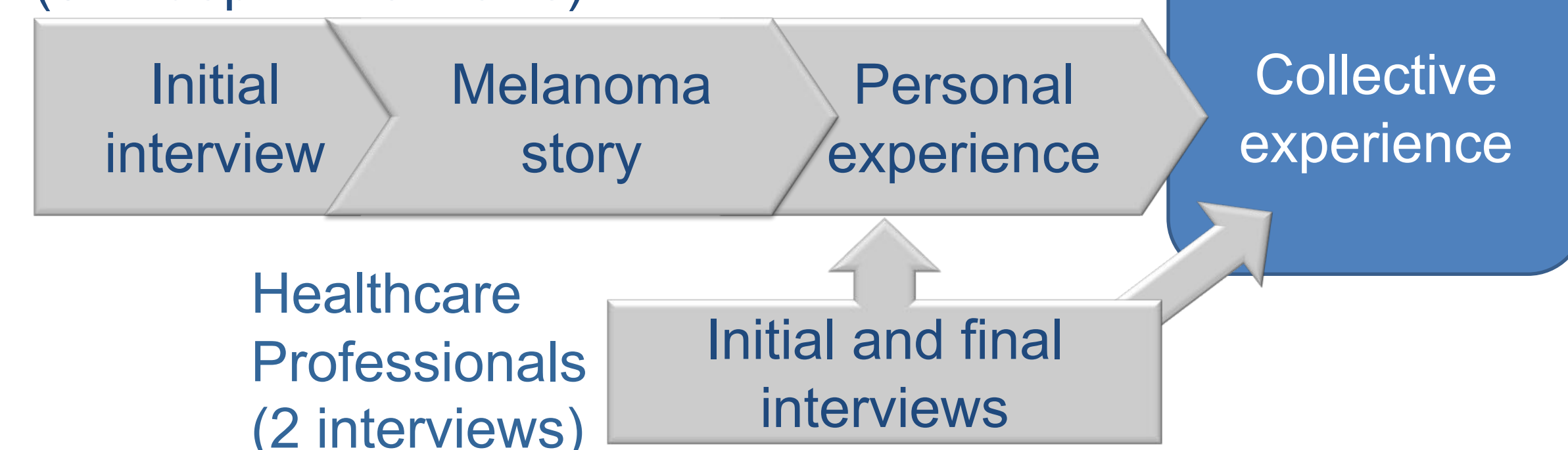
The overall study aim was to explore the changing experiences and support needs of melanoma patients and their carers throughout the disease pathway. Here we report the specific interactions between healthcare professionals and patients.

## METHODS

- Qualitative methodology using a constructivist grounded theory approach.
- 17 melanoma patients (clinics at a UK teaching hospital).
- 11 carers & 11 Healthcare professionals (HCPs) with patient agreement.
- Initial topics were modified as interviews took on an emergent design. Focus groups were conducted at the end of data collection: one with patients and one with CNSs.
- Diagrams were used to aid data collection using the metaphor of a rollercoaster

### Collection of data to form individual and collective theory

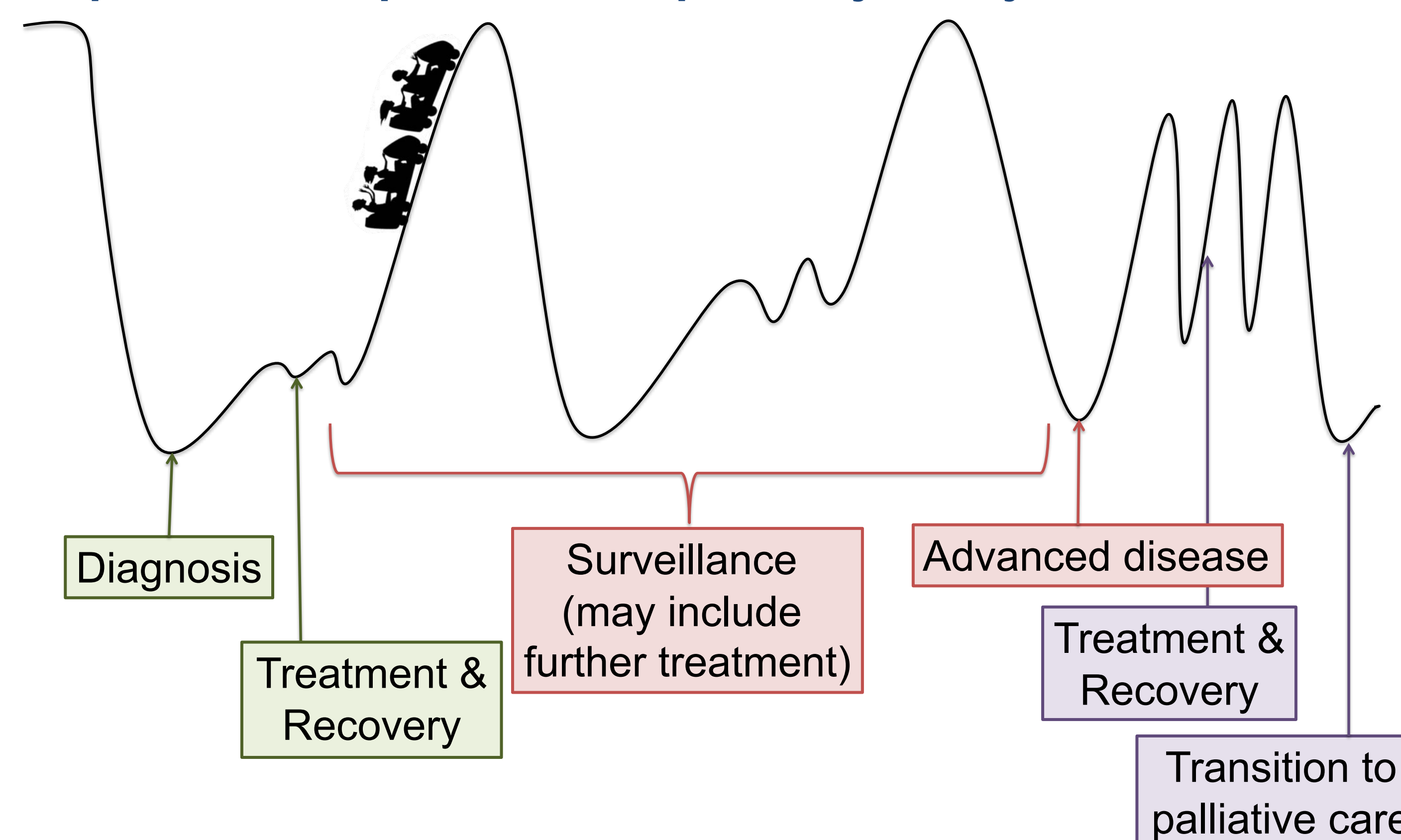
Patients & nominated carers  
(6 in-depth interviews)



## RESULTS

- Patients, carers and CNSs agreed on important points in the pathway resulting in four key phases: Diagnosis and initial treatment, surveillance, metastatic disease and bereavement.
- During all phases HCPs were used as a resource with their expertise being recognised. This gave HCPs the opportunity to influence patients' routines at this stage to facilitate sun protection and help them to lead a 'normal life' with melanoma.

Rollercoaster developed via diagramming to demonstrate important time points in the patient 'journey'



- The quality of initial contact with the healthcare system and the nature of the 'relationships' that they forged with HCPs during diagnosis often proved crucial to their on-going 'journey'
- Having information delivered in a way that patients and carers could understand was crucial to their experience with many not understanding everything they were told.

*"It's quite nice to have that one person just to phone and ask anything really." Helen*

*"I always find with my patients if I say I'm going to ring you, they trust that I will ring them. If you start breaking that then that trust breaks down a little bit." Helen's CNS*

- Patients and carers who had established close relationships with HCPs found the transition difficult when transferred to new services as they had to establish new relationships.
- Where promised support was not delivered, patients and carers lost trust in the healthcare system.

## CONCLUSION

HCPs recognised the key time points where support was most needed. They could influence patient routines following diagnosis and treatment. Developing a trusting relationship with a nurse enabled patients to feel supported but this could only be achieved if patients and carers recognised that HCPs were available for support.

## ACKNOWLEDGEMENTS

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