CARE EXPERIENCES ACROSS THE CANCER CONTINUUM:
A QUALITATIVE STUDY TO INFORM A STATEWIDE CANCER NAVIGATION APPROACH IN AUSTRALIA

Andi Agbejule, Ria Joseph, Sue Merchant, Jolyn Johal, Imogen Ramsey, Jacqueline L. Bender, Cally Jennings, Michael Osborn, Fiona Crawford-Williams*, Raymond J Chan*

*Co-senior authors

BACKGROUND

- This qualitative descriptive study aimed to **identify challenges and facilitators in accessing cancer care in South Australia,** from the perspectives of cancer survivors and caregivers, to inform responsive cancer navigation approaches.

METHODS

- **Data collection methods:** Surveys and Interviews
- **Content Analysis:** Used to categorise the challenges and facilitators experienced by cancer consumers
- **Subjective-Inductive Thematic Analysis:** Guided by the Supportive Care Needs Framework, this approach was employed to develop a statewide navigation system for cancer care support.

THE FLINDERS NEEDS-BASED APPROACH TO CANCER NAVIGATION IN SOUTH AUSTRALIA

The needs-based approach recognises that everyone affected by cancer requires foundational information navigation support, while identifying some may require or want additional navigation support at certain times or situations across their cancer experience.

- **All levels** of navigation support are accessible to all people affected by cancer.
- **Level 1** interventions provided to all affected by cancer. Individuals (self)referred to **Levels 2 & 3** based on their needs and preferences.
- **Levels 1 & 2:** Interventions that provide information, skills, and resources to support individuals in navigating cancer care.
- **Level 3:** Interventions may involve taking actions on behalf of individuals (e.g., symptom management, intensive ongoing interventions, direct advocacy)

RESULTS

- Online qualitative survey (n=75) and semi-structured interviews (n=22).
- Key challenges reported by consumers included **perceived invalidation of medical concerns**, delayed diagnoses, poor communication, inadequate information provision, fragmented care, and limited logistical, cultural, and psychological support.
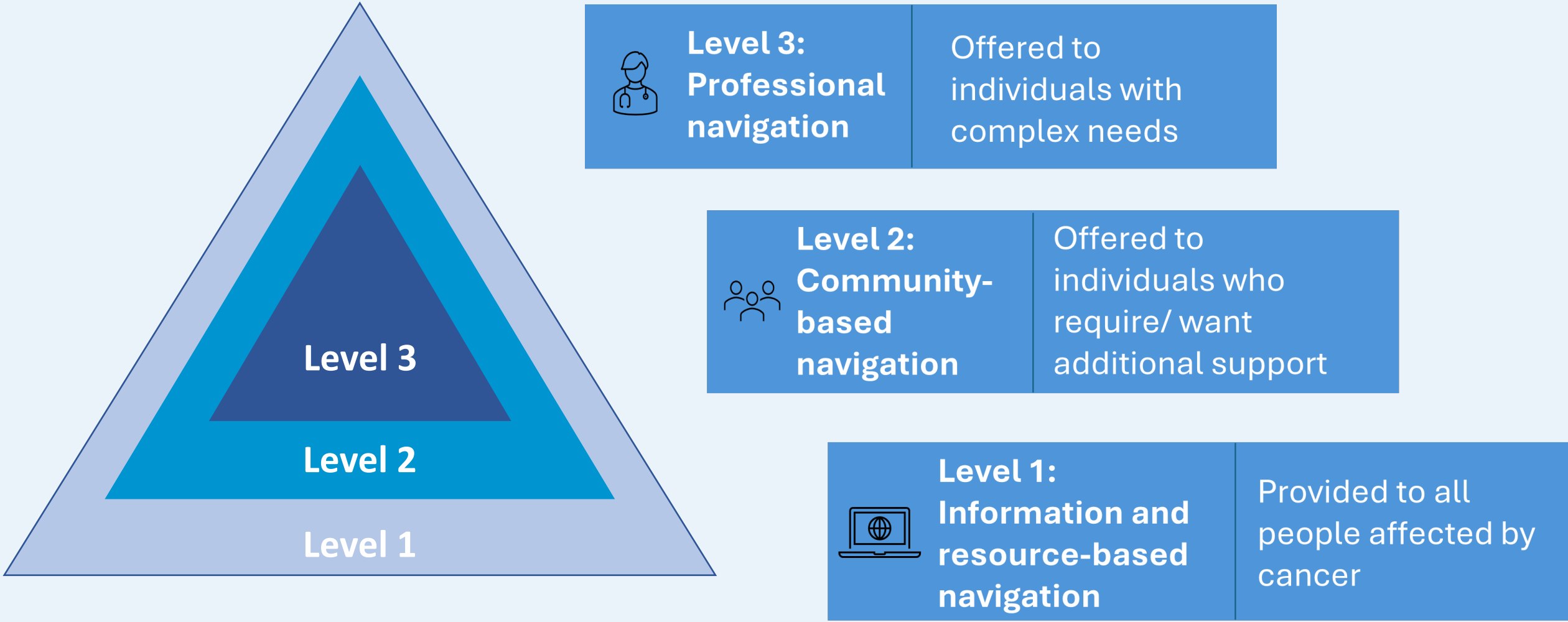
	Pre-diagnosis	Before Treatment	During Treatment	Months to Years post treatment
Gaps and Challenges	**Dismissive** *"[My] Doctor didn't follow up properly and was quite dismissive of symptoms"* **Poor patient-provider communication** *"Health practioners unaware of services"*	**No Support** *Nobody to walk with us on our journey. Too much info to take in (i.e., medication, seizures, no emotional support, just treatment plans, bang, bang, bang)"*	**Limited Rural Support** *"He had to be transported to another hospital for treatment, although I was given a timetable it very rarely actually happened. On top [of that], it [transport] wasn't always late, it was at times early, made it very hard to be a support person"*	**No Support** *"Feeling like we've fallen off the doctor's radar. It feels like the responsibility for monitoring symptoms or potential regrowth lies entirely with me, however I am unable to request access to my own blood tests or CT scans!"*
Facilitators	**Familiar Support Person** *"Would be good to see the same person through the process of diagnosis"*	**Information Support** *"We need someone who can sit down and map the available services and those that are not available"*	**Financial Assistance & Advocacy** *" Need help. Having to leave work, dealing with and navigating Centrelink was not the most enjoyable experience. Constantly having to provide sick certificates and filling out forms."*	**Navigation Support** *"I think it would be beneficial if there was a coordinator who would help patients navigating recovery and available services."*

Table 1: Consumer experience of Cancer Care in South Australia

Level 3: Professional navigation — Offered to individuals with complex needs

Level 2: Community-based navigation — Offered to individuals who require/ want additional support

Level 1: Information and resource-based navigation — Provided to all people affected by cancer

Level 3
Level 2
Level 1

CONCLUSION

- This **pragmatic, person-centered, need-based approach** offers a **framework** for sustainable navigation models.
- Local adaptation will be needed for international use.

CONTACT: Dr Andi Agbejule; Andi.Agbejule@flinders.edu.au

Cancer Survivorship Program

Flinders University

Caring Futures Institute