

Our Lived experience community ...
ensuring it is the heart of everything we do

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Chief Executive Officer
Australia New Zealand Gynaecological Oncology Group

**The Promise of Clinical Trials:
Transforming Tomorrow's Health**

SCRI Clinical Trials Symposium 2024

30 - 31 Jul 2024 • Raffles City Convention Centre



Conflicts of Interest

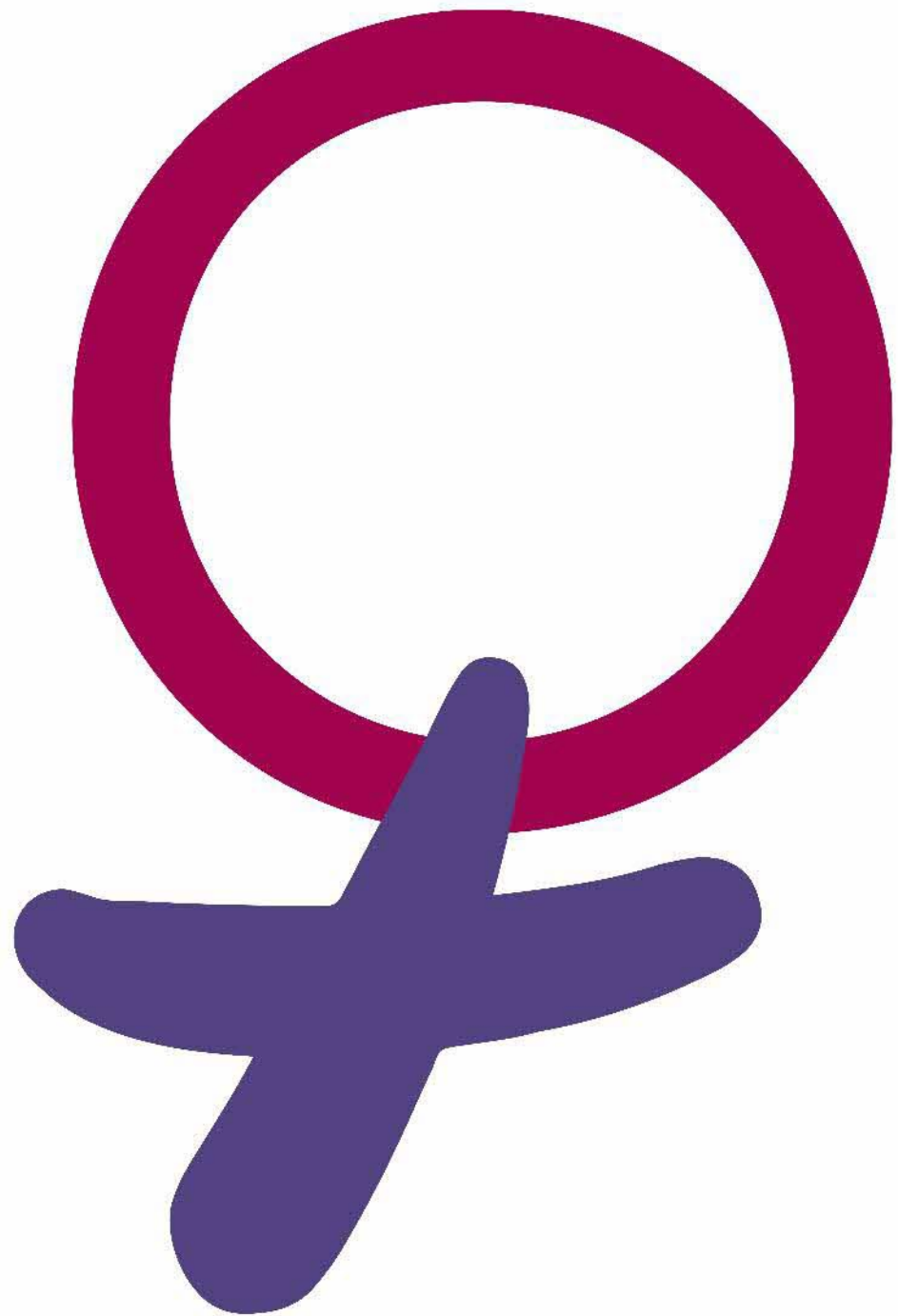
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ANZ
GOG
♀

Who we are

ANZGOG is the peak national gynaecological cancer research organisation in Australia and New Zealand.

Our vision is: **Advancing research, *saving lives***

The group has more than 1450 members representing clinical, allied health and pure research specialities, and includes community.

ANZGOG clinical trials are conducted at over 80 hospital sites and include both local and global collaborations to ensure the best research is available to improve life for women with a gynaecological cancer.



Our Mission

To improve outcomes and quality of life for everyone with a lived experience of gynaecological cancer by conducting and promoting clinical trials and multidisciplinary research.

Our community



Leadership

“The community is at the heart of everything that we do at ANZGOG.

*They remind us how important advancing research is for others,
they keep us on track, focusing on what matters most and
they shape ANZGOG’s research direction by providing their unique
lived experience.”*

Prof Clare Scott AM, ANZGOG Chair

Community Engagement Program

We are creating a model of community involvement at every step along our research process, ensuring community volunteers have a voice both within ANZGOG and our research, and more broadly alongside us with our primary stakeholders.



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Education



Advocacy



Research



Consultation

- Under the program patients and carers with lived experience of a gynaecological cancer are offered individual ways to contribute meaningfully.
- The program was informed by extensive consultation with ANZGOG clinical members and other stakeholders.
- Consultation Workshop held in October 2023 with Community Volunteers to refine the model.
- Officially launched December 2023.
- Referrals from ANZGOG members are encouraged and direct application encouraged.

Dedicated Volunteer Coordinator on staff



Advancing research
saving lives

- Consistent point of contact and support for all volunteers.
- Supports volunteer through onboarding into individual pillars
- Volunteers commit to one program pillar for first 12 months
- EOI invited via website or social media posts
- Follow up by email arranges an introduction to initiate contact.
- Introductory (screening) phone call to discuss experience and area of interest
- Further interview to confirm which pillar most suitable.

Each pillar has a responsible person

- A central care point for all volunteers – ANZGOG's Volunteer Coordinator.
- Each pillar has a responsible person to help coordinate activities.
- Multiple roles available within each pillar requiring different skills, levels of experience and time commitment.
- ANZGOG team interview to determine interest, experience and best pillar.
- Extensive onboarding process including training and ongoing support.
- Each role is guided with a Volunteer Agreement, Code of Conduct, Role Description and supported by their Activity Coordinator.

Community Pillars within ANZGOG

Community Volunteer Roles are available across three pillars:



Education



Advocacy



Research

Education Pillar [Survivors Teaching Students]



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Education

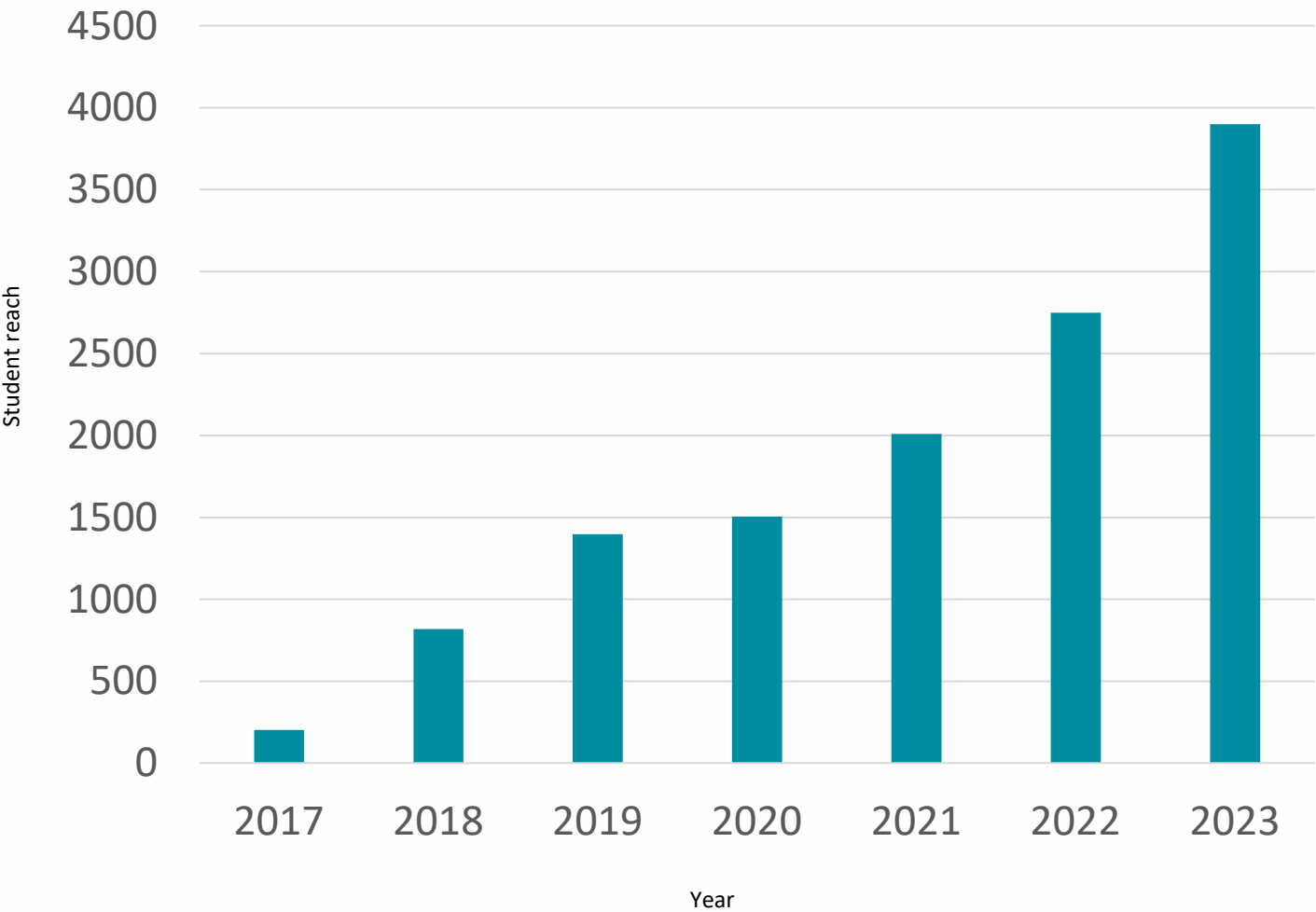
(approx. 150 volunteers)

- Regional Coordinators
- Facilitators
- Presenters
- Education Ambassadors

- Experiential learning program managed by Program Manager and Volunteer Coordinator
- 21 universities across Australia and NZ
- 48 Presentations reaching 3900 students, in 2023
- Survivors and caregivers are in a unique position to help students understand the lived experience of a gynaecological cancer
- 10 teams of volunteers led by a volunteer Regional Coordinator
- Over 150 volunteers with 106 active.

Education [Survivors Teaching Students]

Student Reach 2017 - 2023



Advocacy Pillar



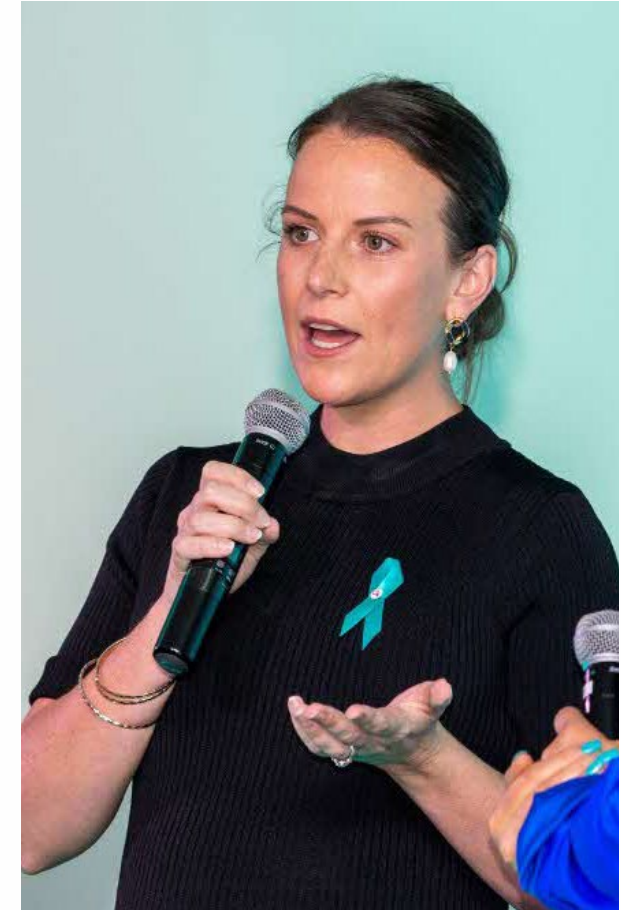
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Advocacy

(approx. 10 volunteers)

- Advocate
- Advocacy Partner

- Share their story to **advocate for funding for ANZGOG research**, highlighting that investment in gynaecological cancer research is an investment in saving lives and empowering women.
- Activity coordination by Advocacy and Development team developing pharma and philanthropic grants and relationships.
- Activities include industry and philanthropic presentations, and media interviews with ANZGOG leading members.
- Receive media training and information kits.



Research Pillar

Research

(approx. 20 volunteers)

- Consumer Associate Investigator
- Research Adviser

- **Consumer Associate Investigators** serve as an investigator on grant applications and go on to be a member of ANZGOG Trial Management Committees.
- **Research Advisers** bring their lived experience to research development committees as active members.
- ANZGOG has 12 research development committees across 5 primary cancers and research initiatives.
- Community voices bring both a personal perspective and the broader views of people with cancer.
- Roles are varied and levels may require additional education and expertise in research analysis.
- ANZGOG provides education opportunities.

Research Pillar

- A **Consumer Research Panel** is available for broader consultation on research idea development for a clinical or scientist.
- Members can consult broadly on strategic or specifically on certain design areas.
- ANZGOG facilitates these meetings for members and volunteers.



Focused fit with government policy



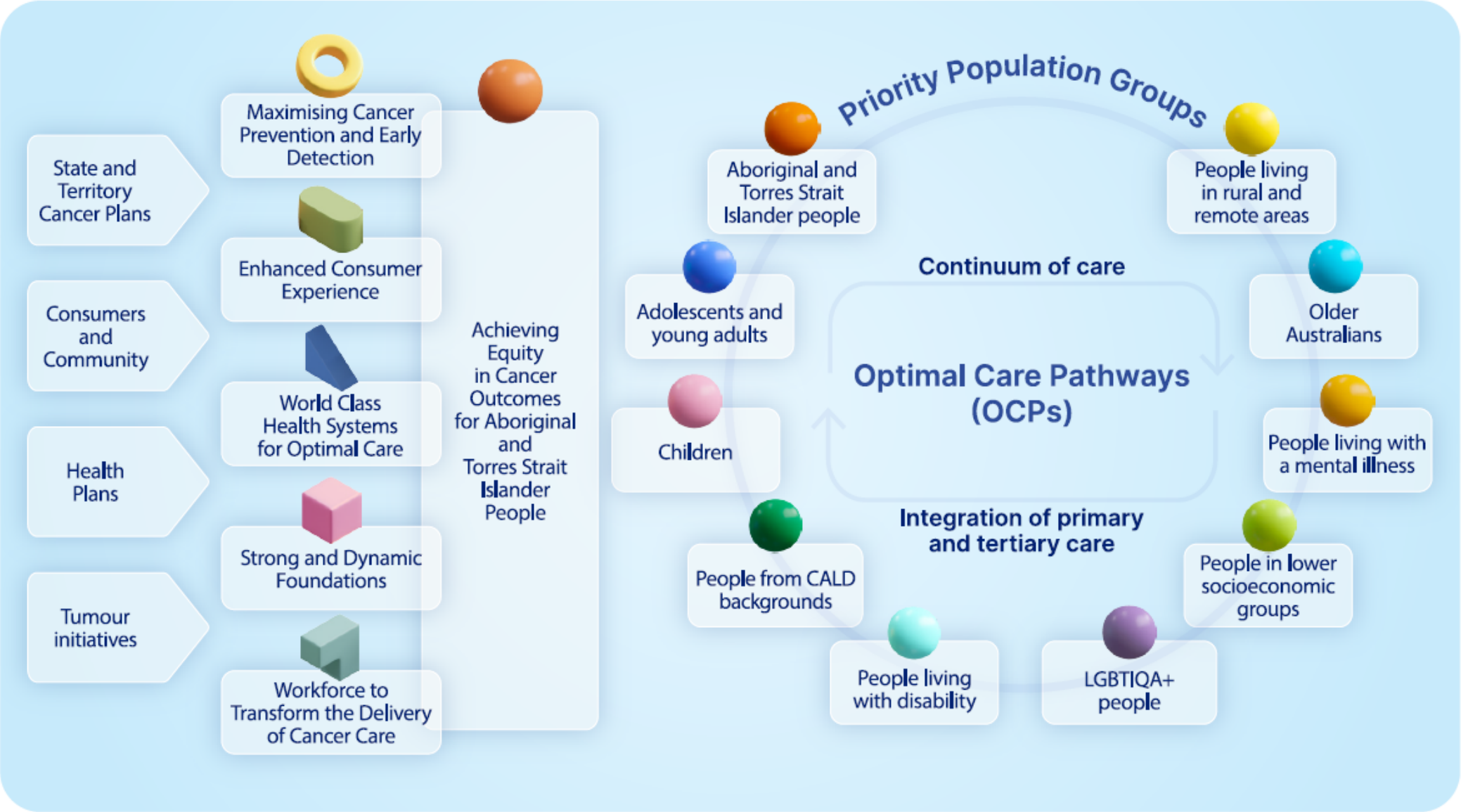
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Cancer outcomes in Australia are among the best in the world, but this is not the story for all Australians. There are significant disparities in cancer outcomes among specific groups in our society.

In 2023 the Australia Government launched 'The Australian Cancer Plan' designed to improve cancer outcomes for all Australians, and particularly for those groups whose health outcomes are poorest.

Achieving equity in cancer outcomes will be a fundamental measure of success for the Plan and will align Australia with global calls to improve cancer outcomes for all people.

Australian Cancer Plan Conceptual Framework



Just as Community needs are at the forefront of the Australian Cancer Plan, so it is with ANZGOG's Community Engagement Program. The future:

- researcher and community workshops to explore and prioritise research
- exchange of information and education through a community conference and
- robust voices advocating for funding for research.
- Diverse voices calling for equity and inclusion.



Thank You!

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