

The Young Onset Dementia Asia Pacific Research Collaborative (YOD-APC): The First 2 Years

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Background

- Young-onset dementia (YOD): symptom onset before 65
- YOD research in Asia-Pacific remains under-represented
- The specific needs of people living with YOD are increasingly being recognised, and clinicians are urged to improve care for this patient group.
- YOD-APC is a newly created multi-national research collaborative committed to improve outcomes for people with YOD and their families in the Asia-Pacific region.

What is this Poster about?

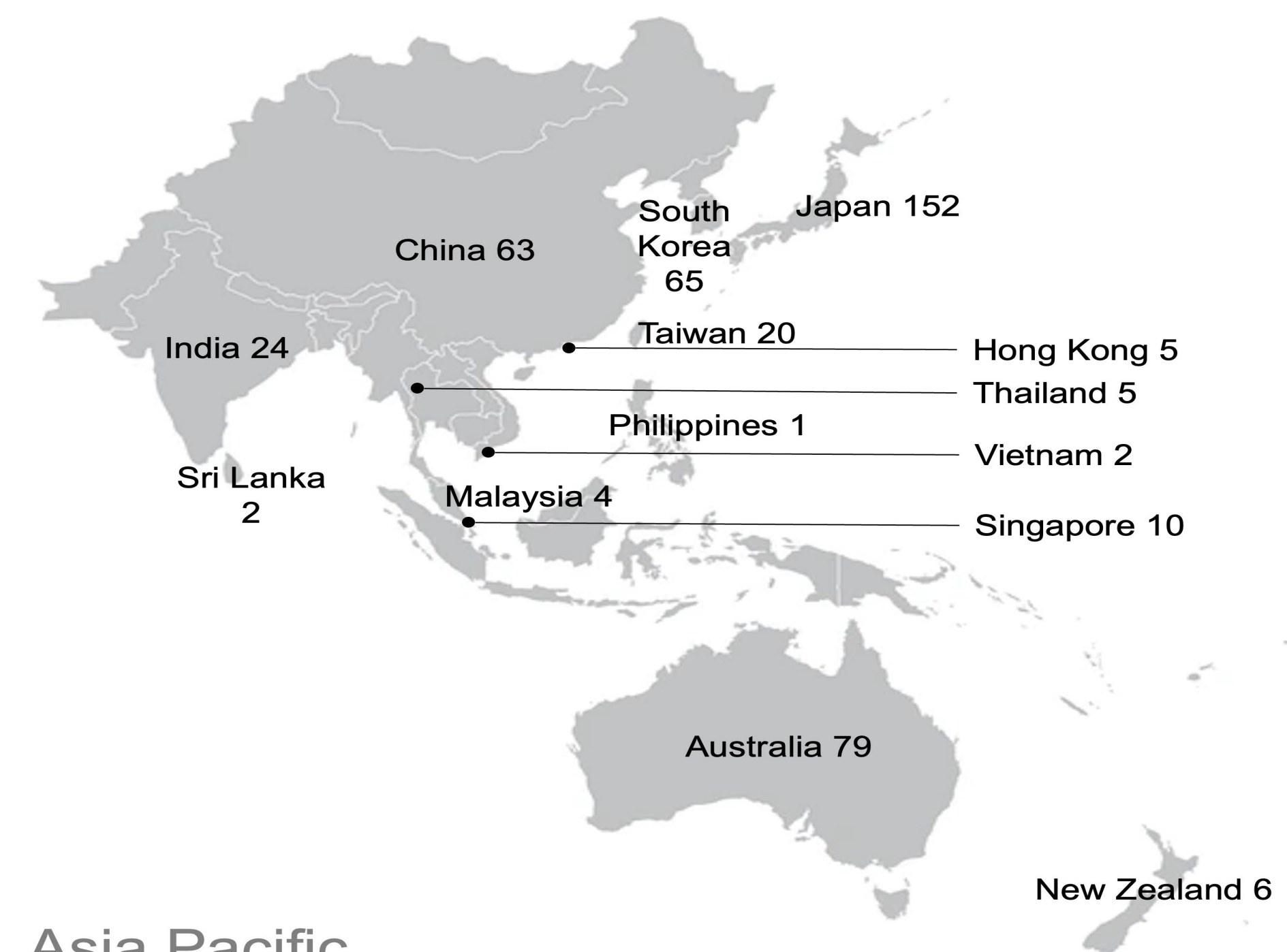
- 1. Describes the first 2 years' progress of YOD-APC
- 2. Presents the findings of a scoping review to map the existing YOD literature from Asia-Pacific and provides an overview of the research topics conducted to date
- 3. Introduces a new project to understand the different YOD models of care across the Asia-Pacific region.

1. YOD-APC

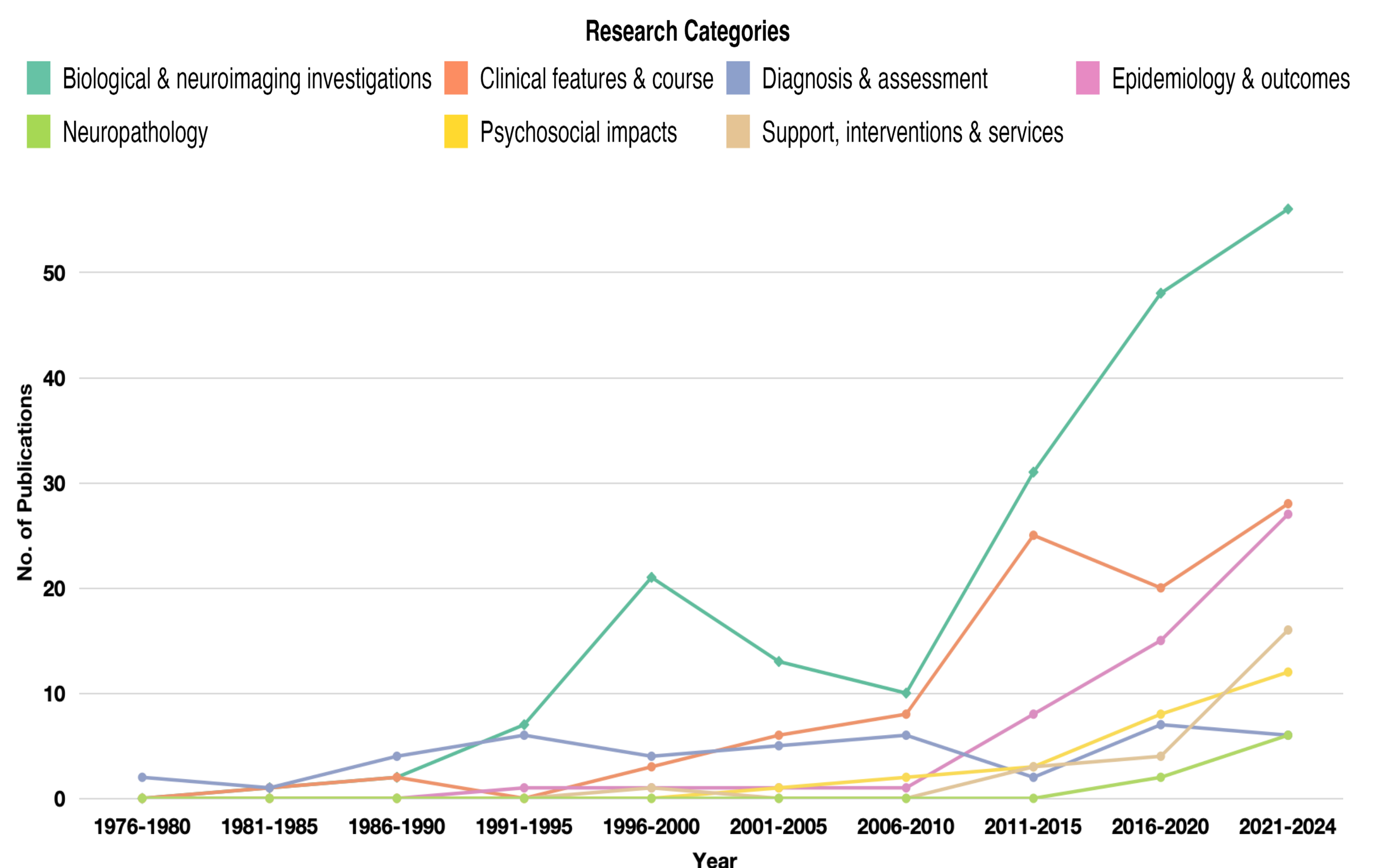
- Founded by key YOD researchers in Australia and New Zealand
- Inaugural meeting in New Zealand in Aug 2024
- 3-monthly online meetings
- Key members in China, Hong Kong SAR, India, Malaysia, Singapore, South Korea and Vietnam.
- Priorities have been driven by key aims such as connecting and collaborating across sectors and countries, sharing expertise, identifying key areas for improvement, and promoting the inclusion of lived experience & community expertise in research
- To join the network, visit our website via **QR code** above or email g.cheung@auckland.ac.nz / samantha.loi@unimelb.edu.au

2. Scoping Review

- To comprehensively map the existing literature of YOD broadly from the Asia-Pacific region published to 31/12/2024
- Followed PRISMA extension for scoping reviews guidelines and searched **Scopus** and **PsycINFO** for empirical studies involving human participants with YOD or family carers in Asia-Pacific.
- 437** publications were identified. 14 of the 42 Asia-Pacific countries/territories have published YOD research.
- Research focused on disease biology such as genetics, neuroimaging, and neuropathology. Only **11.4%** of the publications, mainly from Australia, examined psychosocial impacts and support services.



Asia Pacific
Number of studies by Asia-Pacific country/ territory



Research topics across the 437 empirical Asia-Pacific studies: (a) publications over time; (b) study design by research topic.

3. YOD Models of Care Project (Ongoing)

- This project will describe
 - 1. the diagnostic journey, including diagnostic pathways, specialist services, barriers to care, stigma, cultural issues
 - 2. accessibility and availability of assessment tools (imaging, neuropsychology, lumbar puncture and biomarkers)
 - 3. post-diagnostic support and services, including specific supports for people of working age (e.g. employment, financial, family support).
 - 4. reflections and future directions (key priorities or opportunities to improve care for YOD; effect of COVID)

Around **20 countries/regions** are contributing to this project.

