

Summary: Australian Rare Disease Organisation Community of Practice (ARDO-CoP)

As part of Stream 3 of the Rare Disease Awareness, Education, Support and Training (RAREST) Project, the Australian Rare Disease Organisations Community of Practice (ARDO-CoP) was established. The ARDO-CoP is a direct response to the consultation undertaken with rare disease organisation leaders who identified a need for greater connection, and sharing of knowledge, expertise, approaches and experiences for mutual support and capacity-building for systemic advocacy among Australian rare disease organisations. In keeping with these sentiments, the ARDO-CoP adheres to Rules of Engagement that create an open, flexible, welcoming and non-judgemental environment for all participants regardless of their level of experience or rare disease community.

The ARDO-CoP encourages collaborations and partnerships beyond the group, actively seeking potential speakers to discuss pertinent issues related to rare diseases. The goal of the ARDO-CoP is to produce a collective, evolving pool of knowledge and expertise by sharing learnings and resources. Each member has equal opportunity to participate to the extent they choose, according to their needs and capacity. New members are welcome to participate.

The ARDO-CoP started with 11 organisations actively participating and has grown to now include 19 organisations. It is the intention of the current ARDO-CoP to continue meeting for as long as members find it to be of value.

Below is a summary of the seven ARDO-CoP sessions.

Date	Session focus	Session description	Location
Nov 2022	Advocacy and Co-design Masterclass Series	The inaugural meeting of the RAREST ARDO-CoP. Sharing of consultation findings and an introduction to the RAREST ARDO-CoP, systemic advocacy and co-design in the rare disease sector.	Face-to-face (Rare Voices Australia's National Rare Disease Summit, Sydney)
March 2023	Inclusive Representation of the Diverse Rare Disease Community	With guest speakers from the Federation of Ethnic Communities' Councils of Australia (FECCA), strategies for ensuring inclusive representation of culturally and linguistically diverse (CALD) communities, were discussed.	Face-to-face (FECCA, Canberra)
May 2023	Multistakeholder Engagement Toolkit and MS Teams	ARDO-CoP members reviewed the <i>Taking Action Together Toolkit</i> (a Stream 3 RAREST Project deliverable).	Zoom

Aug 2023	Health Technology Assessment	A member of the ARDO-CoP facilitated this session and talked about their knowledge and experience of navigating the Health Technology Assessment (HTA) process.	Zoom
Nov 2023	Interdisciplinary Care in Medicine and Health	This session was co-facilitated by an ARDO-CoP member and included a presenter from the Behavioural Emergency Response Team (BERT) from the Metro North Hospital and Health Service in Queensland.	Zoom
March 2024	Advocating for Inclusive Transition Care Services for Young People Living with a Rare Disease	A guest speaker from Western Sydney Local Health District presented about the Centre for Adolescent and Young Adult Health (CAYAH). Transition care for young people living with a rare disease was then discussed by the ARDO-CoP.	Hybrid (Zoom/Macquarie University, Sydney)
May 2024	Political Engagement and Workshopping Current Advocacy Challenges	A self-directed session where members discussed their current advocacy challenges and strategies that worked well to achieve advocacy goals.	Zoom

If you would like to know more about the ARDO-CoP, please contact christina.rojas@mq.edu.au or shalini.wijekulasuriya@mq.edu.au