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## Paediatric &amp; Congenital Cardiology (454-481)

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## Administration of a National Disease Registry in Australia: Lessons from the Development of the CHAANZ Congenital Heart Disease Registry

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A review of congenital heart disease (CHD) management across Australia outlined the necessity of a national CHD Registry to improve service delivery [1]. The Congenital Heart Alliance of Australia and New Zealand (CHAANZ) CHD Registry collects information on CHD patients in Australia and New Zealand. The registry will improve understanding of the overall burden of congenital heart disease [2], and will facilitate the delivery of better, more sustainable models of care. In the past 18 months, CHAANZ has developed the framework to govern the 11 major adult and paediatric CHD centres currently contributing to the registry. We provide insight into the challenges of setting up a bi-national registry, navigating the obstacles of establishing a multi-institutional agreement (MIA), and obtaining approval from the various research governance offices.

From July 2020, our timeline to an executed MIA was 283 days, with lead ethics already approved, and time to site governance approvals ranged from 1 to over 220 days. 214 emails were sent during the MIA development and signing, email sent to governance offices ranged from 11–76 with the number of requested points of additional information ranging from 0–29.

Requirements for implementation of governance structures constitutes a major portion of this project's resources and we report a wide range in requirements between jurisdictions. For Australia to be competitive in this vital research area, and to optimise use of its research expenditure, a centralised and streamlined approach to multi-institutional projects, ethics and governance is desperately needed, including accountabilities by administrative staff at the participating centres.

## References

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## Adult Congenital Heart Disease Patient-Reported Psychosocial Measures and COVID-19 Anxiety

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**Introduction:** There is limited data on the psychosocial impact of a congenital heart disease (CHD) diagnosis in childhood and its relationship to adult anxiety. Preliminary CHAANZ CHD patient survey data reported by Strange et al. revealed high anxiety in 71% of patients [1]. As part of our national CHD registry, we aim to profile the psychosocial and resilience impact in a subset of patients.

**Methods:** Patients aged 18 years and older were identified and recruited through stratified random sampling of the CHAANZ CHD registry and underwent comprehensive psychosocial profiling via REDCap patient-reported surveys. Surveys included the Cardiac Anxiety Questionnaire (CAQ, range: 0–72), Impact of Events Scale–Revised (IES-R, subscale range: 0–4), 10-item Connor Davidson Resilience Scale (CD-RISC 10, range: 0–40) and the Coronavirus Anxiety Scale (CAS, range: 0–20). Surveys were completed between October 2021 and March 2022.

**Results:** To date, 38 participants have enrolled and 26 (12 females, aged 40 years [IQR30–54]) profiled. The CAQ revealed 25.5 (13.3–41.8), 22.5 (8.5–30.5) and 17.5 (9.8–29.8) and the IES-R was skewed towards the avoidance subscale with 0.0 (0.0–0.7), 0.2 (0.0–1.3) and 1.1 (0.1–1.5) for mild, moderate and complex CHD severities, respectively. Low resilience among participants (28.5[22.0–34.5]) was found via CD-RISC 10 and negligible dysfunctional anxiety associated with COVID-19 via the CAS (0.00[0.0–0.0]) compared to a normal population [2,3].

**Conclusion:** In this preliminary report, we note patterns emerging of cardiac anxiety, increased avoidance behaviours in relation to a participant's heart condition, low resilience and negligible COVID-19 anxiety. More data is required to investigate these patterns and their impact on transition of care.

## References

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