Our Research

A call for a National Congenital Heart Disease Registry was advised after an extensive review of CHD management across Australia, published in the HeartKids Australia White paper. A feasibility “study” of the CHD registry was executed and the CHAANZ Consortium was established to work toward the planning of a Regional Congenital Heart Disease Registry for Australia and New Zealand covering the spectrum of life for those with Congenital heart disease. A call for a lifetime regional registry was published in *Heart Lung and Circulation* in August 2016.

Recently appearing in *Heart and Lung Circulation*, a Call to Action was published to recommend all adults with non-simple congenital heart disease should be seen regularly in an adult congenital heart centre facility. The publication details the size of the problem and recommends solutions to be implemented.

The Seven key objectives for the ANZ CHD registry identified are:

1. Patient Benefit – This is the key objective, focusing on the understanding of:
   a) Early outcomes
   b) Transition
   c) Late outcomes
   d) Access to follow-up

2. Benchmarking and quality

3. Service planning

4. Natural and unnatural history
5. Clinical research

6. Transition to follow-up

7. Australia and New Zealand Reputation

The projects currently being conducted by CHAANZ include:

**Phase 1** - Epidemiology of congenital heart disease in Australia and New Zealand

**Phase 2** - National Congenital Heart Disease Survey

**Phase 3** - Australia and New Zealand Congenital Heart Disease Registry
References:


2. Celermajer, David et al. *Congenital Heart Disease Requires a Lifetime Continuum of Care: A Call for a Regional Registry,* *Heart, Lung and Circulation,* Volume 25, Issue 8, 750 - 754. (Link to publication)
