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DISCUSSION PAPER

Adult Congenital Heart Disease in Australia and New Zealand: A Call for Optimal Care

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Background Adult congenital heart disease (ACHD) is a relatively new subspecialty in the cardiology field. The prevalence of ACHD is estimated at ~3,000 per million adult population. The ACHD patient group is estimated to grow at ~5% per year and in the next decade it is forecast that 1 in 150 young adults will carry some form of ACHD diagnosis.

These estimates translate to ~72,000 ACHD patients in Australia and ~14,000 in New Zealand, although no current numbers are available. The Cardiac Society of Australia and New Zealand (CSANZ) has recently published Recommendations for Standards of Care for Adult Congenital Heart Disease (ACHD) in 2016. There is currently no long-term plan or proposal to address this huge health care burden within the federal government. This document details the size of the problem insofar as it is known and recommends solutions to be implemented.

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Methods This document was developed by the Adult Congenital Heart Disease Working Group of the Paediatric and Congenital Council (the Congenital Heart Alliance of Australia and New Zealand) as a response to the chronic under resourcing in this area, the risk this poses to patients and clinicians, and the clear need for long-term planning to develop safe care pathways.

Results These issues were raised with the CSANZ Board in December 2015 and the document was developed in response to the Board's request for more information. The current iteration was finalised on 14 November 2017.

Conclusions The authorship group comprised participants in the CSANZ adult CHD standards of care recommendations from 2013 with the inclusion of some newly trained ACHD cardiologists, who represented most states and territories across ANZ. None of the authors has any academic or professional conflict of interest.

Keywords Training • Cardiology: Transition • Standards of care • Adult congenital heart disease

Background

The Cardiac Society of Australia and New Zealand recently published Adult Congenital Heart Disease: Recommendations for Standards of Care [1].

Briefly, this document recommended that every adult with non-simple congenital heart disease (CHD) should be seen regularly in an adult congenital heart (ACH) centre facility, and these facilities should be:

1. Comprehensive ACH centres. These should service regions with a population >2–3 million. They should be staffed by at least two ACHD specialists, ACHD surgeons, a clinical nurse co-ordinator, a nurse educator, and sonographers with congenital cardiac expertise. In addition, specialised arrhythmia, heart failure, transplantation and palliative care services should be readily available, and there should be appropriate access to clinical psychology, genetic counselling and social work.
2. Regional ACH centres. These should be staffed by at least one ACHD cardiologist, a nurse co-ordinator and appropriately trained cardiac sonographers, and should have links to a comprehensive ACH centre.

The rationale for these recommendations was that this type of care results in demonstrably better outcomes than fragmented poorly resourced care, with reduced morbidity and mortality [2,3]. Moreover, this structure is similar to that recommended in a report commissioned by the National Health Service in the UK [4], and in the recent report commissioned by the Government of South Australia, and is considered international best practice [5].

Adult CHD services in Australia and New Zealand (NZ) are under-resourced, both in terms of trained personnel and dedicated facilities. The problem is acute and will increase over time. The number of adults with CHD worldwide now exceeds the number of children with CHD, and is increasing at a constant rate [6]. The demand for specialised ACHD services cannot be met without adequate funding and trained personnel. In the absence of forward planning and significant investment this resource deficit will accelerate.

Preventable death, avoidable adverse clinical consequences and unnecessary inpatient admissions are a well described fact of life for this patient population when there is inadequate access to specialised care [2,7]. Paediatric cardiology services remain the mainstay of the CHD management, but if ACHD services are inadequately planned and funded the benefits of the large financial, medical and social investment made during childhood will be lost to avoidable mortality and morbidity in adolescence and adulthood.

To formulate a strategic plan for the care of this population it is necessary to understand the ACHD population in terms of:

1. Its size and rate of growth
2. The current resources available
3. The utilisation of health care resources
4. The benefits of an adequately specialised and resourced ACHD service
5. The costs and consequences of under-resourcing

Understanding the ACHD Population and its Challenges

Population Size and Rate of Growth

The size of the ACHD population in Australia and NZ is not precisely known, although best estimates place this number in the vicinity of 50,000 to 100,000 individuals. This figure is based on research available from countries similar to our own where the size of the ACHD population has been modelled from reported birth rates, CHD birth prevalence, and survival estimates, or by collecting all CHD cases from administrative databases [8]. Each of these methods has potential limitations in terms of accuracy and bias.

There are limited data relating to long-term survival, and estimates of prevalence have relied on operative survival, natural history, autopsy series, death certificates and expert opinion, all of which may be inaccurate and introduce bias.

A recent meta-analysis [8], identified four cross-sectional studies and six studies that reported ACHD prevalence calculated from birth prevalence and survival estimates.

As shown in Figures 1 and 2, it was estimated from these studies and data included from the Netherlands, that the prevalence of adult CHD is approximately ***3,000 per million adults*** which is close to the number included in the

Table I. Cross-sectional studies prevalence of CHD in adults

Author	Year study	Year estimate	Country	Age population	Population (n)	Cases (n), unspecified excluded	Prevalence unspecified excluded	Cases (n), unspecified included	Prevalence unspecified included	Population
Marelli et al[3]	2007	2000	Canada	>15	5760295	13730	2384	23563	4091	Population of Quebec
Billet et al[22]	2008	2005	UK	>19	2396160	5043	2105	5286	2206	Qresearch population
Videbaek et al[23]	2009	2009	Denmark	>15	4245782	9710	2287	15332	3611	Danish population
CONCOR[19*]	2011	2011	The Netherlands	>18	12859287	11774	916			Dutch population*
Overall prevalence (weighted mean)							2297		3562*	

* CONCOR is still recruiting and therefore not included in the weighted mean.

Table II. Adult CHD prevalence

Author	Year study	Year estimate	Country	Pateints born between	Age in year estimate	Birth prevalence per million	Overall survival	Adult CHD prevalence per million
Warnes et al[4]	2001	2000	USA	1940-1989	11-60	6200	57%	3560
Somerville[24]	2002	2010	UK	1940-1990	20-70	6000	55%	3300
Hoffman et al[25]	2003	2002	USA	1940-1989	16-60	8912	20%-44%	1770-3880
Fredriksen et al[26]	2007	2005	Norway	1940-1989	16-64	7800	62%	4810
Shiina et al[27]	2009	2007	Japan	1947-1992	16-60	10600	37%	3930
Daliento et al[28]	2011	2032	Italy	1982-2023	11-49	6200	63%	3907
Current study	2011	2008	The Netherlands	1940-1989	18-68	8979	36%	3228
Overall prevalence (mean)								3548

Figure 1 Studies reporting ACHD prevalence: Summary statistics [8].
Abbreviations: ACHD, adult congenital heart disease.
Reproduced with permission from van der Bom T, et al. Am Heart J. 2012;164(4):568-75–Table 1 and Table 2 .

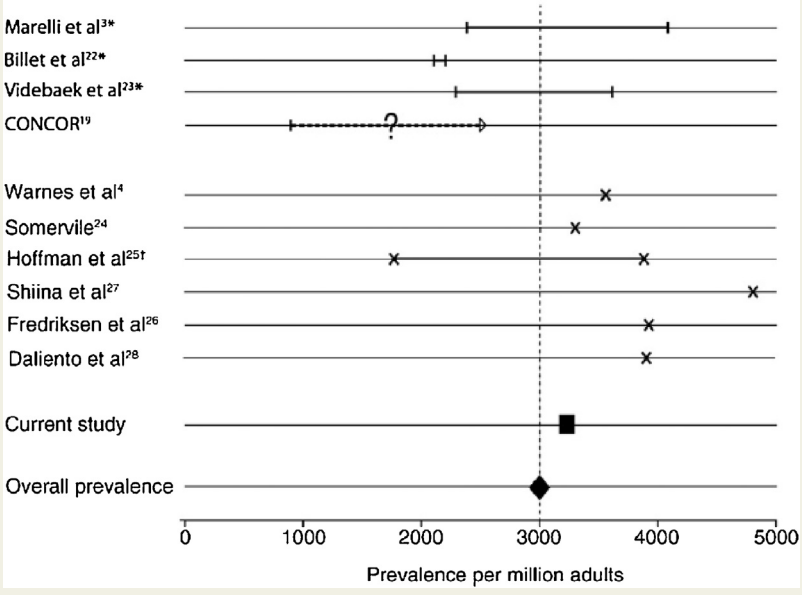

Figure 2 Studies reporting adult ACHD/CHD prevalence: Point estimates and confidence intervals [8].
Abbreviations: ACHD, adult congenital heart disease; CHD, congenital heart disease.
Reproduced with permission from van der Bom T, et al. Am Heart J. 2012;164(4):568-75–Figure 2.

proceedings of the 32nd Bethesda Conference of approximately 2,800 adults with CHD per million population [5].

These data suggest a potential adult congenital heart population in New Zealand of approximately 14,000 and in Australia of approximately 72,000 people.

Growth in the ACHD population is projected to be of the order of 5% per year [9]. In the next decade it is forecast that 1 in 150 young adults will carry a diagnosis relating to some form of CHD [6].

In 2007 the ACHD population in Quebec, Canada had increased to the point where it was larger than the paediatric CHD population. The greatest relative increase was the number of adults surviving with severe forms of CHD (Figure 3) [10].

The Current Resources Available

We recently conducted a survey of the ACHD centres across Australia and New Zealand and identified 7.5 FTE cardiologists who care for the ACHD patients in specialist centres (6 in Australia and 1.5 in NZ). The respective numbers for congenital cardiothoracic surgery are approximately 4.0 (Australia 3.5 and NZ 0.5). We estimate the number of dedicated ACHD nurses to be 5.0 FTE across the region. In contrast, there were approximately 30 paediatric cardiologists in Australia and 7 in New Zealand in 2010 [11].

It should be noted that the New Zealand Government has committed to an increase in funding over the next 5 years with a service expansion plan that includes an increase in senior ACHD cardiologist staffing from 1.5 FTE to 4 FTE, the development of subspecialist training positions and an increased number of senior nursing positions. A similar review of ACHD services and workforce in South Australia has also provided recommendations several years ago that are yet to be actioned. There has been little progress in other Australian states..

Health Care Utilisation

The number of hospitalisations for patients with ACHD is far greater than for the general population [12]. This finding is most striking in patients with severe CHD (Figure 4) [12].

The following table (Table 1) [12] provides a snapshot of the health care resource utilisation by the 22,096 adults with CHD alive in 1996 (8% had severe CHD) over a period of 5 years, in Quebec.

Over a 5-year period 51% were hospitalised, and 16% required admission to intensive care units (ICU). Not surprisingly, those with severe CHD made use of the health care resources more often than those with other CHD. This was especially so for cardiology outpatients visits and days in critical care (Figure 5) [12].

The Benefits of an Adequately Specialised Resourced ACHD Service

In an important and novel contribution, a recent study from the same group assessed the impact of the referral to specialised ACHD care centres on mortality [3]. The authors reported

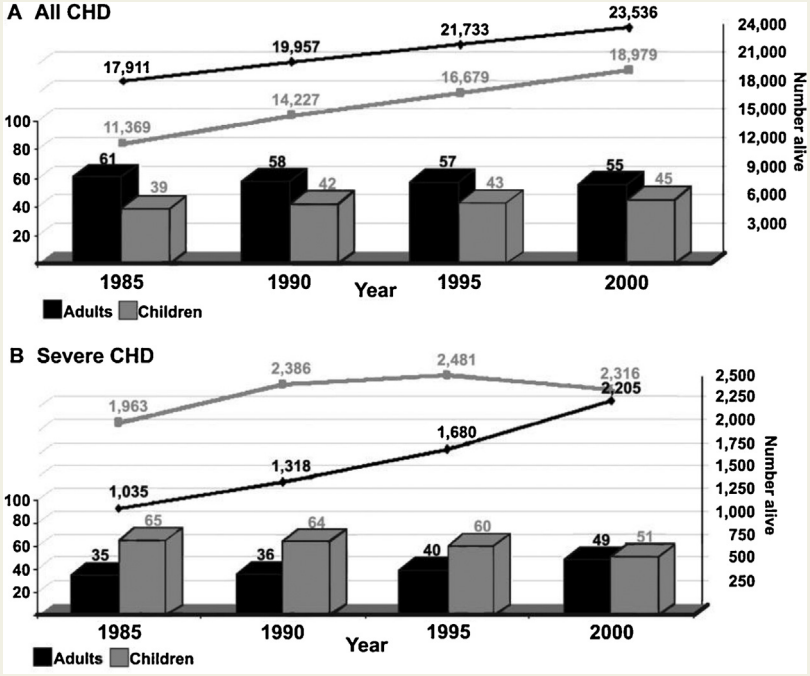

Figure 3 Numbers and proportion of adults and children with all CHD (A) and severe CHD (B) overtime [10]. Abbreviations: CHD, congenital heart disease.
Reproduced with permission from Marelli AJ, et al. Circulation. 2007;115(2):163-172–Figure 2.

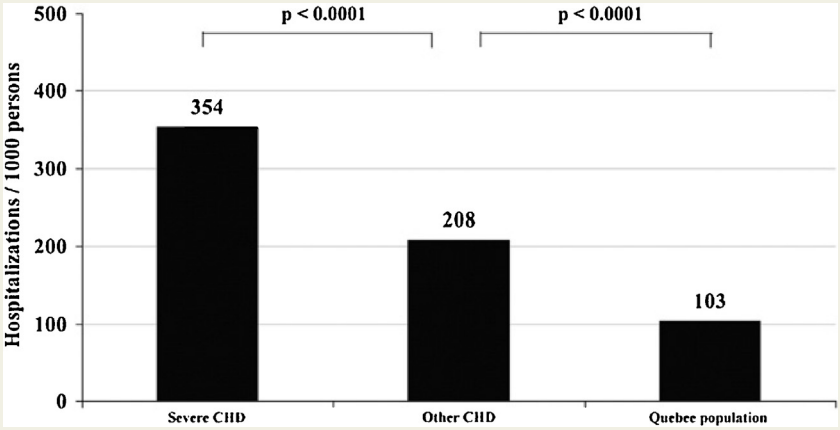

Figure 4 One-year hospitalisation rate of patients with severe and other cardiac lesions compared with the adult population of Quebec (April 1, 1999, to March 31, 2000) [12].
Reproduced with permission from Mackie AS, et al. Am J Cardiol. 2007;99(6):839-43–Figure 1.

ACHD referral centre care was associated with a significant reduction in mortality, independent of age, sex, and comorbidity. This finding was especially relevant for those with severe CHD. In addition, the introduction of national consensus guidelines was found to coincide with a significant reduction in ACHD mortality rates and an increase in referral to specialised ACHD centres (Figures 6 and 7).

Australian data have shown that non-specialised cardiology care for patients with congenital heart disease is commonly non-adherent with clinical guidelines and frequently results in important adverse clinical consequences in contrast to care by cardiologists with CHD training [2].

The Consequences of Under-Resourcing—the "Lost Generation" With CHD

The importance of loss to follow-up in the ACHD population has been highlighted by several investigators. Four recent studies conducted in Europe, Canada, and the USA, noted a significant rate of loss to follow-up of between 50–75% [13–15].

Table 1 Health service utilisation, 1996 to 2000 inclusive [12].

Health Care Service	n* (%)	Median† (IQR)
General practitioner outpatient visits	20,131 (91.1)	15 visits (7–27)
Cardiologist outpatient visits	12,113 (54.8)	4 visits (2–8)
Specialist‡ outpatient visits	19,276 (87.2)	10 visits (4–22)
Emergency department visits	14,994 (67.9)	3 visits (1–6)
Hospitalisation	11,332 (51.3)	9 days (4–26)
Critical care	3,536 (16.0)	5 days (3–10)

Abbreviations: IQR = interquartile range.
*Number of adults who used the service at least once from 1996 to 2000 inclusive.
†Median number of visits or inpatient days among users.
‡Excluding cardiologists.

There are important consequences for ACHD patients relating to loss to follow-up. In a recent study [7], 38% of Tetralogy of Fallot patients known to be alive and over the age of 30 years had not been seen by an ACHD cardiologist and 48% of the late deaths occurred while not under active follow-up. The authors note that, had the patients been under specialist care, it was likely that surgical intervention with pulmonary valve replacement to improve haemodynamics would have occurred in an additional 63 cases. In another study from Denver [15], patients with a lapse of care had a 3.1 times greater likelihood of needing an urgent (i.e., within 6 months after evaluation) surgical or catheter-based intervention. In an interesting study from Denmark, patients returning from loss to follow-up had a high incidence of unrecognised cardiac disease likely to impact prognosis including: moderate to severe pulmonary valvular regurgitation in 56% with Tetralogy of Fallot; moderate or severe mitral regurgitation in 75% with atrioventricular canal defect repair; and significant recoarctation in 20% of those with repaired coarctation of the aorta [16]. More recently, Australian data have also demonstrated an important risk for adverse clinical consequences in CHD patients who are lost to follow-up [2].

Delay in diagnosis of these types of problems has a significant impact on survival, with an estimated one in five deaths in the ACHD population being premature or avoidable [17]. *Half of these avoidable deaths occurred in those who were well, and leading normal lives without symptoms, or with mild disability.*

The Way Forward

The state of current service provision in our region is suboptimal and the need for adequate funding is urgent. The following

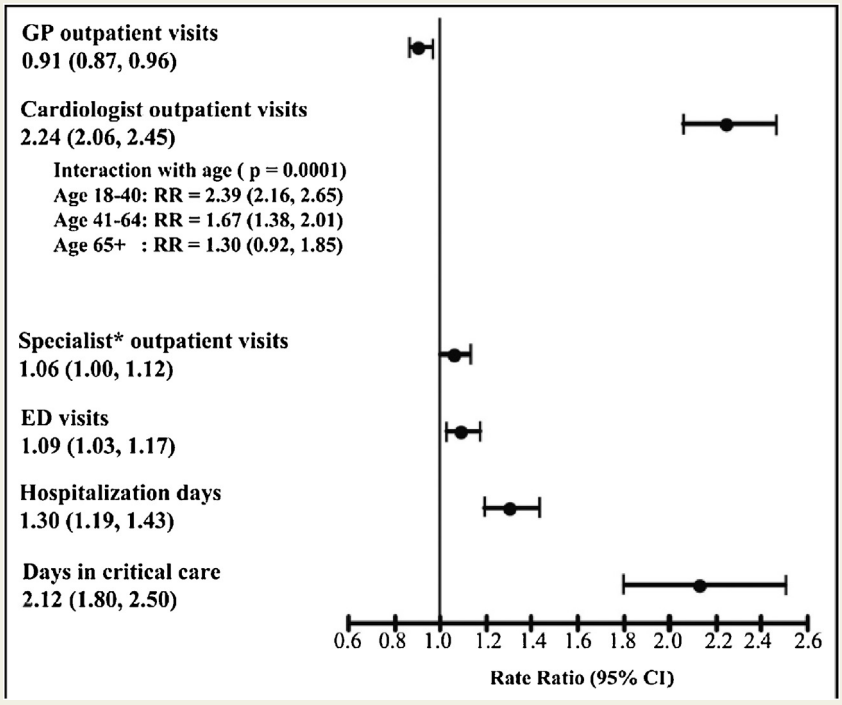

Figure 5 Health service utilisation in adults with severe versus other cardiac lesions [12].
Reproduced with permission from Mackie AS, et al. Am J Cardiol. 2007;99(6):839-43–Figure 3.

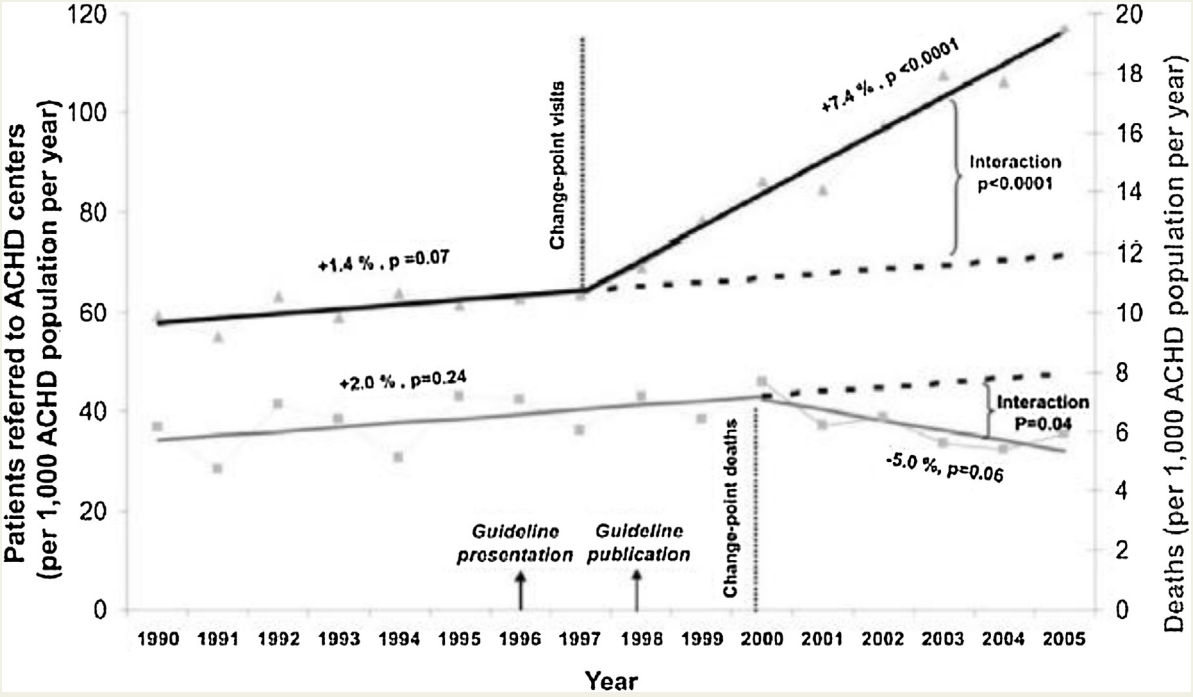

Figure 6 Time-series analysis: referral to specialised ACHD centres and ACHD patient mortality. Time-series analysis illustrating observed specialised ACHD centre referral (black line) and ACHD mortality (grey line) per 1,000 ACHD population per year, between 1990 and 2005. The dashed lines indicate expected trends after the change points identified by Poisson regression, and the black or grey lines represent the observed trends. ACHD indicates adult congenital heart disease [3].
Abbreviations: ACHD, adult congenital heart disease.
Reproduced with permission from Mylotte D, et al. Circulation. 2014 May 6;129(18):1804-1812–Figure 2.

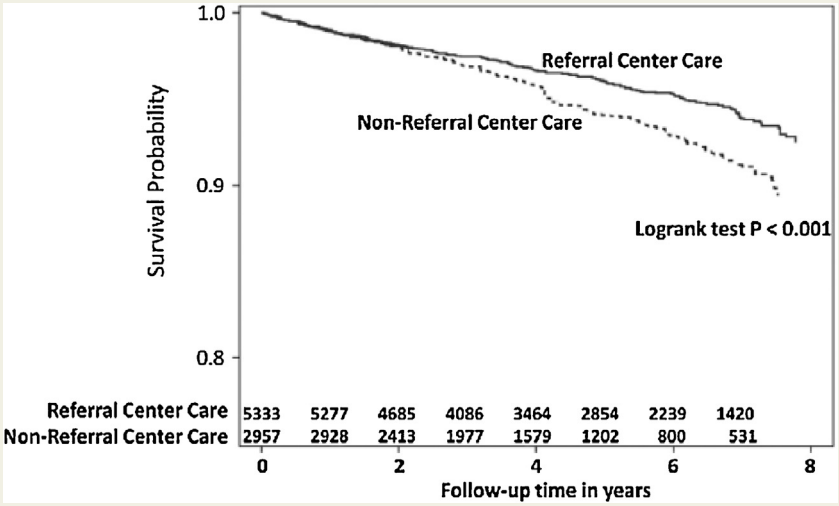

Figure 7 Cohort study: adjusted Kaplan-Meier survival curves. Adjusted Kaplan-Meier survival curves in patients with ACHD referral centre care (solid line) and those with nonreferral care (dashed line). ACHD indicates adult congenital heart disease [3].
Abbreviations: ACHD, adult congenital heart disease.
Reproduced with permission from Mylotte D, et al. Circulation. 2014 May 6;129(18):1804-1812–Figure 4.

are required to avoid excess mortality and morbidity and achieve a safe and sustainable standard of care for those with ACHD. The implementation of these recommendations will require commitment from State and Federal Governments in Australia and the Government of New Zealand.

In the first instance, additional information is needed so that present and future resource needs can be better understood. Patient numbers will increase in a predictable way over the coming years, and careful planning needs to be undertaken to anticipate and meet the resulting increase in demand for services.

Ensure Adequate Funding for Specialised ACHD Centres Across Australia and New Zealand

The development of a network of Comprehensive and Regional Adult Congenital Heart Centres across the region is a priority. We strongly support a ''hub and spoke'' model of care in ACHD with the moderate to severe spectrum of disease being seen at the Comprehensive Adult Congenital Heart Centres (CACH centres), and the milder spectrum of CHD seen at the Regional Adult Congenital Heart Centres (RACH centres), in a shared care collaborative model. This model of care is based on the CSANZ Recommendation for Standard of Care in ACHD [1], and on the recently published NHS review of ACHD services in the United Kingdom [4]. The NHS review has served as a model to the future development of the ACHD services in New Zealand and South Australia, and similarly should be used for future planning of funding and resources required in ACHD services throughout the region.

The ACHD centres need to be recognised and supported by targeted funding, to avoid a situation where there is competition for resources with other areas of adult cardiology.

Establish Training Pathways and Training Positions for ACHD Cardiology

There is a pressing need to increase the number of subspecialists in this emerging field. The requirements for ACHD training in our region are not defined under the Royal Australasian College of Physicians (RACP) cardiology or Royal Australasian College of Surgeons (RACS) cardiac surgery training programs. In the United States, ACHD training is endorsed and certified by the American Board of Internal Medicine. Completion of a 2-year ACHD Fellowship in an accredited centre is mandatory.

We recommend that the RACP includes an ACHD training pathway in their subspecialty cardiology training that follows on from training in adult or paediatric cardiology. For those who have completed training in paediatric cardiology additional experience as an adult cardiology trainee should be considered.

There is a need for funded Fellowship posts. There is currently one funded training position in Auckland and one in Brisbane. Adult CHD Fellowships will need to be made available at the major ACHD centres throughout the region. The availability of these positions needs to be considered in light of the predicted requirement for ACHD cardiologists.

Specialty training pathways for ACHD Nurses should also be considered as part of adequate service provision.

Development of a Bi-National ACHD Database

A crucial step in the promotion of comprehensive and integrated care for this population is to improve data integration [18].

A bi-national congenital heart disease database would enhance transition of care from the paediatric cardiology to the ACHD centre and assist with the major issues around loss to follow-up. In addition, it would provide accurate information in relation to the burden of disease and current resource requirements—information that could then be used to estimate future growth.

Currently, efforts are underway to establish a Congenital Heart Disease database through Australia and New Zealand. Seed funding has been provided by HeartKids Australia. Governmental funding is required to maintain a database that will provide effective monitoring and audit over the long-term.

Establish an ACHD Network Across Australia and New Zealand

There is a major benefit to be gained from the formation of an Australia and New Zealand ACHD Network, similar to those in existence in Canada, USA, Netherlands, UK and Japan. This network would assist in the development of clinical practice guidelines and of criteria for benchmarking. It would also assist in progressing regional ACHD research objectives and enhance collaborative opportunities, building on established links with regional networks (for example via the Asia Pacific Society for Adult Congenital Heart Disease) and the International Society for Adult Congenital Heart Disease.

Conclusions

The goal of this Statement is to highlight the need for action to improve survival and quality of life for ACHD patients in Australia and New Zealand by ensuring appropriate access to specialised cardiac care in a safe and sustainable way.

It is essential that the need for expert health care is understood, as are the consequences when that standard of care is not available.

We recognise this is a population in evolution and that the size of the problem (and of the solution) requires clarification. An adequately funded review is needed to clarify current and future resource requirements.

The current efforts by HeartKids and childhood heart disease community in partnership with the Paediatric and Congenital Council of CSANZ to deliver Australia's first National Action Plan for Childhood Heart Disease, are certainly a step in the right direction. This Plan will be developed with Federal Government funding and sponsorship and is due to be completed by March 2019. It will then be presented by the Department of Health to the Council of Australian Government (COAG Council) Health Council in mid-2019.

The recent pledge in early 2017 by the Hon Minister of Health to allocate significant funding from the Australian Government's Medical Research Future Fund under the 'HeartKids Conquering Childhood Heart Disease Research Mission' is a significant developement which will pave the way for improved collaboration, research and hopefully, improved outcomes..

Conflicts of Interest

None.

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