

AUSTRALIAN ACHD CENTRES OVERVIEW

Dr Mugur Nicolae MD FRACP FRCPC FCSANZ

Adult Congenital Heart Disease Cardiologist

The Prince Charles Hospital and Mater Adults Hospital

Brisbane

ACHD Symposium 2017 – Queenstown, NZ

INTRODUCTION

- ▶ It was initially suggested that an ACHD centre should serve 5-10 million people (32nd Bethesda Conference Report)¹.
- ▶ This was later amended by the Montreal group led by Arianne Marelli, to a population of 3 million, in order to follow ~ 3,000-3,500 ACHD patients.

1. 32nd Bethesda Conference. JACC 2001; 37(5): 1187-1193
2. Am Heart J 2009;157:1-8

Type of Service or Personnel	Local Care	Regional ACHD Center
Pediatric ACHD cardiologist	Optional	One or several 24/7*
Adult medical ACHD cardiologist	Optional	One or several 24/7*
Mid-level practitioner	Optional	Two/several
Congenital heart surgeon	No	Two/several 24/7*
Cardiac anesthesia	No	Several 24/7*
Echocardiography** Includes TEE, intraoperative TEE (required for surgery)	Refer to regional ACHD center	Two/several 24/7*
Diagnostic catheterization**	Refer to regional ACHD center	Yes 24/7*
Noncoronary interventional catheterization**	Refer to regional ACHD center	Yes 24/7*
Electrophysiology**	Consult regional ACHD center unless unrelated to CHD	Yes 24/7*
Exercise testing	Standard	Echo, radionuclide, cardiopulmonary, metabolic
Transplant	Optional	Heart, lung, heart-lung desirable
Cardiac imaging/radiology services	Optional	CT scan, cardiac MRI with fast-pulse sequencing*, nuclear medicine
Cardiac pathology	Optional	Yes
Information technology	Optional <ul style="list-style-type: none"> • Interface with regional ACHD center • Data collection • Participation in patient-care and best-practice guidelines review 	<ul style="list-style-type: none"> • Data collection • Database support • Interface with local practitioners, including internet-based applications • Quality assessment review and protocols • Optional development of best practice guidelines • Adolescent transitional unit • High risk obstetrics • Genetics • Rehabilitation services • Social services • Vocational services • Financial counselors
Other		

* "24/7" denotes availability 24 hours/day, 7 days/week. **These modalities must be supervised/performed and interpreted by physicians with specific skills and knowledge in CHD, as outlined.

Table 1

Patient population, personnel and location of facilities

Institution	UCLA	Toronto	Cleveland	Massachusetts	Mayo	Royal Brompton
Year established	1978	1959	1980	1976	1987	1975
<i>Patients</i>						
Registered active patients	2500	7000	1700	3200	2000	5000
Patients with cyanosis	20%	5%	17%	9%	9%	5%
Repaired patients	55%	75%	67%	81%	52%	70%
Department(s)	Med and Ped	Medicine	Ped Cardiology	Med and Ped	Medicine	Cardiology
<i>Core Senior Personnel</i>						
Adult cardiologists	3	7	0	1	4	3
Pediatric cardiologists	1	3	4	2	0	2
Cardiovascular surgeons	2	4	2	2	4	3
Specialty nurses	1	1	3	none	1	none

SURVEY OF MAJOR ACHD CENTRES IN 2004

ACC-AHA 2008 RECOMMENDATIONS

The background is a blue gradient, transitioning from a lighter blue at the top to a darker blue at the bottom. On the right side, there are several white, parallel diagonal lines that create a sense of motion and depth, extending from the bottom left towards the top right.

Delivery of Care and Ensuring Access

Healthcare for ACHD patients should be coordinated by regional ACHD centers of excellence that would serve as a resource for the surrounding medical community, affected individuals, and their families.



Every academic adult cardiology/cardiac surgery center should have access to a regional ACHD center for consultation and referral.



Each pediatric cardiology program should identify the ACHD center to which the transfer of patients can be made.



All emergency care facilities should have an affiliation with a regional ACHD center.

Delivery of Care and Ensuring Access

PERSONNEL AND SERVICES RECOMMENDED FOR REGIONAL ACHD CENTERS

Type of Service

- Cardiologist specializing in ACHD
- Congenital cardiac surgeon
- Nurse/physician asst./nurse practitioner
- Cardiac anesthesiologist
- Echocardiography*
 - Includes TEE, intraoperative TEE
- Diagnostic catheterization*

Personnel/Resources

- One or several 24/7
- Two or several 24/7
- One or several
- Several 24/7
- Two or several 24/7

- Yes, 24/7

*These modalities must be supervised/performed and interpreted by physicians with expertise and training in CHD.

ACHD indicates adult congenital heart disease; 24/7, availability 24 hours per day, 7 days per week; TEE, transesophageal echocardiography

Warnes, et al. J Am Coll Cardiol 2008;52. Table 2. Published ahead of print November 7, 2008, at <http://content.onlinejacc.org/cgi/content/full/j.jacc.2008.10.001>

Delivery of Care and Ensuring Access

PERSONNEL AND SERVICES RECOMMENDED FOR REGIONAL ACHD CENTERS

Type of Service

- Noncoronary interventional catheterization
- Electrophysiology/pacing/AICD implantation*
- Exercise testing

Personnel/Resources

- Yes, 24/7
- One or several
- Echocardiography
- Radionuclide
- Cardiopulmonary
- Metabolic

*These modalities must be supervised/performed and interpreted by physicians with expertise and training in CHD. ACHD indicates adult congenital heart disease; 24/7, availability 24 hours per day, 7 days per week; TEE, transesophageal echocardiography; AICD, automatic implantable .

Warnes, et al. J Am Coll Cardiol 2008;52. Table 2. Published ahead of print November 7, 2008, at <http://content.onlinejacc.org/cgi/content/full/j.jacc.2008.10.001>

Delivery of Care and Ensuring Access

PERSONNEL AND SERVICES RECOMMENDED FOR REGIONAL ACHD CENTERS

Type of Service

- Cardiac imaging/radiology*

- Multidisciplinary teams

Personnel/Resources

- Cardiac MRI
- CT scanning
- Nuclear medicine

- High-risk obstetrics
- Pulmonary hypertension
- Heart failure/transplant
- Genetics

*These modalities must be supervised/performed and interpreted by physicians with expertise and training in CHD. ACHD indicates adult congenital heart disease; CT, computed tomography; MRI, magnetic resonance imaging.

Warnes, et al. J Am Coll Cardiol 2008;52. Table 2. Published ahead of print November 7, 2008, at <http://content.onlinejacc.org/cgi/content/full/j.jacc.2008.10.001>

Delivery of Care and Ensuring Access

PERSONNEL AND SERVICES RECOMMENDED FOR REGIONAL ACHD CENTERS

Type of Service

- Multidisciplinary teams

Personnel/Resources

- Neurology
- Nephrology
- Cardiac pathology
- Rehabilitation services
- Social services
- Vocational services
- Financial counselors

ACHD indicates adult congenital heart disease.

Warnes, et al. J Am Coll Cardiol 2008;52. Table 2. Published ahead of print November 7, 2008, at <http://content.onlinejacc.org/cgi/content/full/j.jacc.2008.10.001>

Delivery of Care and Ensuring Access

PERSONNEL AND SERVICES RECOMMENDED FOR REGIONAL ACHD CENTERS

Type of Service

- Information technology

Personnel/Resources

- Data collection
- Database support
- Quality assessment review/protocols

ACHD indicates adult congenital heart disease.

Warnes, et al. J Am Coll Cardiol 2008;52. Table 2. Published ahead of print November 7, 2008, at <http://content.onlinejacc.org/cgi/content/full/j.jacc.2008.10.001>

- ▶ Recommendations for organization of care for adults with congenital heart disease and for training in the subspecialty of ‘Grown-up Congenital Heart Disease’ in Europe: a position paper of the Working Group on Grown-up Congenital Heart Disease of the European Society of Cardiology

EUROPEAN HEART JOURNAL (2014) 35, 686–690

Table 1 Staff requirements of a specialist grown-up congenital heart centre

Adult/paediatric cardiologist with GUCH certification	At least 2
GUCH imaging specialist (echo, CMR, CT)	At least 2
Congenital invasive cardiologist	At least 2
CHD surgeon	At least 2
Anaesthesiologist with CHD experience and expertise	At least 2
Invasive electrophysiologist with GUCH experience	At least 1
Psychologist	At least 1
Social worker	At least 1
Cardiovascular pathologist	At least 1

Table 2 Equipment requirements of specialist grown-up congenital heart disease centres

ECG

Holter monitoring

Stress ECG

Ambulatory blood pressure monitoring

Event recorder

Cardiopulmonary exercise testing

Echocardiography (including transoesophageal echo, 3D echo)

CMR imaging

Cardiac computed tomography

Catheterization laboratory

Electrophysiology laboratory

Pacemaker/ICD implantation

Pacemaker/ICD after care equipment

Cardiac surgery operating room

Table 3 Training in subspecialty grown-up congenital heart disease: specific recommendations

Outpatients [majority with great or moderate complexity (see Supplementary material online, Table S2 and S3)]	≥ 400
Inpatients	≥ 200
Echocardiography in CHD	
TTE performed	≥ 250
TEE performed	≥ 50
CMR/CT in CHD	
Interpreted	≥ 50
Heart catheterization in CHD	
Interpreted	≥ 30
Catheter intervention in CHD	
Participated	≥ 20
Electrophysiology in CHD	
Participated	≥ 5

Review of Adult Congenital Heart Disease Services

Engagement on Proposed
Model of Care and Draft
Designation Standards

11 April – 10 May 2013



Circulation

JOURNAL OF THE AMERICAN HEART ASSOCIATION



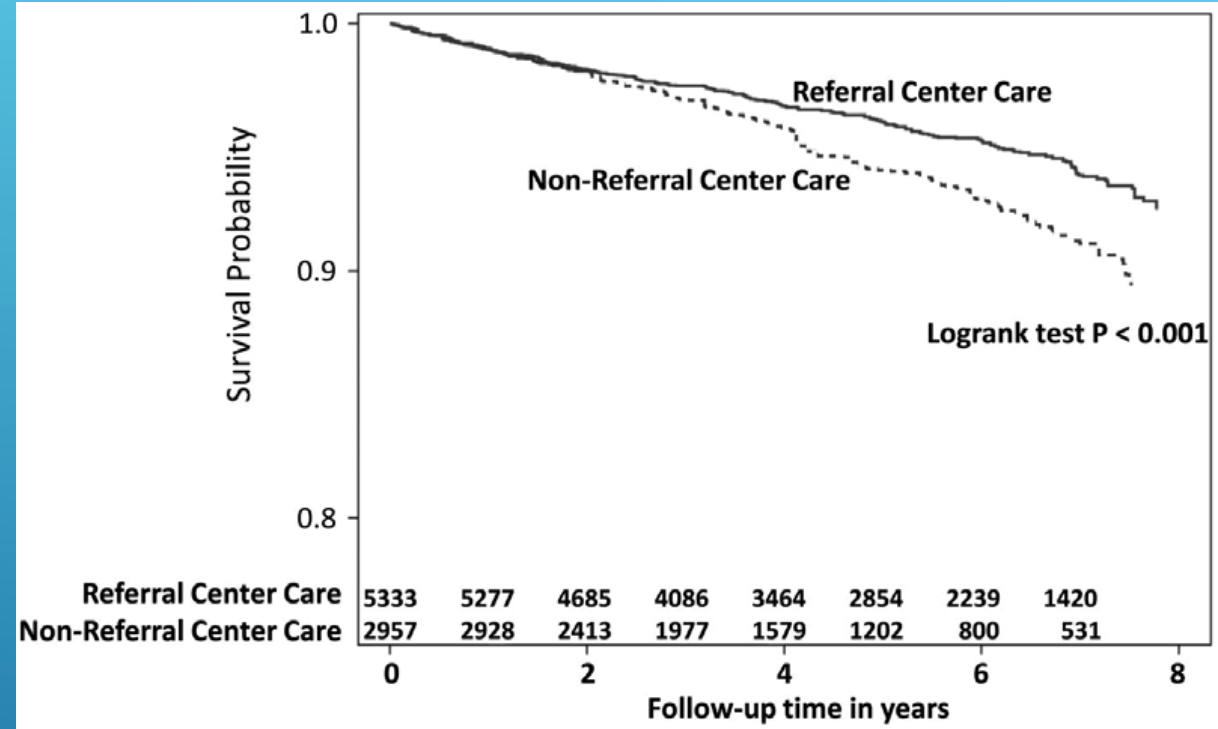
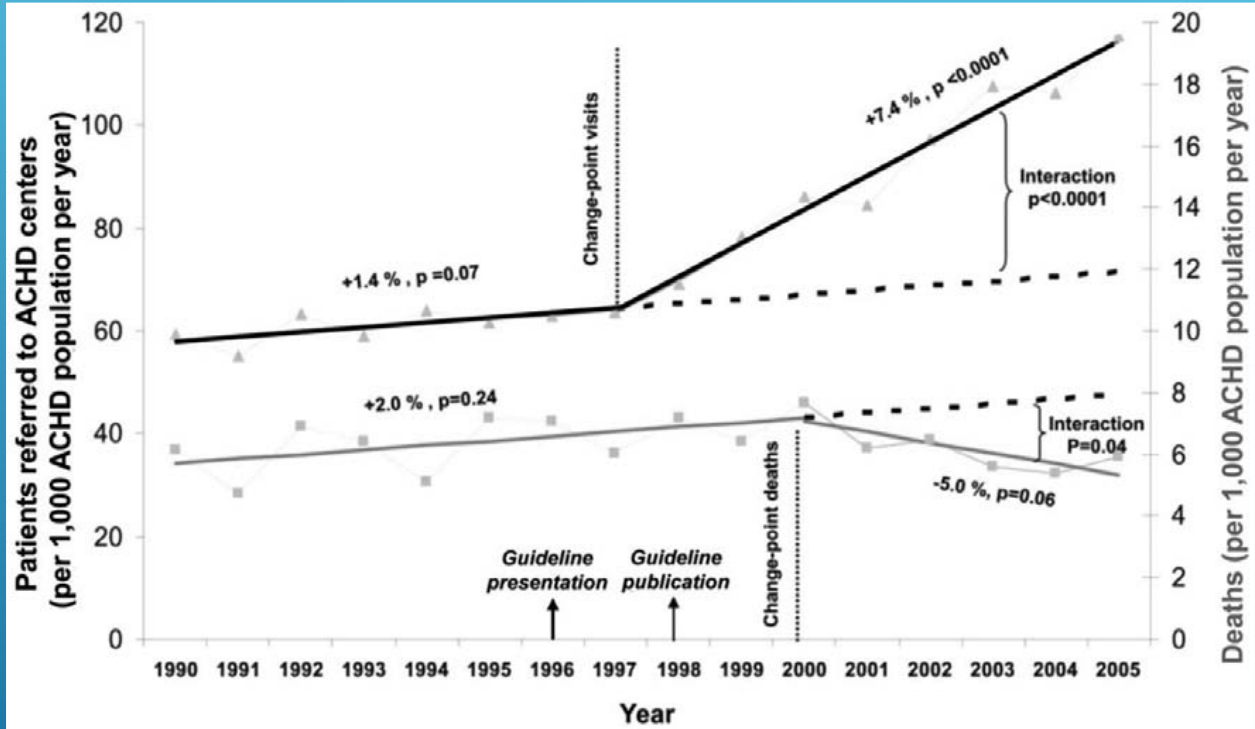
American
Heart
Association®

Specialized Adult Congenital Heart Disease Care: The Impact of Policy on Mortality
Darren Mylotte, Louise Pilote, Raluca Ionescu-Ittu, Michal Abrahamowicz, Paul Khairy, Judith
Therrien, Andrew S. Mackie and Ariane Marelli

Circulation. 2014;129:1804-1812; originally published online March 3, 2014;
doi: 10.1161/CIRCULATIONAHA.113.005817

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***Circulation*. 2014;129:1804-1812**





The Cardiac Society of Australia and New Zealand

Adult Congenital Heart Disease (ACHD) Recommendations for Standards of Care

Development of this Position Statement was co-ordinated by Prof David Celermajer, Drs Muger Nicolae, Tim Hornung, Clare O'Donnell and members of the Paediatric and Congenital Council; Drs Robert Justo, Andrew Bullock, Michael Cheung, A/Prof Andrew Cochrane, Drs Tom Gentles, James Ramsay, A/Prof Gary Sholler and Dr Gavin Wheaton. No authors have any relevant Conflict of Interest to disclose.

The position statement was reviewed by the Quality Standards Committee and ratified at the CSANZ Board meeting held on Friday, 11th March 2016.

Across Australia and New Zealand there should be:

- a) A Comprehensive Adult Congenital Heart (CACH) Service in those regions serving populations of ≥ 2 -3 million people. Where the population served is over 5 million people, consideration should be given to 2 CACH services; depending on local factors and geographies.
- b) A Regional Adult Congenital Heart (RACH) Service for regions which are at a substantial distance from a CACH service.
- c) If possible, CACH and RACH centres should develop an Information Brochure explaining their location, staff, contact details and purpose of follow up, for Paediatric Cardiac Units to distribute as part of easing the concerns of patients and families around the Transition process.

Comprehensive Adult Congenital Heart Centres (CACH) should have established links to the regional Paediatric Cardiac centres. They should hold regular Multidisciplinary Case Conferences, to optimise decision making. CACH centres should comprise:

- a) At least 2 ACHD specialists, who are adult FRACP cardiologists who have spent at least 12 months of training in dedicated paediatric or adult congenital cardiology units; or paediatric cardiologists with specific experience in ACHD (acknowledging that no formal accreditation system for ACHD specialisation currently exists).
- b) At least 2 ACHD surgeons, who are FRACS-qualified paediatric cardiac surgeons with specific experience in ACHD.
- c) Access to the following services:
 - i. Cardiac MRI and a cardiologist or radiologist experienced in ACHD.
 - ii. Electrophysiology services with at least one EP specialist with ACHD expertise.
 - iii. An interventionalist with experience in treatment of ACHD.
 - iv. An Intensive Care Unit with adequate capability for peri-procedural support.
 - v. A high risk/medical Obstetrics Unit that supports ACHD patients.
 - vi. A heart and heart/lung transplant program, in the same city.
- d) A Clinical Nurse Coordinator and a Nurse Educator.
- e) Access to Clinical Psychology, Genetic Counselling and Social Work support services.

Regional Adult Congenital Heart Services should have at least one ACHD cardiologist, as defined above; a Clinical Nurse Coordinator (at least part time); and established links to a CACH service.

Every young adult with repaired CHD should be seen at least once in an ACHD specialist centre, except those who have been discharged from follow up by their paediatric cardiologist.

Every young adult with unrepaired CHD should be seen regularly at an ACHD facility.

Every adult with non-simple CHD (where simple CHD is small or repaired ASD, VSD or PDA without residual haemodynamic abnormality; or mild pulmonary or aortic valve disease) should be seen regularly at an ACHD centre, with or without shared care by community-based specialists.

AUSTRALIAN ACHD CENTRES

- Australian population as of November 27th, 2017 was projected to be **24,753,504**
- Australian ACHD population estimated ~ **72,000** (**3,000 per million** population)
 - In 2010, **1,4 million** ACHD patients were living in USA – 300,000 with severe CHD; it represents a **63% increase** since the estimates in 2000; likely, > 200 ACHD centres would be required in USA currently ~ 114 centres)¹.
 - In 2013, **2,3 million** ACHD patients were estimated to live in Europe; this represents a **77% increase** since 2001².
- Australia should have ~ 8 CACH Centres (x 1 Unit for every 3,000,000)

1. Circulation. 2016;134:101–109

2. European Heart Journal (2014) 35, 673–679

Table 1
Global distribution of ACHD centers by country.

	n	Centers per 10 million population	Centers per 106 km ² area	% world population	
Europe	190	3.6	35.2	7.70%	
Austria	4	4.8	48.5	0.12%	
Belgium	6	5.5	198.2	0.16%	
Czech Republic	2	1.9	25.9	0.15%	
Denmark	4	7.2	94.3	0.08%	
Finland	3	5.6	9.9	0.08%	
France	21	3.2	38.3	0.95%	
Germany	39	4.8	111.9	1.19%	
Greece	4	3.5	31.0	0.17%	
Hungary	2	2.0	22.1	0.15%	
Iceland	1	31.5	10.0	0.00%	
Ireland	2	4.5	29.0	0.07%	
Italy	29	4.8	98.6	0.88%	
Malta	1	24.2	3125.0	0.01%	
Netherlands	10	6.0	296.5	0.24%	
Norway	5	10.0	16.4	0.07%	
Poland	8	2.1	26.3	0.56%	
Portugal	7	6.6	76.5	0.16%	
Romania	1	0.5	4.3	0.31%	●
Slovak Republic	1	1.8	20.8	0.08%	
Slovenia	2	9.7	99.3	0.03%	
Spain	8	1.7	16.0	0.67%	
Sweden	5	5.3	12.2	0.14%	
Switzerland	5	6.4	125.0	0.11%	
United Kingdom	20	3.2	82.7	0.91%	
North America	106	1.7	4.9	8.99%	
Canada	12	3.5	1.3	0.50%	
USA	90	2.9	9.8	4.52%	
Guatemala	1	0.7	9.3	0.21%	●
Mexico	3	0.3	1.5	1.66%	●

Oceania	6	1.5	0.7	0.59%	
Australia	5	2.2	0.7	0.33%	
New Zealand	1	2.3	3.8	0.06%	
South America	14	0.4	0.8	5.73%	●
Argentina	1	0.2	0.4	0.59%	●
Brazil	9	0.5	1.1	2.85%	●
Chile	1	0.6	1.3	0.25%	●
Colombia	2	0.4	1.8	0.68%	●
Uruguay	1	3.0	5.7	0.05%	
Asia	129	0.3	2.7	61.72%	●
China	28	0.2	3.0	19.56%	●
Georgia	1	2.2	14.4	0.07%	
India	16	0.1	5.4	17.12%	●
Indonesia	1	0.0	0.6	3.51%	●
Iran	4	0.2	2.2	3.51%	●
Israel	7	9.2	323.5	0.11%	
Japan	43	3.4	118.0	1.86%	
Korea, Rep.	5	1.0	51.5	0.71%	
Lebanon	1	2.4	97.8	0.06%	
Malaysia	2	0.7	6.1	0.42%	●
Pakistan	2	0.1	2.6	2.54%	●
Philippines	1	0.1	3.4	1.36%	●
Russian Fed.	2	0.1	0.1	2.07%	●
Saudi Arabia	1	0.4	0.5	0.40%	●
Singapore	1	2.0	1428.6	0.07%	
Thailand	4	0.6	7.8	1.01%	●
Turkey	10	1.4	13.0	1.06%	
Africa	9	0.1	0.3	15.04%	●
Algeria	1	0.3	0.4	0.52%	●
Cameroon	1	0.5	2.1	0.29%	●
Egypt	1	0.1	1.0	1.19%	●
Ghana	1	0.4	4.4	0.36%	●
Kenya	1	0.2	1.8	0.59%	●
Nigeria	2	0.1	2.2	2.32%	●
Sudan	1	0.2	0.4	0.64%	●
Tunisia	1	0.9	6.4	0.15%	●

Countries without scientific output in the field are not listed. These countries, by definition, have zero ACHD centers per 10 million population. Russian Fed. without accounting separately for European and Asian part. ● – country with less than one center per 10 million population.

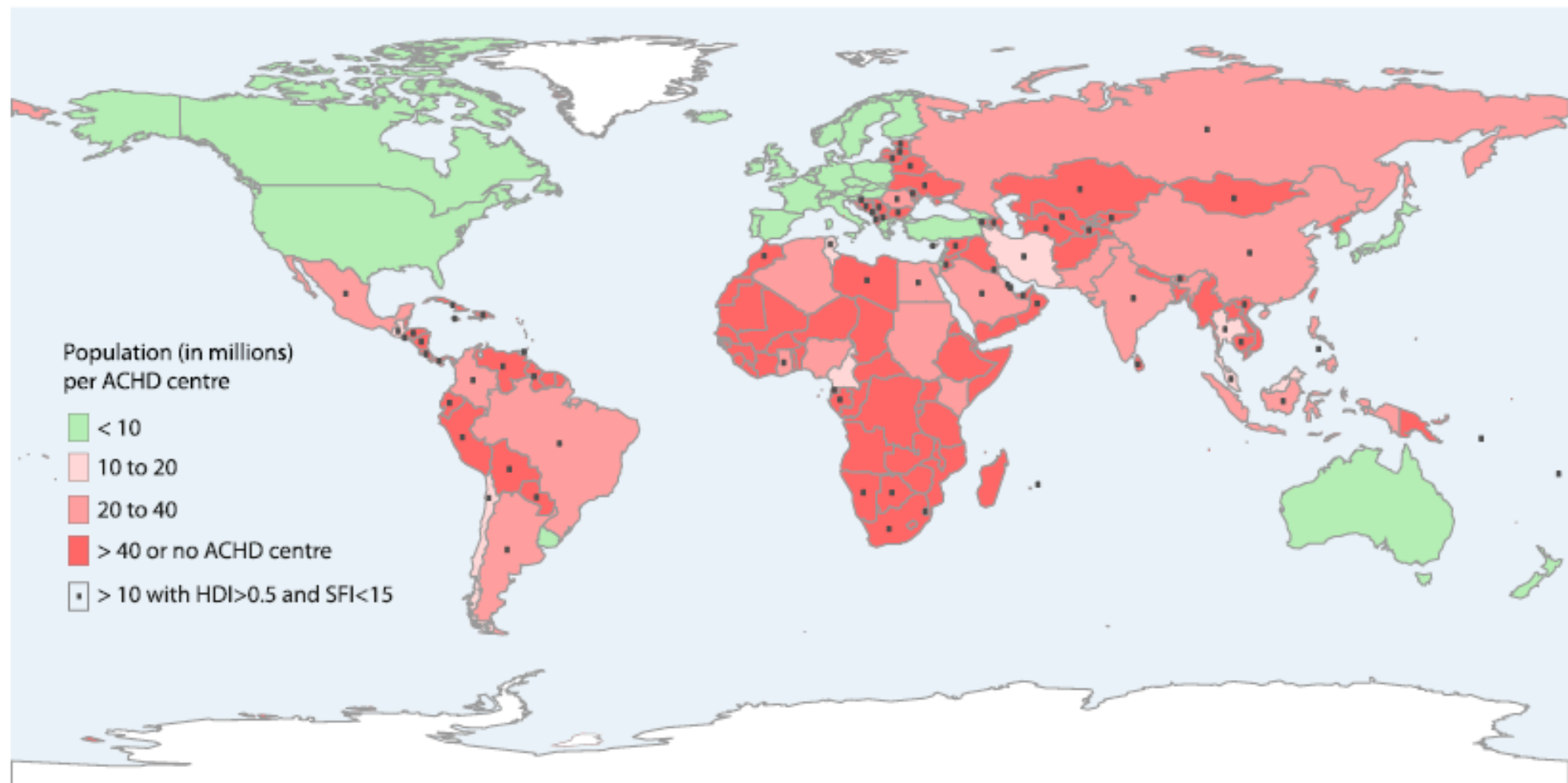


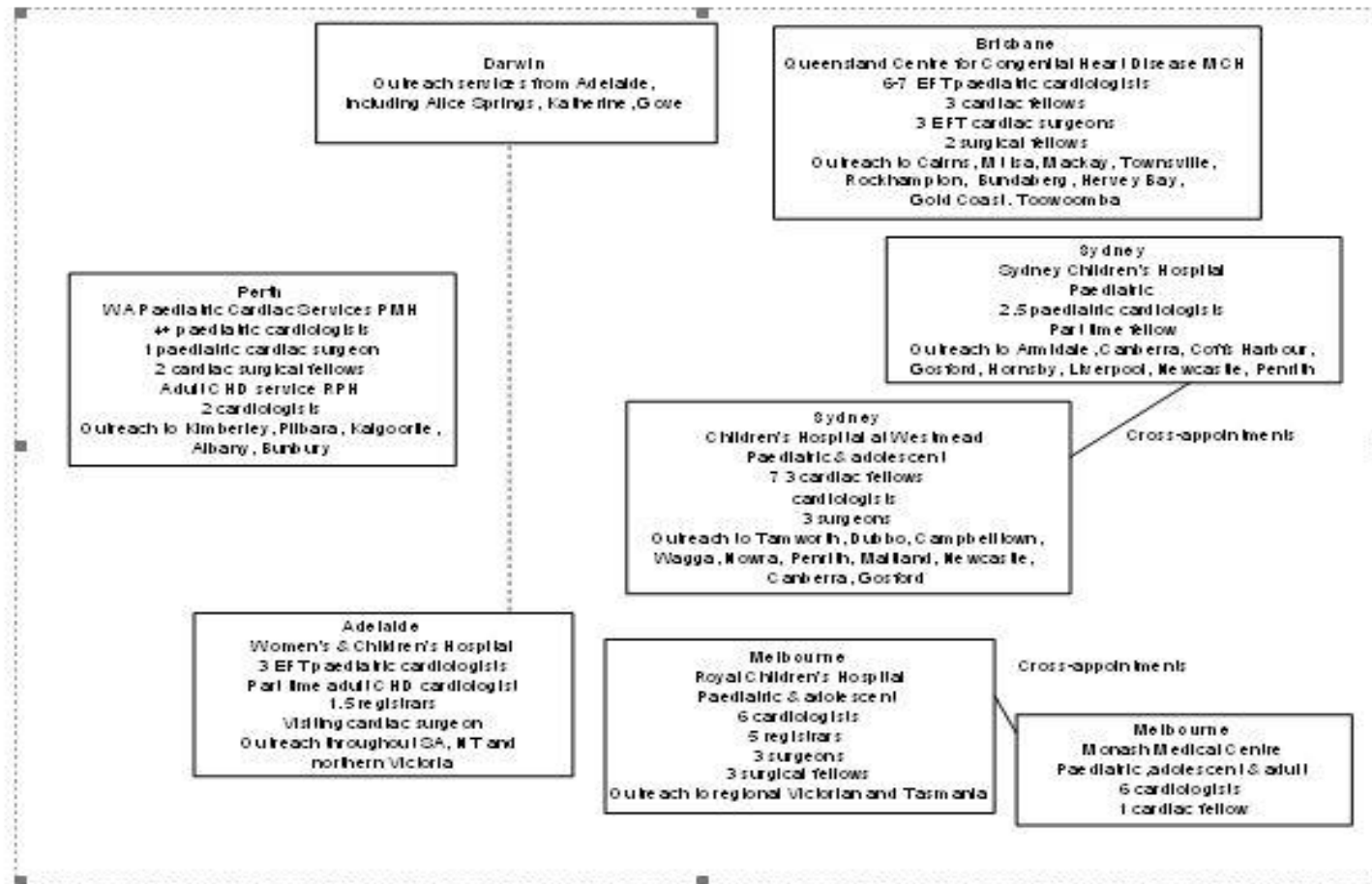
Fig. 1. Number of ACHD centers in relation to country population. The black dots indicate countries with a population above 10 million per ACHD center and a human development index (HDI) above 0.5 as well as a state fragility index (SFI) below 15 (based on 2008 data), which could be presumed to have sufficient resources to develop ACHD services.

AUSTRALIAN ACHD CENTRES

- There are currently 5 designated CACH Units across Australia:
 - Sydney RPA/Westmead – Dr David Celermajer, Dr Rachael Cordina, Dr David Tanous
 - Royal Melbourne Hospital – Dr Leanne Grigg, Dr Dominica Zentner, Dr William Wilson
 - Brisbane ACHD Unit (TPCH and Mater) – Dr Dorothy Radford, Dr Vish Wijesekera, Dr Mugur Nicolae, Dr Chris Whight
 - Outreach clinics to Townsville and Rockhampton: in 2018 – 8 weeks/52 weeks
 - Royal Adelaide Hospital – Dr Patrick Disney
 - Perth – Dr Andrew Bullock
- There are no CACH Centres in ACT, Northern Territories, Tasmania
- There is only x 1 RACH Centre: Newcastle (x 1 FTE ACHD Cardiologist)

AUSTRALIA CHD PAEDIATRIC SERVICES

Figure 1



- In 2010, there were ~ 30 paediatric cardiologists in Australia

1. Sandra Leggat. HeartKids Discussion Paper. Childhood Heart Disease in Australia: Past Practices and Future Needs

SNAPSHOT OF AUSTRALIAN ACHD UNITS AND RESOURCES NOV 2017

	Sydney RPA	Sydney Westmead	Melbourne	Adelaide	Perth	Brisbane	ACC- AHA/ESC/CSANZ
ACHD Cardiologist	0.9	0.3	1.0	0.3	0.5	2.0	> 2.0
ACHD Surgeons	0	0.5	0.2	0.1	0.1	0.5	> 2.0
ACHD Nurse Coordinator	1.0	0.1	0.6	0.1	0.3	1.0	> 1.0
ACHD Nurse Educator	0	0	0	0	0.3	0.2	> 1.0
ACHD Admin Staff	0.3	0	0.3	0	0.2	0.8	> 1.0
ACHD Social Worker	0	0	0	0	0	0.5	> 1.0
ACHD Psychologist	0	0	0	0	0	0	> 1.0
Number of Patients	5,500	500	3,500	1,000	1,050	3,000	
ACHD operations	50-60	50-60	50-60	10-15	20-30	50	

FTE equivalent

ACHD FELLOWSHIP OPPORTUNITIES IN ANZ

- Sydney Royal Prince Alfred Hospital – non-funded ACHD Fellowship
- Royal Melbourne Hospital – funded combined Echo/ACHD Fellowship
- The Prince Charles Hospital in Brisbane – funded ACHD Fellowship
- Starship Green Lane Hospital in Auckland – funded ACHD Fellowship

CONCLUSIONS

- The ACHD Centres in Australia are significantly understaffed and under-resourced, well below the current recommended national and international guidelines
- We need to identify and provide adequate resources for the RACH Centres
 - Townsville, Rockhampton, Cairns in Queensland
 - Newcastle, Wollongong, Port Macquarie, Dubbo, in New South Wales
 - Geelong, Bendigo, Ballarat in Victoria
 - Hobart in Tasmania
 - Port Augusta in South Australia

CONCLUSIONS

- There needs to be adequate planning for future needs in ACHD across Australia
 - The newly formed CHAANZ group will advise the Federal Government regarding organisation of care and funding
 - At the recent CHD round table, the Health Minister made an announcement about developing a National Action Plan for CHD – hopefully, this will include ACHD as well
 - The current development of a binational CHAANZ Registry and Database will help towards improved clinical care across borders and understanding of the number of patients with CHD
- We need to continue to train ACHD Fellows in the future and more funding is needed for the existing Fellowships

CONCLUSIONS

Adult Congenital Heart Disease in Australia and New Zealand

A Call for Optimal Care

Mugur Nicolae, Tom Gentles, Geoff Strange,

David Tanous, Patrick Disney, Andrew Bullock, Leeanne Grigg, Rajesh Nair

Sanjeevan Pasupati, Sam Menahem, Sylvia Chen,

Lynne Pressley, Rachael Cordina, Tim Hornung, Clare O'Donnell, David S Celermajer |

Soon to be submitted for publication