FOREWORD

HeartKids is proud to have commissioned this independent study into the clinical and community needs of children and adolescents suffering from congenital heart disease (CHD).

CHD is the biggest single cause of child mortality and early childhood hospitalisation. Beating it depends on high-quality analysis and advice based on a genuine understanding of the needs of patients and their families, the medical and social challenges they face, the role of clinicians and health care workers who provide their health care and the organisation of medical and social services in Australia.

HeartKids commissioned the Discussion Paper to raise awareness of the extent and issues associated with CHD, to highlight the unmet needs of patients and their families and to attempt to identify best practice and the most efficient and effective model of care for managing CHD in Australia. Professor Sandra Leggat’s study highlights the significant incidence and impact of CHD in our community. She is a distinguished leader in the fields of public health and health services reform and has provided a “fresh pair of eyes” on the challenges of living with and treating CHD.

Professor Leggat also identifies significant gaps and inconsistencies across Australia in present CHD-related services and programmes. Drawing on current best practice from Australia and abroad, she provides practical recommendations to improve the quality of care and to reduce the significant hardship and suffering associated with the disease.

HeartKids thanks Professor Leggat for her dedication and hard work in researching and compiling the report, and consulting so extensively in doing so.

Developing this paper would have been impossible without the full support and involvement of the Paediatric and Congenital Council of the Cardiac Society of Australia and New Zealand who have generously assisted Professor Leggat in the provision of clinical and health policy advice. As an advocacy and support charity HeartKids works closely with clinicians, medical institutions and researchers to pursue our common interests in best clinical practice for the diagnosis and treatment of CHD. We extend our warmest thanks to the Council and the Society.

We would also like to thank HeartKids Family Support Coordinators, and HeartKids families, who participated in interviews and workshops as part of preparing the Discussion Paper and shared their insights and experiences so freely.

HeartKids Australia hopes that Professor Leggat’s Discussion Paper leads to enhanced treatment and care for affected children and their families, and informs policy and funding decisions by Federal and State Governments, to develop over time world-leading clinical and social support for children, adolescents and adults with congenital heart disease. Our children affected by CHD deserve no less.
FOREWORD

The delivery of high quality healthcare in the Australasian environment has unique requirements in that care must be delivered to a small population spread over great distances. This requires effective and efficient coordination of government and medical resources. The Whitepaper represents a unique opportunity to review delivery of healthcare to children with acquired and congenital heart disease in Australasia and provide strategies and solutions to develop improved levels of care. This document has involved a major collaborative effort between clinicians, families of children with significant cardiac disease and the parent support group, HeartKids. The significant efforts of Professor Leggat in coordinating these groups and facilitating workshops and discussion must be recognised.

This comprehensive document describes the current state of healthcare delivery to children with acquired and congenital heart disease in Australasia. It should be acknowledged that the current health system does provide high quality health outcomes, recognising that there remain significant areas of deficit within service delivery and family support. Differences of service delivery between different regions are also highlighted. The family perspective, with descriptions of their journey through the healthcare system, highlights deficiencies and the stress that these families can be placed under. This provides valuable information and demonstrates the importance of planning improved healthcare delivery and support.

The recommendations contained in the report have been considered by all major Paediatric Cardiology units in Australasia and provide an excellent platform for further evaluating healthcare delivery models and planning future service development both at a local level and on a national basis. Because Paediatric Cardiology is a small highly specialised subspecialty major advantages could be expected from planning healthcare delivery on a national basis, allowing for the special needs of each state within this framework.

We would like to thank Heartkids for providing the impetus for the development of the Whitepaper and the valuable support it provides to children with congenital and acquired heart disease and their families.

Dr Rob Justo
Chairman
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of the Cardiac Society of Australia and New Zealand
EXECUTIVE SUMMARY

Childhood heart disease comprises congenital heart disease (CHD) and heart disease, such as arhythmia, myocarditis, cardiomyopathy, Kawasaki disease and rheumatic heart disease, acquired at a young age. Congenital heart disease is not a single disease but a general name for malformations of the heart, heart valves or major blood vessels which are present at birth. In Australia the prevalence of congenital heart disease for the general population has been recorded at around 7.8 cases per 1,000 births. Although there is no indication that the incidence of CHD is increasing, as Australian birth rates increase and enhanced medical care and technology continue to improve survival rates following medical interventions, the prevalence is predicted to increase. In particular, there are an increasing number of adults with congenital heart disease who are not well served by the existing health care system.

As enhanced medical interventions have significantly improved the survival rates for infants and children, there has been an increased focus on the quality of life of these individuals and their families. Recent studies have identified the neuro-developmental, psychosocial and behavioural outcomes that may have a negative impact on the schooling and activities of individuals with childhood heart disease. These quality of life outcomes have generally not been supported by access to treatment and support resources.

The other identified major gaps in service availability related to the transition from paediatric to adult care, the difficulties in ensuring up-to-date information was available among all of their service providers, and the lack of consistent support for travel and accommodation when care was required in a centre away from home. The families recounted how disruptive and expensive travel routines to access specialist care and the frequent surgical cancellations added to the difficulties they faced.

Recent health system reviews in Victoria, New South Wales and Queensland have highlighted that the current paediatric health system organisation may be contributing to suboptimal patient outcomes. These reports recommended paediatric health service planning and funding that is based on international best practice. In the first instance this would require the establishment of a comprehensive national patient registry, with dedicated data management, reporting and analysis resources to track diagnosis, treatment and outcomes to provide accurate information for health system planning. There is also a need to define the role and relationships of the services and programs throughout Australia to enhance the coordinated care network for children and adults with childhood heart disease, with the need for additional resources to match international standards. This could best be achieved by the development of a national paediatric and adult congenital heart disease clinical services plan with the involvement of specialist clinicians, through the Paediatric and Congenital Council of the Cardiac Society of Australia and New Zealand.

There was also concern expressed that the national and state governments did not have a workforce plan in place to ensure sufficient, trained staff would be available to meet the future needs for health care services for the growing population with congenital heart disease, particularly when the existing financial incentives encouraged cardiac specialists to work in adult programs.

A series of recommendations is proposed to consider how best to support the congenital heart specialist clinicians in realising a world class health service system for children, adolescents and adults with congenital heart disease. A closely related series of recommendations are directed to Australian and State Governments to support the improvement of clinical and support services. In addition recommendations are made for HeartKids to enhance the support provided to heart kids and their families, with a focus on expansion of support services into the community including regional areas, dissemination of essential information and raising the general awareness of the issues and needs of heart kids and their families.
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1.0 INTRODUCTION TO THE REPORT

HeartKids is an Australian charity that focuses on children’s heart disease, with operations in New South Wales, Queensland, South Australia, Victoria and Western Australia and the state operations also extend to a variable degree to Tasmania, Northern Territory and the ACT. HeartKids aims to reduce the incidence and decrease the mortality rates of childhood heart disease, and to support families who have a child with heart disease. This Report was initially commissioned by HeartKids to:

- Raise general awareness of the extent of and issues associated with childhood heart disease
- Highlight what the needs are, both from a clinical and family/community perspective
- Identify best practice and the most efficient and effective model of care for children, adolescents and adults with childhood heart disease
- Make a series of informed recommendations to refine the various systems that will ensure Australia develops a uniform standard of world’s best practice in the total care and management of children and families affected by congenital heart disease.

The Paediatric and Congenital Council of the Cardiac Society of Australia and New Zealand promotes the highest standards of education, training, research and practice in paediatric and congenital cardiovascular medicine and surgery. Representatives of the PCC were active participants in the development of this report, as it is seen that their role is to promote and defend equitable access of all Australians and New Zealanders to high quality cardiovascular healthcare.

The Report was completed with a review of the relevant literature, data analysis, and interviews of clinicians, family support coordinators and families touched by childhood heart disease, and specifically congenital heart disease. The interview participants were generally enthusiastic about HeartKids’ role in commissioning this paper, while recognising the challenge for the writer in developing recommendations that were relevant for all of Australia.

I would like to thank all of those involved who provided their time, their expertise and their stories to assist in the development of this Discussion Paper. To ensure confidentiality the interview participants have not been identified, but some direct quotes from the interviews and family stories have been provided throughout.
2.0 CONGENITAL HEART DISEASE IN AUSTRALIA

Childhood heart disease comprises congenital heart disease (CHD) and heart disease, such as arrhythmia, myocarditis, cardiomyopathy, Kawasaki disease and rheumatic heart disease, acquired at a young age. Congenital heart disease is not a single disease but a general name for any type of malformation of the heart, heart valves or major (great) blood vessels which are present at birth. Defects can range from simple to complex and can occur alone or in groups, depending on how the heart has developed. The disorders include:

**Congenital Heart Defects**

**Less complex**
- Patent Ductus Arteriosus
- Coarctation of Aorta
- Atrial Septal Defect
- Ventricular Septal Defect
- Aortic Valve Disease
- Pulmonary Valve Disease

**Complex**
- Atrioventricular Septal Defect
- Tetralogy of Fallot
- Transposition of Great Vessels
- Pulmonary Atresia
- Single Ventricle Pathology

**Disorders of Rhythm**
- Supraventricular Tachycardias
- Ventricular Tachycardias
- Long QT Syndrome
- Complete Heart Block

**Acquired Heart Disease**
- Rheumatic Heart disease
- Kawasaki Disease
- Dilated Cardiomyopathy
- Coronary Artery Disease

It has been suggested that most congenital heart disease is the result of multiple gene defects and/or an interaction between single or multiple defective genes and the fetal environment. Over time we have seen increases in the number of congenital heart defects that have been shown to have defined genetic markers (1).

A 2007 paper from the American Heart Association summarised the evidence on the causes and potential areas for prevention of CHD (2). Multivitamins and folic acid were seen as an area of promise (3-4). Canadian researchers found no change in the levels of CHD in the eight years before fortification of grain products was introduced in Canada and a 6.2% decrease per year in the birth prevalence of CHD following fortification, providing support for folic acid intake in the period around conception (5). While it must be stressed that the evidence is not unequivocal as yet and further study is required, the United States Centers for Disease Control and Prevention states "CDC urges women to take 400 mcg of folic acid every day, starting at least one month before getting pregnant, to help prevent major birth defects of the baby's brain and spine." (6)

Other areas addressed included diet control before conception and during pregnancy for the genetic disorder phenylketonuria and strict glycemic control for diabetes (2). The paper also identified the higher risk experienced by mothers reporting febrile illnesses during the first trimester or with contact with organic solvents (2). The American Heart Association recommended that mothers who wish to become pregnant should:
Take a multivitamin with folic acid daily
Obtain preconception and prenatal care with specific attention to detection and effective management of phenylketonuria and diabetes and vaccination for rubella
Discuss any medication use with their doctor, even over-the-counter medications
Avoid contact with people with flu or other febrile illnesses
Avoid exposure to organic solvents (2 p. 3008).

2.1 International incidence and prevalence of congenital heart disease
Although congenital heart disease has not received as much attention as other childhood conditions, such as cancer and asthma, congenital heart disease has significant incidence and prevalence, measures that are used to track and understand diseases and medical conditions. Incidence provides a measure of the increase in the number of identified cases, while prevalence is defined as the proportion of individuals in a population who have a disease at a specific point in time. Throughout the world the reported prevalence of congenital heart disease varies between 4 and 10 per 1,000 live births (7-11). The larger prevalence figures account for all cases, many of which may be mild and not require active medical intervention. For severe CHD, in 1980 the New England Infant Cardiac Registry reported a prevalence of 1.5 per 1,000 (11). The following section summarises the results of prevalence studies from other relevant jurisdictions.

2.1.1 United States
Each year approximately 35,000 babies are born with CHD in the United States (USA) and over 10,000 of these have CHD severe enough to require surgery before they are one year of age. A recent study looking at waiting lists for heart transplant in the USA found that children awaiting heart transplantation had the single highest waiting list mortality as compared with all other age groups and all other solid organ transplants (12). This study also found that non-white race and the presence of mechanical ventilation were important independent risk factors for mortality while on the waiting list. The authors suggested that medical urgency was not well captured in the existing ranking system and children with very different short term risks are competing for the same scarce donor organs. This highlighted the issue of length of time on the list versus medical urgency. The authors suggested that a system that better captures medical urgency may reduce the high levels of waiting list mortality (12).

There has also been some study of the number of missed diagnoses of congenital heart disease. A California study of 898 infants who died of critical CHD estimated that every year there was an average of 10 patients with a missed diagnosis of CHD and 20 patients with a late diagnosis. The authors suggested that because the median age at death was younger than two weeks there was a need for careful cardiovascular evaluation during the first post-discharge visit at 3 to 5 days of age (13).

There has also been a notable growth in adults with congenital heart disease. The Mayo Clinic estimates that about one in every 120 babies is born with some form of heart defect and because most of these babies grow to adulthood, there are now about one million adults in the United States with congenital heart disease (14).

2.1.2 Canada
A Canadian study reported that in 2000 the prevalence of CHD was 11.89 per 1,000 children, 4.09 per 1,000 adults, and 5.78 per 1,000 in the general population in the province of Quebec in Canada. The prevalence of severe CHD was 1.45 per 1,000 children and 0.38 per 1,000 adults, accounting for 12% and 9% of all CHD lesions in children and adults, respectively. In children and adults, conotruncal anomalies and AVSD were the most prevalent lesions among those with severe lesions, whereas ASD, VSD, and patent ductus arteriosus (PDA) were the most common lesions among those with other CHD. Females accounted for 52% and 57% of the CHD population in children and adults and the proportion of females in the CHD population was significantly higher than that of the Quebec population (15).
This study also reported that the prevalence of all CHD increased from 1985 to 2000 in both adults and children. However, the prevalence of severe CHD in adults increased by 85% (prevalence ratio for year 2000 versus year 1985, 1.85; 95% CI, 1.72 to 2.00) from 0.21 to 0.38 per 1,000 adults, whereas the prevalence of severe disease in children increased by only 22% (prevalence ratio for year 2000 versus year 1985, 1.22; 95% CI, 1.15 to 1.30) from 1.19 to 1.45 per 1,000 children over the same time period. The highest increase in prevalence occurred among adolescents 13 to 17 years of age, followed by adults in the age group of 18 to 40 years. The median age of those with severe disease increased (15).

The economic cost in the late 1990s associated with CHD in Canada was estimated to exceed $216 million per year, and account for almost half of the economic burden of all birth defects (16).

### 2.1.3 Europe

In Europe the average reported prevalence of CHD is 8.0 per 1,000 births, including live births, still births and termination of pregnancy for fetal abnormality (TOPFA). In comparison to the Canadian prevalence, the European data reported fetal and perinatal mortality of 0.7 per 1,000 births, suggesting a comparative prevalence of 6.3 per 1,000 live births (17).

### 2.2 Congenital heart disease in Australia

#### 2.2.1 Mortality from CHD

The Australian Institute of Health and Welfare (AIHW) collects data on conditions of interest to the health and wellbeing of Australians. The AIHW data suggest that congenital heart defects are one of the biggest killers of infants less than one year old and account for approximately 20% of perinatal deaths, more than 5,000 years of life lost and 2,500 years of life associated with disability (18). In 2002 congenital heart diseases accounted for 224 deaths (0.17% of all deaths) in Australia. Perinatal deaths comprise stillbirths (fetal deaths) and deaths of infants within the first 28 days of life (neonatal deaths). In 2002, there were 72 perinatal deaths, of which 29 were fetal deaths and 43 were neonatal deaths. The mortality rates for CHD in Australia in 2002 are presented in Table 1.

The doctor said, “Your baby has a serious heart defect. It is best if you consider terminating your pregnancy”.

Parent interview

<table>
<thead>
<tr>
<th>Age Group (years)</th>
<th>Males</th>
<th>Females</th>
<th>Persons</th>
</tr>
</thead>
<tbody>
<tr>
<td>0–4</td>
<td>8.1</td>
<td>6.8</td>
<td>7.5</td>
</tr>
<tr>
<td>5–14</td>
<td>0.5</td>
<td>0.4</td>
<td>0.4</td>
</tr>
<tr>
<td>15–24</td>
<td>0.8</td>
<td>0.4</td>
<td>0.6</td>
</tr>
<tr>
<td>25–34</td>
<td>0.9</td>
<td>0.8</td>
<td>0.9</td>
</tr>
<tr>
<td>35–54</td>
<td>0.7</td>
<td>0.5</td>
<td>0.6</td>
</tr>
<tr>
<td>55–74</td>
<td>0.8</td>
<td>0.7</td>
<td>0.8</td>
</tr>
<tr>
<td>75 and over</td>
<td>1.5</td>
<td>1.4</td>
<td>1.5</td>
</tr>
<tr>
<td>Total</td>
<td>1.3</td>
<td>1.0</td>
<td>1.2</td>
</tr>
</tbody>
</table>

Table 1 Congenital Heart Disease Deaths in Australia 2002 (deaths per 100,000 population)

Source: AIHW National Mortality Database
Improvements in treatments and the early diagnosis of complex congenital heart diseases in pregnancy resulting in some terminations, as well as earlier interventions have been credited with reducing the death rate for CHD. While it is not possible to obtain Australian data on the terminations, the data on mortality shows significantly improved survival rates. For example, surgical repair of common conditions, such as tetralogy of Fallot, has a mortality rate of less than 3% (19). Between 1991 and 2002, death rates from congenital heart diseases in Australia declined at 4.8% per year for males and 4.9% per year for females. This produced a total decline of 27.6% for males and 32.2% for females over the 12-year period.

Among children under five years, declines in death rates were steeper; 50.1% for males and 40.4% for females. The proportion of deaths from congenital heart diseases occurring in young children has declined markedly over the last two decades. In 1983 deaths were most common in children aged less than five years, accounting for 73.7% of deaths. By 2002, only 42.4% of deaths from congenital heart diseases occurred in this age group (20). It has been suggested that modern diagnostic and treatment procedures enable around 90% of CHD patients to reach adulthood and enjoy good quality of life (21). Although many would argue that from a patient and family perspective, quality of life is diminished as a result of the constant stress associated with the knowledge of a cardiac condition. Fewer deaths as a result of treatment improvements and increase in the number of terminations of pregnancies after antenatal diagnosis have likely contributed to the decrease in mortality rates. However life expectancy continues to be below normal (22), as is quality of life (23).

Mortality rates for CHD do not appear to be related to socioeconomic status or location (other than the significantly higher rates in remote Australian communities linked to the higher rates in the Aboriginal population discussed below). In 2001/02 death rates for congenital heart diseases varied between the states, from 17.3% above the national average to 17.4% below the national average. Death rates were highest among residents in New South Wales and lowest among the residents in Western Australia. The number of deaths in Tasmania and the territories was too small to draw any reliable conclusions.

Table 2  Selected CHD Incidence in 2003 and Deaths in 2005

<table>
<thead>
<tr>
<th>Incidence new cases 2003</th>
<th>Deaths 2005</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transposition of great vessels</td>
<td>103</td>
</tr>
<tr>
<td>Tetralogy of Fallot</td>
<td>82</td>
</tr>
<tr>
<td>Hypoplastic left heart syndrome</td>
<td>37</td>
</tr>
</tbody>
</table>


The Australia and New Zealand Paediatric Intensive Care Registry provides an annual report on paediatric intensive care. In 2006 the median length of stay for patients with cardiovascular conditions was 1.8 days, comprising 24% of the occupied bed days (OBD). Only respiratory conditions accounted for a larger proportion of the OBD at 31% (24). In 2000 the Registry completed a thorough analysis of deaths associated with cardiovascular surgery. The authors recognised that the paediatric intensive care unit (PICU) data may under report deaths, as some children may not be admitted to the PICU and some children may die after discharge from the PICU. With these caveats, the analysis suggested that the mortality rates for children admitted to the PICU following cardiovascular surgery compared very favourably with previously published mortality rates (25).

2.2.2 Prevalence

In 1997 there were 1,380 births diagnosed with congenital heart diseases in Australia, a rate of 54 per 10,000 live births. AIHW data show that the rates of diagnosed congenital heart defects have remained stable between 1998 and 2003. From 1999 to 2002 Chew and colleagues found a prevalence of CHD in Victoria of 7.8 per 1,000 births (26), which is consistent with previous and
international reports (8, 27), and given that this is the most recent validated Australian study it is reasonable to accept a birth prevalence of 8 cases of congenital heart disease per 1,000 births. It would also be expected that Australia would see similar increases to the proportion of adults with CHD as found in the Quebec study and if the prevalence were measured as a rate per 1,000 children it would likely be similar to the 11 cases found in Quebec.

Consistent with the findings from other jurisdictions that 5 to 30% of infants with CHD may be discharged from their birth hospitals undiagnosed (28), there may be some level of missed or late diagnosis in Australia. However there has been a recommendation made that routine pulse oximetry would be a cost-effective way to screen for CHD before discharge from the hospital (28-29). A systematic review also indicated that pulse oximetry was effective in detecting congenital heart disease in asymptomatic babies, with low false positive rates. It was suggested that large, well-conducted prospective studies were needed to assess its sensitivity with higher precision (30). The implementation of routine pulse oximetry would require a major increase in access to echocardiography technology and professional staff to follow up on positive babies that would have substantial resource implications for the Australian system.

It is expected that Australia will experience increasing prevalence of CHD. While there has been no recorded increase in incidence, the growing number of births and the increasing survival rates, will mean that the number of cases in the population will be continuing to increase. Although Australia witnessed a substantial decrease in the total fertility rate (TFR) from 3.5 in 1961 to the current level of 1.8, in recent years the fertility rate has been climbing. Total fertility rate is defined as the average number of babies that a woman could expect to give birth to in her lifetime if she experienced current age specific fertility rates. The recent increases in the total fertility rate have been largely due to births to women in the 30 to 39 years age group, while the fertility of women aged 20 to 29 years has continued to decline. For example, the median age of all Victorian mothers giving birth was 31.3 years in 2004, compared to a median age of 29 years in 1994 (31). This relative increase in conception rates for older women and decrease in rates for women in their twenties have been observed in many developed countries (32).

Analysis by the Australian Bureau of Statistics, applying the age-specific fertility rates for 2003 to the 2004 female population, found that the 1.2% increase in Australian births from 251,200 in 2003 to 254,200 in 2004 was solely a result of the changes in fertility rates (and not just the population growth) (33). Research suggests that the delay of childbearing is associated with increases in the numbers of low birth weight babies and greater numbers of preterm deliveries (34). Among the group of 14,000 18-23 year olds who form the young cohort of women in the Australasian Longitudinal Study on Women's Health, 92 per cent indicated that they would like to have children by the time they are 35 years old. Sixty five per cent wanted one or two children and 27 per cent wanted more than two. If these women are representative of the total population and if these figures were attained there would be an increase in the total fertility rate.

The increasing age of women having babies is significant, as an association was found in some studies of advanced maternal age (greater than 30 years and 35 to 40 years) and some congenital heart defects (35-36).

This would suggest that while the 2006 prevalence rate for CHD in Australia was around 8 per 1,000 births, with the increasing birth rate and improvements in life expectancy, there is an expectation that number of individuals with childhood and congenital heart disease in the population would be increasing. Applying prevalence data from the Netherlands national CHD registry to the Australian population, it is estimated that there would be around 32,000 children under 18 years of age with CHD in Australia (37).

2.2.3 Hospital utilisation
It is reported that up to 50% of children with CHD require surgery to correct the defect (38), and a
third of these need surgical or catheter-based intervention in the first year of life (22). If these children do not receive the required interventions in time, 70 to 80% of children with CHD would die in early childhood (21). In 2001/02, there were 4,960 hospitalisations of children and adults in Australia where congenital heart diseases were the principal diagnosis (0.08% of all hospitalisations). Of the hospitalisations for congenital malformations, congenital heart diseases accounted for 14.6% (20). Between 1993/94 and 2001/02, there was a 19.2% increase in the age-standardised hospitalisation rate for congenital heart diseases. The increase in congenital heart disease hospitalisations may be influenced by the changes in diagnostic technology over this period, such as fetal diagnosis. In 2001/02, male and female hospitalisation rates for congenital heart diseases were similar. Children aged less than 10 years accounted for 59.7% of hospitalisations. Only 15.3% of hospitalisations were in people aged 45 years or more.

In 2001/02 there were 889 procedures for closure of an atrial septal defect, 466 for closure of patent ductus arteriosus and 387 for closure of ventricular septal defect. These include both surgical and catheter-based procedures. Where procedures were performed for patent ductus arteriosus and ventricular septal defect, most were done on children aged less than 10 years (90.6% and 85.8% respectively). Procedures for atrial septal defect were spread more evenly over all ages, with only 42.5% of procedures in those aged less than 10 years (20).

In recent years the focus of the health care system has been on cardiovascular disease among adults. The health care system has been concerned with addressing the increasing burden of disease from cardiovascular disease through health promotion, prevention and revascularisation and surgical repair. This emphasis on the health care needs of the ageing population in Australia appears to have decreased the focused planning for the needs of individuals with congenital heart disease and their families.

2.3 Incidence and prevalence of congenital heart disease among the Aboriginal and Torres Strait Islander population

In a study completed in the 1980s, the researchers calculated the prevalence of CHD from a sample of 3,562 children who had been seen, for one or more reasons, by an outreach health service over a 4 and a half year timeframe. At this time prevalence (cases/1,000) of congenital heart disease among this population was 20 for Aboriginal children and 44 for Torres Strait Islander children. Extrapolation to the census population resulted in an estimated population prevalence of 12 per 1,000 for both Aboriginal and Torres Strait Islanders (39). AIHW data indicated that in 2000 to 2002 the death rates from congenital heart diseases among Indigenous Australians were 2.6 times those of other Australians. The incidence of CHD in Central Australia of 17.5 per 1,000 was found to be significantly higher than in other parts of Australia (40), with the majority of this difference attributable to indigenous people. It is suggested that this higher incidence may be related to the observation of more minor conditions that may not have been reported in other population studies.

In addition to the reported higher incidence and prevalence of congenital heart disease among Aboriginal and Torres Strait Islander populations, the higher levels of rheumatic fever are related to higher levels of acquired heart disease among children in general among these populations. It is clear that much needs to be done to diagnose and treat rheumatic fever, and to provide screening, timely treatment and support for infants and children with congenital heart disease within Aboriginal and Torres Strait Islander communities. The national government objectives to close the gap in life expectancy between Indigenous and non-Indigenous Australians within a generation and to halve the mortality rates for Indigenous children under five within a decade.
have resulted in additional health and social service funding for Indigenous Australians. In recognition of the lower life expectancy among Aboriginal and Torres Strait Islander communities the National Health and Hospitals Reform Commission (NHHRC) recommended that the National Government monitor and report the rates of rheumatic heart disease in the Prime Ministerial statement (41).

Interview participants suggested that there may be an opportunity for HeartKids Australia to facilitate the provision of information and support for Indigenous patients who require treatment for CHD that may be required at a distance from their place of residence. These services should be informed by the professionals within the paediatric cardiac care hubs and could be provided in partnership with existing Australian Aboriginal networks and health services.

2.4 Incidence and prevalence of congenital heart disease among Australian adults

Advances in paediatric cardiac care have resulted in an increasing number of adults with CHD requiring follow up (7, 42-43). These data have been important in generating interest in adult CHD as a new subspecialty of cardiology (42-43), because “a repaired congenital defect does not imply a ‘normal’ heart”(44). Clinicians have recognised that these patients, especially those with complex and severe CHD with surgically palliated or repaired defects, present with distinct problems that current health care systems do not have the capacity to treat effectively. These disorders typically include conduction disorders, arrhythmias, myocardial dysfunction, altered coronary flow and ischaemia that occur many years after successful CHD repair and early recognition of adverse changes followed by rapid intervention may mitigate progressive myocardial deterioration among this population (45).

In NSW, Australia 379 adults received an operation for CHD between 1982 and 1995. For 86% the surgery was their first cardiac operation, which may suggest that some CHD is not diagnosed and treated in childhood, in addition to the fact that it may only be in adulthood that surgical intervention is required. Penny and Shekederman completed a detailed study of the current and future adult patients with CHD who would need access to a specialised centre in Victoria. These data suggested that by 2012 there would be 2,562 patients requiring access to a regional adult CHD centre (46).

It is suggested that more general health issues need to be considered in conjunction with CHD treatment issues (45). Family planning, genetic counselling, pregnancy, lifestyle choices related to alcohol or recreational drugs, dietary strategies, work choices and physical limitations are some of the issues made more complex by an underlying congenital cardiac condition. Although the progress of some adult illnesses in CHD patients will not differ markedly from that of the general population, there may be factors that make management of chronic conditions, such as diabetes, more difficult. Dental procedures and dental hygiene require particular care and non-cardiac surgery carries increased risk among patients with moderate or complex CHD.

Despite the knowledge that early recognition of issues may mitigate progressive myocardial deterioration, there is limited data by which to identify and monitor people who have had CHD. Applying prevalence data from the Netherlands national CHD registry to the Australian population, it is estimated that there are between 26,000 and 32,000 adults with CHD in Australia, with an annual increase of around 5% (37). Studies in the USA have suggested that too many of these adults arrive too late at tertiary centres with avoidable complications (47), and it is suggested that a similar situation exists in Australia.
2.5 Government Child Health Policy
Previously the Australian Government identified the health of children and young people as a key policy area, with a series of documents:

- Health Goals and Targets for Australian Children and Youth (1992)
- The National Health Policy for Children and Young People (1995)
- The National Health Policy for Young Australians (1997).

These documents provided broad national goals for children and young people:

- Reducing preventable premature mortality
- Reducing the impact of disability
- Reducing the incidence of vaccine preventable disease
- Reducing the impact of conditions occurring in adulthood with their origins or early manifestation in childhood or adolescence
- Enhancing family and social functioning.

In recent years the Government has not developed overarching policy positions, but has focused on addressing important health issues, such as mental health or obesity. There has been concern around the lack of an up-to-date coherent child health policy. The Garling Report in NSW suggested the establishment of NSW Kids as one way to address this concern (48).
3.0 FEEDBACK FROM PATIENTS AND THEIR FAMILIES

3.1 Quality of life
Aspects of quality of life that troubled patients and family members were the perceptions of insufficient resources for neuro-development follow-up and access to allied health services. Participants also mentioned that the education systems were often not well equipped to effectively support the education of children and adolescents with heart disease.

Throughout the consultation interviews, the parents and Family Support Coordinators indicated that many of the children with CHD who had undergone surgical repair suffered from incapacitating migraine headaches. Studies suggest that while the prevalence of migraines is around 12% for the general population, the prevalence for adult CHD patients who have undergone cardiac catheterisation is closer to 45% (49). While these data suggest that children and adults with CHD are likely to suffer migraines, with a substantial negative impact on quality of life, this link has not been fully verified and requires further study. However, strategies to address migraine could be included in patient and family information.

3.2 Organisation of hospital services

3.2.1 Emergency services
Many hospitals have established Accelerated Care through Emergency (ACE) programs. These programs are welcomed by families of children with CHD, as identification cards enable faster response to dehydration and other issues associated with CHD. The programs also reduce the amount of time that children with CHD spend in the waiting room with potential exposure to patients with communicable diseases.

3.2.2 Procedures
From the family perspective, while the need for concentrated expertise was acknowledged, the fact that these treatments often required many weeks away from home was seen as a financial hardship and very stressful for the family. Families suggested that step-down units with the appropriate services might be located in centres such as Darwin and Hobart, enabling children to return to a location closer to their communities much earlier.

In addition it was suggested that the Adelaide program, which provides outreach services throughout South Australia and the Northern Territory, as well as some parts of northern Victoria, could have an identified regional role. Up until the early 2000s, major CHD surgery was being provided in Adelaide, but when the number of cases decreased the patients were transferred to Melbourne. In the future, with the growing number of children and adults with CHD additional services may be considered for Adelaide.

Multi-site programs
In order not to lose the existing clinical expertise, it was suggested by many interview participants that a range of organisational solutions needed to be evaluated, such as establishing a ‘multi-site program’ for cardiac care. This might enable the patients and families to remain in their communities, while the specialist clinicians had cross appointments to all of the designated centres and attended the various sites on a regular rotation, supporting the local clinicians. This then raised the question as to whether the limited number of specialists that are available in Australia should be spending time travelling among various sites when their practice could be more efficiently provided at a single site.

Clearly, CHD in Australia faces unique geographical problems which need to be addressed. Centralisation of paediatric cardiac services is a logical approach from a medical, administrative and financial perspective but not from a practical point of view. Decentralisation is the more humane approach. However, it is very difficult to find a widely accepted compromise.
3.2.4 Services for adolescents and adults

Families and support workers consistently outlined their perceptions that there were limited options for comprehensive care for adolescents and adults who had CHD as children. While patients with moderate and complex CHD will have periods of clinical stability, they face unique medical issues requiring access to qualified medical practitioners at many stages throughout their life. Australia has a severe shortage of cardiac centres and medical specialists fully equipped to care for adults living with complex heart defects.

There is a need for transition processes to assist teenagers to understand how to assume responsibility for their own health care, and ease the change to adult care. Families indicated that this was not well done currently, and they reported, which was backed up by the literature, that many adults with CHD do not participate in appropriate medical follow up. It was also reported that there were limited options for these teens to access medical and life insurance, often leading to financial disadvantage.

3.3 The shortcomings of the current system

The strengths, weaknesses, issues and barriers of the current health care system response to CHD were identified through review of the literature and a series of interviews with family members and support workers.

3.3.1 Access to support funding

All of the interview participants identified lack of access to funding and inconsistencies in access to supportive funding as a limitation of the current system. Consistently, families mentioned that parking at most of the hospitals was expensive and a substantial financial drain given the number of times they were required to visit hospitals. In order to increase revenue to support operations most hospitals across Australia have had to institute, and then regularly increase parking fees. This has created a financial hardship for heart kid’s families.

Given that it has only been relatively recently that the neuro-developmental aspects of CHD have begun to be investigated in-depth, many families have been coping with brain injuries and psychological and psychosocial conditions with very little support. In many cases, one parent was not able to work, as the child with CHD required additional care. Family support workers suggested there was a need for an allowance for children with CHD who suffer brain injuries.

Children don’t fit the tick boxes on the Centre Link forms.  
Family support coordinator interview

Although a number of funding sources were identified, such as crisis payments from Centre Link and Salvation Army payments, it was suggested that the criteria were too difficult for most families in need to meet. It was suggested that HeartKids could have a strong role in increasing understanding of the needs for and access to support funding, for transportation accommodation and support services.

The Blue Book [My First Health Record used in New South Wales] should have a section on what supports are available.

3.3.2 Access to social, psychological and allied health support

The HeartKids Family Support Coordinators and family members consulted consistently identified the lack of support services as a major weakness of the current system. In particular the lack of access to social work services was noted. Many families indicated that they were not aware they were eligible for carer’s allowances or mobility stickers for parking. Other families indicated they
had waited three to 12 months to access occupational therapy, physiotherapy and eight to 15 months for speech therapy services. The waits were even longer to access services in regional and remote areas.

**We didn’t get any more information – just told that we needed to come for regular checkups, and that he would go ‘blue’ from time to time when he cried.**

Parent feedback

It was also suggested by interview participants that they would have liked more information on prevention and there were suggestions that there was a need for brochures about CHD to be available in more languages. It was suggested that the cardiac care hubs be asked to consider translating information into the most common languages spoken within their service communities. The topics that Family Support Coordinators felt were important to be addressed through translated brochures included:

- Feeding: there was an identified need to help families understand about breast feeding, nasogastric tubes, and assistance in helping children gain weight.
- Living with a transplant: including understanding the side effects of the associated medications, such as excess body hair and ideas for solutions.
- Body image for teenagers.
- Assistance for teachers to better understand the conditions and resulting limitations.

**There is nothing worse than your children on the phone crying, wanting to know when you are coming home and the guilt of leaving your baby in intensive care to go home to comfort them, even if it is only for a few hours.**

Parent interview

All participants interviewed identified the problems that patients and their families have in ensuring the health and medical records are current and available for the team of professionals. It has been suggested that children, adolescents and adults with CHD would be an ideal population to trial patient-held medical records. This could be designed as a ‘medical passport’.

**She was exhausted after giving birth 24 hours previously. Our baby was in intensive care, she had said goodbye to our other two very distressed children, and she was alone. That would have been the time someone could have talked to her about what was ahead.**

Parent feedback

Recent study has suggested that parents prefer information sources that provide person to person contact in relation to illness among their children, such as telephone triage services. In this study parents indicated less desire for Internet, television, video or even written information (50). Improving the provision of patient and family information is critical for the future, as the NHHRC has recommended that the patient experience regarding the provision of adequate information needs to be measured and reported. It was suggested that this would require the development of a nationally agreed patient experience survey (41).

### 3.3.3 Bereavement support

Lack of bereavement support was identified by many of the interview participants. Bereavement support was seen to be particularly difficult for families living outside of the major metropolitan centres. When a family has lost a child the family members rarely want to interact with families
whose children have had successful outcomes. HeartKids may be in a position to consider a role in bereavement support.

The family that has lost a child does not really belong anywhere.
Family support coordinator interview

3.3.4 Dental care
Interview participants identified the fact that heart surgery is occasionally cancelled because of dental issues with a child. It was suggested that investment in public dental services for children with CHD would assist. This is consistent with the recommendations from the National Health and Hospitals Reform Commission (NHHRC) for improved access to public dental health service (41).

3.3.5 Insufficient family facilities in hospitals

Many of the existing children’s hospitals were built years ago, when it was not common practice to provide facilities for parents. Recent literature has promoted the concept of therapeutic environments in health care, suggesting we need to view the hospital environment from a different perspective. This concept requires us to consider the environment as supporting clinical excellence, meeting the psycho-social and spiritual needs of the patient, family and staff, and producing measurable positive effects on patients’ clinical outcomes and staff effectiveness (51). Unfortunately few existing hospitals can be considered to have been built as health promoting therapeutic environments, but the concept is likely to have a substantial impact on future hospital design. Of greater concern, it has been suggested that the existing noisy, cheerless, cold and poorly designed hospitals contribute to the high level of medical errors in our health care systems (52) and may contribute to psychological damage. Substantial changes are required for future hospital design and development that provides a therapeutic environment. For example, specific to children’s hospitals, Shepley and her colleagues identified six key requirements for therapeutic environments (53):

- Need for privacy and personalisation of space
- Opportunities for distraction, such as nature, music, play, technology
- Design that facilitates supervision by staff
- Age-appropriate environments
- Access to family supportive spaces
- Use of healing sensory dimensions, such as sound, light, humidity, temperature and colour.

We spent two weeks at the hospital, one of us sleeping on a mattress on the floor and the other in an old single bed in old family accommodation.
Parent feedback

More recent children’s hospital construction has aimed to provide sufficient family space. For example, DeVos Children’s Hospital described the family support space that was built based on input from parents, staff and doctors, including patient and family rooms of 370 squares on each unit, support for nursing at the bedside with elimination of central traditional nursing stations,
centralised greeting areas and incorporation of the concept of on-stage and off-stage purposely designed areas (54).

Traditional hospital designs have been shown to communicate the message that people are sick and dependent and should behave in an accordingly passive manner (55). In support of increasing patient and consumer participation in their health care, future hospital design should move beyond traditional dated concepts to respond better to the needs of patients and their families.

3.3.6 Overemphasis on acute care

Given the increasing prevalence of children and adolescents with chronic conditions and disabilities there is a need to rebalance the system from the strong focus on medical cure to local community care and support directed to improving quality of life. The NHHRC indicated that the health system does not respond to people with multiple health needs, where there is a requirement for continuity of care over many providers and over time. The Commission suggested that care for people with rehabilitation and support needs was a particular gap that needed to be addressed (41). This is an essential area for health system reform for children with CHD.

We came back to two traumatised children. We had given birth to a brand new little brother, then within hours of them seeing him for the first time, their mum, dad and new baby brother had vanished from their lives.

Parent feedback

Others suggested that while the support received in the paediatric cardiac hospitals was sufficient, when they returned to their local communities they often felt isolated with limited support. This happens because apart from HeartKids there are not many organisations that are available to provide help.

In addition, a number of hospitals had difficulty scheduling true multidisciplinary clinics and still required patients and their families to attend on separate days to see the various health professionals. It was suggested that the lack of coordinated clinics was difficult for families and did not represent best practice health care delivery.

3.3.7 Respite care

Interview participants identified the need for respite for families while children were in hospital, as well as respite for families at home. It is difficult for families to eat, sleep and generally look after themselves while their child is in hospital. Family support coordinators suggested that vouchers for day spa care, hairdressing or a meal for the parents would be enthusiastically received. It was also noted that while it is very stressful, it can also be difficult for parents to fill the time during the day while their child is in the hospital, particularly when interaction between parent and child has to be limited.

It was suggested that many families required greater access to respite care services at home. Enhanced respite would enable families to better cope with the complex needs of a child with CHD. In general when a child is chronically ill, everything else stops.

Our older girls had to give up their activities, swimming and playgroup, and we isolated ourselves from family and friends for fear of bringing bugs into our home and therefore jeopardising our baby’s chance of survival.

Parent interview
3.3.8 Surgery cancellations

The families indicated that their greatest frustration was related to the all too frequent cancellation and rescheduling of surgery. The families understood that the hospitals were unable to provide the surgery when there were insufficient hospital beds (particularly paediatric intensive care beds (PICU)) or trained nursing staff available, but reported the difficulty in working around rescheduled operations (for example, taking leave from work, booking child care for other children), as practical issues over and above the stress for the family. This was particularly stressful for country families and interstate transfers impacting on South Australia, Northern Territory and Tasmanian patients. While the new Royal Children’s Hospital will provide additional PICU facilities, the Australian Medical Association believes Victoria needs another seven paediatric intensive care beds and another eight neonatal intensive care beds right away. Planning for expansion of the PICU services at the Children’s Hospital at Westmead in Sydney is currently underway. The clinicians and families recognised the further concern of the potential for further deterioration in the health of the patient when surgery was not timely. This had the potential to reduce the health outcomes of the surgery.

3.3.9 Transition to adult care

There is a need for transition processes to assist teenagers to understand how to assume responsibility for their own health care, and ease the change to adult care. Families indicated that this was not well done currently, and they reported, which was backed up by the literature, that many adults with CHD do not participate in appropriate medical follow up. It was also reported that there were limited options for these teens to access medical and life insurance, often leading to financial disadvantage.

The Queensland Review of Paediatric Cardiac Services identified this as an issue, but did not have recommendations on the best model of care that should be provided. “Specific arrangements will need to be developed to accommodate those patients with congenital heart disease who have grown to adulthood. Various models exist for this transition from paediatric to adult care. Whether selected adult cardiac and non-cardiac specialists are cross accredited to the new Queensland Children’s Hospital, or some (or all) Queensland Children’s hospital staff are accredited to selected adult hospitals, will need to be determined locally according to need and opportunities” (56 p. 26).

The Garling Report in NSW also recognised the need for a better mechanism for managing the transition of paediatric patients to adult services (48), to be incorporated into the recommended NSW Kids authority (48).

Parent feedback

Once they become adults, then the provision of services … becomes very fragmented (48 p. 112).
3.3.10 Travel for care

The interview participants provided many examples of the difficulties associated with the need to travel for health services. The issues included: lack of sufficient funding to support travel (airfares, taxis, petrol etc), need for financial support for child care for siblings, the cost of food while away from home, the lack of visitors when in hospital away from their community, the lack of access to Ronald McDonald Houses (and the practice of some hotels to continue to charge for accommodation when the family moves to Ronald McDonald House), the policy of parent hostels not to allow children and the cost and inconvenience of travel when surgery is cancelled.

The department of health in the UK specified that “Specialist centres should work with local paediatric or cardiology services so that as much cardiac diagnosis and care as possible is provided in a network of locally accessible outreach services. The patient and family should be asked to travel to the specialist centre only when essential” (57).

The National Health and Hospital Reform Commission stated “All state and territory governments provide a patient travel and accommodation assistance scheme (PATS) to help people in remote and rural areas to access specialist medical appointments and treatment. But there are significant differences among the jurisdictions in eligibility and operation. We propose that PATS be funded at a level that takes better account of the out-of-pocket costs of patients and their families and facilitates timely treatment and care.” (41 p. 16).

Consistent with the recommendation of the NHHHRC there is a need for the introduction of national standards for interstate travel for health care. This should include reimbursement for travel by car and include a formula that factors in fluctuations in the price of petrol. It was also suggested that arrangements be made to allocate some Ronald McDonald House rooms to CHD families, as it appeared that paediatric oncology families had priority access.

Some interview participants suggested that HeartKids might take a stronger role in sourcing appropriate accommodation for heart kids and their families.

4.0 FEEDBACK FROM CLINICIANS

The primary focus of the previous section of this Report was on the experiences of the children with CHD and their families, as well as people who provide support to the families. These experiences highlighted issues in relation to the existing systems of care, and these ‘consumers’ made suggestions for improvement based on their experiences. Working within the health care system are the clinicians, who also have intimate knowledge of what is working well within the

With 2 grandmothers and 4 children we flew to Melbourne where we had to rent 2 apartments. Unfortunately, due to a shortage of intensive care beds and nurses, days turned into weeks as we waited and waited. This was incredibly stressful, as the surgery was cancelled 4 times.  

Parent feedback

The 2008 Mother of the Year organised her own mortgage on a property that offered services to CHD families.  

Parent feedback

We spent two weeks at the hospital, one of us sleeping on a mattress on the floor and the other in an old single bed in old family accommodation.  

Parent feedback
system and what could be improved. In June 2010 a group of paediatric cardiologists and a paediatric cardiac surgeon made time available to discuss the delivery system from their perspectives.

This section of the Report provides their feedback aimed at improving the health system for children and adults with CHD.

Of importance, the clinicians recognised the need for their leadership in the planning and implementation of health system changes to enhance care processes, with ultimate impact on improving the quality of life for heart kids and their families throughout their lifespan. The clinicians committed the Paediatric and Congenital Council (PCC) of the Cardiac Society of Australia and New Zealand to this leadership role.

4.1 Proposed Service Principles
The clinicians proposed a set of guiding principles for service enhancement in relation to CHD among children and adults:
1. Quality of care is the overriding consideration in planning and delivering health care services.
2. Care should be provided as close to home as can be safely provided, with a particular emphasis for children and adolescents on maintaining the child/adolescent in their family and community environments.
3. Cardiac programs provide comprehensive cardiac care, which includes support for family wellbeing as an essential component of the treatment program. This comprehensive care also includes neuro-developmental and psychological follow up as appropriate.
4. Residents of Australia should have equitable access to care, with recognition that some populations who are more at risk may have special needs.
5. Children, adolescents and adults with CHD have different needs may require distinct therapeutic environments.
6. There is a need to design the system for sustainability, with sufficient appropriately trained staff and plans for succession.
7. Preventative heart care should commence in childhood.
8. Health system planning should be informed by comprehensive and valid data and research on the needs of individuals with CHD and their families throughout the continuum of care. Clinical standards should be agreed and met by all centres.
4.2 Organisation of hospital services

Currently, Australians have access to paediatric cardiac care services in each of the states. Outreach programs are provided in Tasmania and the Territories, with children and adults with CHD in these areas who require procedures travelling to one of the larger centres for this care. All of the programs are seeing increasing demand for services. This is related to substantial population growth, as well as the increasing need for follow up services among the CHD populations.

In June 2010 the Sydney Children’s Hospital Network (Randwick and Westmead) was created to ensure a coordinated approach to paediatric service planning and delivery. Children’s CHD services are provided at the Westmead and Randwick sites, with each concentrating on their priority services. The NSW Children’s Heart Service informally coordinates the CHD programs in the two sites. While there are approximately 7.7 EFT paediatric cardiologists and around 2 EFT surgeons available, the population would require 15 EFT cardiologists and 3 EFT paediatric cardiac surgeons to meet recommended standards. The lack of medical staff has resulted in longer waiting lists for care.

The Children’s Hospital at Westmead provides fetal, paediatric and adolescent care, and is the lead service and provides all surgical procedures, except heart transplants, which are currently completed at the Royal Children’s Hospital in Melbourne. It is collocated with Westmead Adult Hospital where patients diagnosed prenatally are delivered and from where they are transferred, and with Royal Prince Alfred Hospital is one of the two sites for the adult CHD program, with a small team of cardiologists who provide some outreach to the State. Adult congenital heart surgery is most performed at Westmead Adult Hospital by surgeons who also work with paediatric patients.
In Queensland the paediatric cardiac service is currently located at the Mater Children’s Hospital and will transfer to the new Queensland Children’s Hospital slated for opening in 2014. There is a concern that the current service is having difficulty in responding to the increasing demand for services in the north. The large volume of outreach clinics held throughout Queensland, while valued by children and their families and local practitioners, means that the medical staff are not available for service delivery within the hospital in Brisbane, leading to longer waits for service. The Adult Congenital Heart Disease Service is a separate service located at Prince Charles Hospital.

In South Australia (SA) the program serves the populations of South Australia and the Northern Territory (NT). The relatively small number of very complex procedures resulted in bypass being transferred to Melbourne as of 2002, with closed cases continuing to be performed in the Women’s & Children’s Hospital. There are plans for collocation of all congenital cardiac services. The service functions within the cardiology statewide clinical network.

The SA service has a strong role in rheumatic disease to meet the needs of the population in SA and NT, and the Closing the Gap initiative has set goals that will require additional resources to achieve. This includes both services and research.

In Victoria CHD services are provided at the Royal Children’s Hospital (RCH) and Monash Medical Centre (MMC) and while there are two cross appointments, the services are largely structured as separate services. Adult CHD procedures are occasionally completed at RCH, with the majority at the Royal Melbourne Hospital. RCH provides the cardiac magnetic resonance imaging (MRI) service for RCH and RMH patients. RCH has seen the benefit of consolidation of some of the low volume highly complex surgeries such as the Fontan procedures, with documentation of increasing survival rates. Demand continues to increase, with the suggestion that 3 to 4 cardiologists and another surgeon will be required.

While MMC serves both adults and children, it is recognised as the third largest children’s hospital by volume in Australia. MMC has all of the paediatric subspecialty services and provides comprehensive non-invasive paediatric cardiology services. Future expansion is proposed in the areas of adult CHD, with the requirement for medical staff specifically trained in adult CHD practice.

In Western Australia the service has steadily grown based on the need. The distance from other services, for example it takes 6 to 8 hours to transport neonates from Perth to Melbourne or Brisbane, has required the development of a sustainable local response. Prior to 1986 all open heart surgery was performed at the adult hospital, but in 1986, following an audit of outcomes the cardiac service moved to the Princess Margaret Hospital for Children.

In the early 2000s a new cardiac surgical service was introduced with purpose built facilities. In 2008 the WA Paediatric Cardiac Service underwent a review, which resulted in additional resources being allocated to the service. Adult CHD services are provided at the Royal Perth Hospital with around 30 operations per year and 2 cardiologists. Current plans include the collocation of the children’s and adult CHD programs in a new children’s hospital to be opened in 2015/16. The geography of Australia, with vigilant monitoring of surgical results and detailed audit and quality assurance, has justified a smaller volume surgical unit in WA.

In comparison, New Zealand, with a population of 4 million people, has the Green Lane Paediatric and Congenital Cardiac Service, a national service based at the Starship Children’s Hospital that is the sole provider of cardiology and cardiac surgical services for infants and children with congenital and acquired heart disease in New Zealand. The Service also provides a fetal cardiology service and investigation and treatment of those born with congenital heart disease who are now adults. The service provides an extensive network of outreach clinics throughout New Zealand and the South Pacific, and provides consultation and support to clinicians caring for patients within the regional hospital setting. In addition there is an active clinical research and...
audit programme that includes collaborative ventures with academic groups nationally and internationally. Adult CHD has been a focus of health system planning and a hub and spoke model has been established in accordance with the recommendations of the 32nd Bethesda Conference. The adult service in Auckland includes 2 paediatric and 2 adult cardiologists and the paediatric and adult CHD services are located in the same building.

Like the Australian services, the New Zealand volumes have increased over the past 5 years. This has largely been related to an increase in follow-up visits. These trends are indicative of multiple changes in practice, including: primary referrals from out of region have been devolved to paediatricians in West, North, and South Auckland; an increasing trend for heart disease to be diagnosed prenatally or in the new born nursery; increased numbers of infants and children surviving complex cardiac surgery; and more intensive surveillance of at risk groups has resulted in earlier treatment and reduction in long-term morbidity and mortality.

Peripheral paediatric cardiology clinics are undertaken in all major metropolitan centres and in most regional centres in New Zealand. There are 102 clinic days per year including seven adult congenital clinics. Patients seen in these clinics are solely the result of referral from secondary and tertiary sources. There is a continuing, albeit small, unmet need for visiting clinics and it is likely numbers will increase further in 2010 with the addition of a further cardiologist to the team.

4.2.1 Screening and genetics services

It is clear that early antenatal detection of congenital heart disease can improve outcomes (58). In particular, there is lower perinatal mortality and morbidity with transposition of the great arteries with early detection enabling in-utero transport to a specialist centre providing prostaglandins and early intervention (59-60), and decreased use of preoperative ventilator, administration of antibiotics, cardiac catheterization, and emergency surgery (61).

Recent Australian study that compared antenatal detections with actual incidence for seven important congenital heart lesions found that the detection rates at only 15% and 52.8% were significantly lower than expected, and 55.3% of chromosomally abnormal CHD cases were not diagnosed antenatally (26, 62). An earlier UK study found that only 18% of detectable lesions were found by antenatal screening during a two year period, with some centres detecting none and others detecting up to 58% (63). Based on findings that the centres where staff had undergone additional training had better detection rates (63), regular cardiac training sessions for ultrasound operators is recommended to improve detection rates (26).

It has also been suggested that screening can be improved through high frequency vaginal probes with increased colour sensitive Doppler technology in the first trimester (especially after the 12th week gestation) (64). With the appropriate technology and training, it was suggested that clinicians should set and monitor national target detection rates.

The clinicians suggested that screening could be enhanced through (65):

- Continuing education, support and skills training for obstetric sonographers involved in screening
- Establishment of uniform management guidelines across the country
- Clear and direct communication between obstetricians, ultrasound specialists and fetal cardiologists
- Improved access to resources for diagnosis, counselling, support and education regarding the issues surrounding congenital heart abnormality within the CHD care hubs
- Careful antenatal planning with engagement of the relevant obstetric services, neonatal nurseries, intensive care units and other medical and nursing specialists
- Development of coordinated, cardiac centre initiated programs of psychological and social support and family education.
Population studies suggest that the genetic component of CHD is high, with heritability estimates ranging from 0.6 to 0.7 (66-67) and average risk for siblings of affected children of approximately 2 to 5%. Risk for offspring is 3 to 5% (66), but 10 to 15% for certain lesions (68), with the risk to offspring from affected females greater than that for affected males (69). This relatively modest risk to recurrence within families is consistent with non-syndromic (or common) CHD. At present genetics consultations for CHD are relatively uncommon in Australia. Genetic counselling can play an important role in providing clinical health care, risk assessment, information and emotional support to individuals and families affected by CHD. There is a need for increased capacity and accessibility to genetic counselling services.

4.2.2 Emergency services
Critical links in the availability of tertiary hospital care are the services required to transport seriously ill babies and children and there are neonatal emergency transport services throughout Australia from Western Australia (WA NET), Queensland (QNETS), South Australia (MedStar Kids) and NETS in Victoria and New South Wales. NETS Victoria have a self-directed learning package for registered nurses and midwives providing care for infants suspected of CHD awaiting transfer to a higher level of care (netseducation@netsvic.org.au). The package aims to assist these nurses and midwives to facilitate recognition of and effective stabilisation of infants with suspected CHD. There is a need to ensure adequate skills within hospitals caring for infants with suspected CHD during the period of time before the transfer to a specialist centre. The costs of transport, especially for children on Extracorporeal Membrane Oxygenation (ECMO) are high, with a figure of $80,000 quoted as the cost of transporting a sick child from Perth to Brisbane.

4.2.3 Diagnostic Services
Access to diagnostic imaging is an important aspect of service provision for children with CHD. Diagnostic imaging of complex congenital heart disease requires time, experience and expertise, ideally completed by paediatric cardiologists, or in the case of computed tomography (CT) or magnetic resonance imaging (MRI) jointly by cardiologist and radiologist. Echocardiography is the imaging technology of choice, providing more detailed images than x-ray, with no exposure to radiation.

More recently, CT and MRI have been found to provide detailed information for diagnosis and treatment. Both CT and MRI need to be planned and supervised by a paediatric cardiologist and possibly a cardio-thoracic surgeon. Future planning must ensure adequate access to the diagnostic technologies.

4.2.4 Procedures
Many children with congenital heart defects are treated with surgery or catheter-based techniques, usually in infancy or early childhood. In the early years of cardiac surgery, diagnosis and surgical treatment of congenital heart disease were a major component of all cardiology and cardiac surgery. However, from the 1970s onwards the growth in cardiac valve surgery, and subsequently, coronary artery surgery have changed the balance within the health care system from congenital conditions to domination by adult cardiac surgery from the point of view of caseload, numbers of specialists involved and expense. However paediatric cardiology and cardiac surgery have made rapid advances and have increased in complexity, especially in the very young. Many babies born with congenital heart disease have more recently been treated by repair rather than temporary palliative procedures, and results of surgery have steadily improved. These advances in medical and surgical treatments have steadily improved survival rates for even the most complex conditions.

Dedicated children’s hospitals and system consolidation
It has been consistently recommended that infants and children with serious illnesses (including cardiac disease) are best cared for in a dedicated tertiary children’s hospital (56, 70), with sufficient volumes to ensure a quality outcome (71). Interview participants suggested the need for age appropriate preparation for surgery.
It is not appropriate for sick children and their families to be shuttled from hospital to hospital during various phases of their treatments, which is costly with potential for errors and poor outcomes, plus a source of extreme frustration, confusion and costs for families (56, 72-73). The collocation of paediatric CHD services with obstetrics and with adult services was identified by some as a benefit.

One of the areas where there are differences of opinions is in regard to the physical organisation of the health care system. Many of the clinicians interviewed suggested that congenital heart services should be consolidated within regional centres of clinical expertise. In particular, low volume and complex conditions such as transplants and hypoplastic left heart syndrome were identified as rare conditions that were difficult and expensive to treat, suggesting that designated centre(s) in Australia would provide better clinical outcomes at lower cost and reduce the risk to the patients. However, other clinicians suggested that while there should be national standards and clinical guidelines, the population distribution and geography of Australia would be best accommodated through a state-based model of service organisation. Some of the options with regard to managing low volume and complex conditions are currently under study through a Nationally Funded Centre Initiative.

Recent Australian studies have indicated that there is a need to consolidate low volume, complex services and that the current practice in Brisbane, Melbourne and Sydney where two hospitals shared lower volume paediatric cardiac procedures, was not considered to be consistent with international best practice (48, 56, 74). In a recent review it was concluded that there was an inverse association between paediatric surgical volume and mortality that became increasingly important as case complexity increased (75). Although volume was not associated with mortality for low-complexity cases, lower-volume programs underperformed larger programs as case complexity increased. Patients 18 years of age or less who had a cardiac operation between 2002 and 2006 were identified in the Society of Thoracic Surgeons Congenital Heart Surgery Database (32,413 patients from 48 programs). When the data were displayed graphically, there appeared to be an inflection point between 200 and 300 cases per year (75). In addition an inverse volume mortality relationship was recently reported for the complex Norwood and arterial switch operations (76).

On the other hand, Bazzani and Marcin analysed more then 13,000 cases and found a weaker and less consistent volume-mortality relationship than had been reported previously and the lack of a statistically significant association may reflect that low-volume hospitals already avoid specific surgeries that they are ill-equipped to perform (77).

From the family perspective, while the need for concentrated expertise was acknowledged, the fact that these treatments often required many weeks away from home was seen as a financial hardship and very stressful for the family. Families suggested that transition units with the appropriate services might be located in centres such as Darwin and Hobart, enabling children to return to a location closer to their communities much earlier.

The clinicians stressed the need for designated adult and paediatric CHD care hubs in each of the states and suggested that the growing volume of demand for service would support additional service hubs in the larger centres, with a shared plan to distribute the services in a manner that didn’t duplicate the low volume, complex services, and which was consistent with best international practice. It was also stressed that service planning in Australia needed to recognise that the geography and population density of Australia would not be best served by a model from Europe or the United Kingdom.
Multi-site programs

In order not to lose the existing clinical expertise, it was suggested that a range of organisational solutions needed to be evaluated, such as establishing a ‘multi-site program’ for complex cardiac care, considering the local networks approach of the UK (78). This might enable the patients and families to remain in their communities, while the specialist clinicians had cross appointments to the designated centres and attended the various sites on a regular rotation, supporting the local clinicians. This then raised the question as to whether the limited number of specialists that are available in Australia should be spending time travelling among various sites when their practice could be more efficiently provided at a single site.

Clearly, CHD in Australia faces unique geographical problems which need to be addressed. Centralisation of paediatric cardiac services is a logical approach from a medical, administrative and financial perspective, but not from a practical point of view. Decentralisation is the more humane approach. However, it is very difficult to find a widely accepted compromise and it was suggested that the Government should provide the PCC clinical leadership with resources to enable gathering of the planning data, establishing the standards, outlining plans for the system and ensuring ongoing evaluation and improvement. The clinical engagement outlined in recent reform documents of the NHHRC could be the mechanism for the design of the health care system, and the care of children and adults with CHD could form a pilot project to implement and test this approach.

It was suggested that the success of multi-site programs was associated with effective communication and data transfer, as well as the provision of resources to enable clinical networks to be effectively developed. Advanced information technology could help align the existing services. Ideally, an Australia wide congenital heart disease service network would provide the necessary infrastructure for transfer of medical data among the care hubs. Hypoplastic left heart syndrome is a perfect example of a disease that can only be successfully treated if every member of the ‘team’ (cardiologist, surgeon, intensivist, anaesthetist, nursing staff, allied health staff, local paediatrician or GP, members of the local hospital and parents) is provided with all the necessary information on-line and on-time.

NSW has one collaborative service (NSW Children's Heart Service – The Children's Hospital at Westmead and Sydney Children’s Hospital) with multiple cross appointments and clinical organisation, such as meetings, morbidity and mortality reviews and outreach clinics to best serve children in NSW. It was suggested that the two sites for cardiology for the one service has significant strategic advantage for the paediatric population of NSW, allowing better access to cardiac services for more families and the two ICUs in Sydney give protection against infection or disaster. Similar arguments could be made regarding the Royal Children’s Hospital and Monash Medical Centre in Melbourne. The important issue is to ensure that the services are working together in a coordinated manner, without the duplication that potentially adds to health systems costs.

In two recent European studies the researchers suggested that the workload of paediatric cardiology consultation services and ambulatory paediatric cardiology services has been “increasing alarmingly” (79-80). The interview participants confirmed the increase in demand for services in Australia, while expressing concerns that there were insufficient specially trained clinicians to meet future needs and that Governments needed to be planning for future growth in paediatric health professionals. The official guidelines of the CSANZ require one paediatric cardiologist per 500,000 population and strategies need to be put in place to ensure this capacity.

Recent reports from the NHHRC and the Victorian Department of Human Services have stressed the need for measurable performance indicators and performance reporting (41, 81). Specialist care hubs and/or multi-site programs would assist in enhancing patient outcomes and hence improve key performance indicators. The interview participants stressed the need to ensure meaningful functional indicators were used. Performance indicators that were solely focused on in
hospital care would not provide the necessary focus on the quality of life of individuals with CHD. Regardless, there is a need to concentrate on better communication and information and communication technology infrastructure.

The Northern Territory plan for Cardiac Services in the Northern Territory 2006-2015 suggested that children needing surgery for cardiac valve disease and congenital heart disease were best managed in major paediatric cardiac surgery centres, such as the Royal Children’s Hospital, Melbourne (82). The Queensland review of Paediatric Cardiac Services concluded “As a statement of principle, and in any definitive planning for Queensland, children with heart disease requiring tertiary care should be cared for in the new Queensland Children’s Hospital” (56 p. 23).

4.2.6 Continuum of care

Services for adolescents and adults
The current system does not offer consistent options for the care of adolescents and adults who had CHD as children. This is not unique to Australia, as a recent European study found that only 19% of the centres dealing with adults with CHD (ACHD) (or Grown Up Congenital Heart Disease (GUCH) as it is referred to in the European Union) met the standards for optimal care (83). In particular, the European centres were not able to achieve the volume requirement of 50 congenital heart operations per year and did not have nurse specialists involved with the care of these patients (83). This variability in care may impact negatively on the clinical outcomes and quality of life of these people, as there are substantial international data that show that planned and coordinated care provided through designated ACHD centres results in better outcomes (47, 84). It has been recommended that programs be developed that inform adults with CHD about the rationale for ongoing follow-up, as well as teaching them how to navigate the health care system (85).

There is ongoing debate as to whether adult or children’s hospital and adult or paediatric heart surgeons are best qualified to treat ACHD patients. Some suggest that there are few similarities between the field of adult congenital heart disease and acquired heart disease, suggesting a need for specialised care for adults with congenital heart disease (86). American guidelines suggest that adults with CHD should have their care coordinated by regional ACHD centres that represent a resource for the medical community (87). Initially it was suggested that there should be an adult congenital heart disease regional centre for every 5 to 10 million people (87), but this was later amended to suggest that a population of 3 million people may require a regional ACHD Centre, given the growth in the ACHD population (15). It is also suggested that more than 50% of adults with CHD should be evaluated every 12 to 24 months by a cardiologist with specific expertise at a regional centre (7, 88).

Studies in 2008 and 2009 provided further evidence for designated CHD centres for adults, by showing that the death rates for adults with congenital heart disease were significantly lower when the operation was performed by a paediatric heart surgeon as compared to cardiac surgeons without the experience in congenital heart disease (89-90). Consistent with other studies that have shown a volume quality relationship in surgery (91-93), death rates decreased as the number of paediatric heart operations performed by individual surgeons increased (89). However, the location of surgery has had mixed results, with Kogon et al. finding better outcomes for adult congenital heart surgery performed by a paediatric surgeon in an adult hospital (90).

In many states in Australia the government health department has put limits on the age range of treatment in designated paediatric hospitals (for example the Department of Health in Victoria limits admissions to the Royal Children’s Hospital to children younger than 18 years old) and as a result many adults with CHD cannot be operated on by paediatric surgeons (even though the evidence suggests that surgery by paediatric CHD surgeons is associated with better clinical outcomes). Cases are dealt with on an individual basis and patients considered at particularly high risk/complexity are admitted to RCH for treatment.

The Monash Medical Centre is developing a surgical unit, led by a paediatric surgeon for teens
and adults with CHD, accommodating some older patients from Victoria and South Australia. In Adelaide a cardiologist has established clinics for teens and adults at the Women's and Children’s Hospital (WCH), and provides options for patients to attend the WCH, the Royal Adelaide Hospital or a private collocated heart clinic.

In Queensland the Queensland Centre for Congenital Heart Disease was located within the Prince Charles Hospital, providing a major tertiary level cardiothoracic referral service for Queensland. The service focused on paediatric cardiology and paediatric cardiac surgery for neonates, infants, children and adolescents (up to the age of 17). The Review of Paediatric Cardiac Services for Queensland indicated it was inappropriate for children with cardiac conditions to be treated within an adult hospital and recommended that the cardiac service be relocated to the Royal Children's Hospital in Brisbane, pending construction of the new children’s hospital. The report also recommended establishment of a transition clinic for children to move to adult CHD services and the formation of an adult CHD service.

The clinicians reinforced the need for strong links between the paediatric and adult programs and suggested that formal transition clinics aided the transition process for the patients, their families and the clinicians.

The Queensland Review of Paediatric Cardiac Services identified this as an issue, but did not have recommendations on the best model of care that should be provided. “Specific arrangements will need to be developed to accommodate those patients with congenital heart disease who have grown to adulthood. Various models exist for this transition from paediatric to adult care. Whether selected adult cardiac and non-cardiac specialists are cross accredited to the new Queensland Children’s Hospital, or some (or all) Queensland Children’s hospital staff are accredited to selected adult hospitals, will need to be determined locally according to need and opportunities” (56 p. 26). In England it has been recommended that the process of transition be initiated no later than 14 years (94). The Garling Report in NSW also recognised the need for a better mechanism for managing the transition of paediatric patients to adult services (48), to be incorporated into the recommended NSW Kids authority (48).

Once they become adults, then the provision of services …. becomes very fragmented (48 p. 112).

Neuro-developmental services

We need to be focusing on outcomes beyond just survival – we need to move to a focus on quality of life.

Clinic interview

There has been substantial study on the neuro-developmental and behavioural outcomes of children who have experienced cardiac surgery, with mixed results. For example, a study of the educational outcomes for a group of 109 children, aged five to 10, who had undergone cardiac surgery for complex congenital heart disease when they were newborns, found a large proportion of these children had difficulties in school. Of the 109 children, 53 children (48.6%) were receiving remedial services at school, and 15 percent were in special education classrooms. The researchers indicated that schoolchildren who required surgery as infants for congenital heart disease had a significant risk of having problems with inattention and hyperactivity, and often required remedial services in school (23). The authors suggested the need for more formalised diagnostic tools, with ongoing follow-up and neuro-developmental screening, including prescribed follow-up protocols for these children (23).

On the other hand, a Dutch study concluded that at school age there were no negative effects on
neuro-cognitive functioning following cardiac surgery with full-flow cardiopulmonary bypass at an earlier age (95). It is clear that more research is needed in this area to explore the conflicting findings. In addition, it is not clear whether medical therapies commonly used for the treatment of attention deficit/hyperactivity disorder (ADHD) would be helpful in the CHD population, suggesting the need for more study (23).

The use of MRI improves understanding of brain injury among these children, as previously it was not possible to observe the full extent of the neuropsychological issues until well into school age (96). While it has been reported through MRI studies that up to 40% of newborns with CHD have preoperative brain injuries (97-98), such as abnormal brain development and delayed brain maturation, and an additional third acquire new brain injuries during surgery (97), in many cases these MRI findings have no clinical implications. Recent findings suggest a greater risk of preoperative brain injury with longer time to surgical repair and lower arterial oxygenation for transposition of the great arteries (98), with a 2007 study suggesting that 32% of newborns with CHD had white-matter brain injury preoperatively which reflected abnormal brain development in utero (99).

In a 2004 systematic review Imms concluded that children with CHD as compared with control children were at risk for poorer self-esteem, poorer psychological and psychosocial functioning and compromised school performance (100). As an occupational therapist, the author concluded that these problems lead to reduced ability to participate in age-appropriate childhood activities (100). A USA study found consistently lower scores in the mental and psychomotor indices of the Bayley Scales of Infant Development among children with CHD (101).

Many of the clinicians interviewed discussed the fact that now that more children were surviving surgery, there needed to be a greater emphasis on the neuro-developmental aspects of CHD. This lead to the suggestion that funding was required from the government so that children with CHD could receive regular neuro-developmental assessment and a comprehensive database could be established to assist in outcome analysis. The National Health and Hospitals Reform Commission also recommended that the time from referral to diagnosis and/or treatment and intervention be monitored and reported by each of the States for all children with suspected disability or developmental delay (41). Monitoring this performance indicator may assist in improving access to treatment.

Studies have found that parents of children with congenital heart disease experience more anger and sadness than parents of healthy children (102). They also report more social problems and less leisure activities (103), greater feelings of distress and hopelessness (104), and higher levels of overall stress than parents with children with other chronic conditions such as cystic fibrosis (105-106). “Caring for children and families with chronic conditions, such as congenital cardiac malformations, requires attention not only to their physical health, but also to their psychosocial health” (107 p. 113). It is also suggested that the siblings of a child with CHD would have similar issues.

After surgical repair for CHD, children have been found to experience symptoms of posttraumatic stress disorder (108). In addition, children with CHD report poorer body image and self-concept, greater anxiety, and higher incidence of behavioural problems than healthy children (109-110).

Access to social, psychological and allied health support
The clinicians stressed that families have unique needs for information and support when confronted with a diagnosis of congenital heart disease. Although families may report that they
had not been given sufficient information, this perception could also be due to their processing of the information. This means that the system must be organised to ensure that the information and support is available at the right time in the right place, and this may not always be in the acute phases. It was generally agreed that while some support is available, much more should be done as part of the comprehensive and coherent care delivered through the service hubs, including appointments with psychologists and social workers with special commitment to supporting this population, and greater support to more local health care professionals.

4.3 Funding models for service delivery

Interview participants outlined the difficulties caused by existing State funding models. In addition, the Victorian Strategic Framework document reported that the problems associated with episode-based funding for paediatric services were raised throughout their consultation processes (81). It was specifically suggested that in Victoria the funding model needed to be changed to reverse the flows from tertiary services to local hospitals, to better support outreach services and home-based equipment and care.

The different state and territory based funding models resulted in inequities in access to services. For example, clinicians across the country worried that their system did not provide adequate resources for follow up and this meant that the clinicians were not able to conduct regular reviews, which was not consistent with quality best practice.

4.4 System organisation that does not represent best practice

A 2006 report on paediatric cardiac services in Queensland suggested the existing model was “outmoded, does not produce ideal patient outcomes, is potentially dangerous, and is an inefficient use of scarce resources (56 p. 5). The two competing tertiary children’s hospitals in metropolitan Brisbane and treatment of all infants and children with cardiac disease in an adult cardiac unit at The Prince Charles Hospital (TPCH) was identified as “a situation that is far from ideal for clinical care, training, resource allocation, and research” (56 p. 5). The Queensland Review Panel carried out an extensive, statistical comparison of 30 day survival rates of children having cardiac surgery at TPCH and the Starship Hospital in New Zealand and found a trend for higher death rates at TPCH (it was clarified that the numbers were small and therefore the poorer outcomes were not necessarily statistically significant, but even still the authors thought it essential to include the findings in their report). It must be noted that the identified deficiencies have been addressed and are further being incorporated in the planning for the new children’s hospital in Brisbane.

The findings of the Queensland report are consistent with many studies that have shown a link between volume, quality of care and clinical outcomes in health care. Larger service volumes are related to better clinical outcomes and more efficient service provision. There is strong evidence that paediatric cardiac outcomes (usually measured as in-hospital mortality) are positively related to service volumes for both practitioners and hospitals (57, 91-92, 111-115).

Most recently the Garling Report in New South Wales recommended the establishment of a single statewide authority called NSW Kids to provide the full range of health care for children and young people, including the amalgamation of all paediatric services to create a single specialist children’s hospital for metropolitan Sydney (48). Within the Report, Garling provided examples of the difficulties in transferring the care of complex paediatric patients from the specialist children’s hospitals to local providers and services (48), a situation that is not unique to NSW. The recommendation of the NSW Kids authority was meant to address this lack of continuity of care.

The Department of Human Services in Victoria recently released a discussion paper for a strategic framework for paediatric services (81). This document also suggested the need for a Paediatric Clinical Network, with a Paediatric Leadership group responsible for engaging stakeholders in setting strategic directions and priorities.
The Queensland and NSW reports, and an earlier review of paediatric service in Victoria (74), have been clear that improved clinical outcomes would be achieved by consolidating complex paediatric services. The improved clinical outcomes are related to the ‘infrastructure’ that can be assembled with sufficient critical mass. While individual clinicians may have sufficient training and experience to complete complex paediatric procedures, the clinical outcomes will be better where there is well organised support for these clinicians. It is only through consolidation that health service provider organisations can efficiently ensure the required interdependencies in clinical and support service are addressed. Importantly this infrastructure support comprises:

- the full range of staff (medical, nursing, allied health and support services staff) with sub-specialty availability and up-to-date relevant skills in child and adolescent health care
- strong parent support, including accommodation, that would not be possible in lower volume centres
- facilities and equipment dedicated to the needs of children and adolescents
- specialised paediatric pain management
- sufficient clinical volumes for teaching and research
- multidisciplinary resources required by paediatric and adolescent patients with multiple, complex needs
- interdependencies
- 24 hour cover by paediatric registrars, and efficient on-call coverage.

Studies have also suggested that in addition to better clinical outcomes, higher volume paediatric centres demonstrate greater efficiency than comparable lower volume centres. Although there were no studies found that specifically evaluated the cost implications of consolidation of specialist paediatric services, general studies on the impact of consolidation of hospital services support cost savings, but only when services (not just ownership) are consolidated (117-118). The cost savings are thought to result from capitalising on economies of scale in operating costs (119-120), as well as reductions in the capital investment in facilities and equipment (117). The evidence indicates that the improved quality and efficiency of care delivery that is achieved by consolidating services to enhance clinical volumes outweighs the resulting loss of local access to these services (121).

As a recent, well researched report, the Queensland study provides clear implications for the organisation of paediatric cardiac services:

- low volume, highly complex services should be amalgamated within designated paediatric cardiac services. This does not preclude arrangements of the organisation of single cardiac programs, with appropriate services provided through more than one site, where the volumes and staff expertise support such an approach. The report indicated that "Immediate steps should be taken to provide an integrated paediatric cardiac program, with all staff currently treating children, reporting to the Royal Children's Hospital" (56 p. 26).
- paediatric cardiac surgery should be provided within a designated paediatric hospital (56).

These recommendations are consistent with studies from other countries with similar public health care systems including:

- one national tertiary paediatric centre for Ireland (122)
- national network of children’s tertiary services with PICU operating as one service from two sites in Scotland (123)
- the safe and sustainable network approach for the NHS (78)
- one paediatric specialist facility for cardiac surgery and transplantation for the Ontario (Canada) provincial population of 13 million (124-126)
- one paediatric cardiac surgery centre in Edmonton, Alberta for the provinces of British
A thorough review is required of current and projected future service volumes to enable health system planning, the geography and population distribution of Australia present some unique challenges. The general consensus is that CHD care hubs for children, adolescents and adults should be identified in each of the states, and if volumes are sufficient to justify more than one hub, mechanisms be put into place to ensure coordinated, supported and non-duplicative service delivery.

A major barrier to system reform that was identified throughout the interviews related to the lack of incentives for clinical staff to work within the CHD field. The literature is clear that it is not appropriate to provide complex paediatric cardiac work as an offshoot of adult practice. But the funding and remuneration for paediatric service is seen as disadvantaged as compared to adult cardiac services. For example in radiology, the current Medicare rebate for a paediatric cardiac MRI is approximately $649.60 when all item numbers are included. During the same time period required for a paediatric MRI the service could accommodate three head scans of $492.80 each for a total rebate of close to $1,500. This suggests that there is little financial incentive to complete the more complex paediatric diagnostic work.

This has an impact in reducing the number of qualified staff available to work within the system. There is a need for the government and private health insurance funders to review the funding mechanisms to ensure the existing income gradient that is discouraging health professionals of all types from working in paediatric cardiac services is addressed.
5.0 REQUIREMENTS FOR CHD

5.1 Trends in international models

5.1.1 Cardiac networks

*Canadian Adult Congenital Heart Network*

In 1991 15 regional adult CHD centres in Canada formed the Network, to pool knowledge and expertise of the CHD professionals. This was based on consistent research findings that clinical networks are successful in improving health service delivery (130).

The National Specialised Commissioning Group has outlined a network approach to safe and sustainable paediatric congenital services in England. The network comprises: tertiary surgical centres, designated to perform surgical and interventional procedures on children; children’s cardiology centres which perform the full range of inpatient and outpatient non-invasive diagnostic procedures and ongoing management of children with CHD and; paediatric cardiology periphery services at some local hospitals. Each of the components of the network has clearly defined standards and measures (94).

5.1.2 Adult congenital heart centres

*Ahmanson/UCLA Adult Congenital Heart Disease Centre*

The UCLA Adult Congenital Heart Program was established in 1981, organised to provide expert patient care, physician training and research. The ACHD Centre was the first, and remains one of the largest in the United States.

*Boston Adult Congenital Heart and Pulmonary Hypertension Service (BACH)*

This service at the Children’s Hospital Boston began accepting patients in 1992. The service provides a monthly Transitional Resources Seminar to assist young adults in their transition from the children’s service to BACH. A database similar to the BACH Adult Registry for Congenital Heart Evidence, Evaluation and Standardisation (ARCHES) was identified by many of the clinicians interviewed as an essential resource that was missing in Australia.

*MAUDE Unit (Quebec, Canada)*

The Montreal Adult Unit for Congenital Heart Disease Excellence (MAUDE Unit), Canada was established in the McGill University Health Centre (MUHC) in 2000. The basis for the operation of the MAUDE Unit is a multidisciplinary approach, where a group of clinical specialists and support staff work with congenital heart surgeons to ensure adult CHD patients receive the services and care they require. These clinicians and diagnosticians frequently work with both children and adults, developing valuable dual expertise. Transition from paediatric to adult cardiac care is facilitated by a working connection between the MAUDE Unit and the MUHC paediatric department, the aim being to provide consistent monitoring and care which begins in infancy (or even before a baby is born) and continues throughout the life of a CHD patient.

*Philadelphia Adult Congenital Heart Centre*

This centre designed to meet the needs of adults with CHD is a partnership between the Children’s Hospital of Philadelphia and the Hospital of the University of Pennsylvania. This model brings together the necessary paediatric congenital heart disease (89-90) expertise within an adult hospital environment.

*Royal Brompton Adult Congenital Heart Centre*

The Royal Brompton Centre was one of the first, to provide specialised care for adults with CHD, established in 1975. In 2003 this Centre was designated as the national centre for adults with pulmonary hypertension.
5.1.3 Collocated paediatric heart services

*Cleveland Clinic, USA*

There is an increasing trend to collocate all service required by heart patients. For example, the design of new facilities for the Cleveland Clinic was based on patient needs which resulted in physical organisation with the physician’s and surgeon’s offices, and all the inpatient beds and outpatient clinics in one area in the same building. Everything related to the heart and blood vessels were located together. This design was seen to provide quicker access for doctors and facilitates a higher level of collaboration among the health professional team (131).

*Children’s Hospital of Philadelphia, USA*

Similarly, at the Children’s Hospital of Philadelphia the cardiac operating theatres and imaging services are located adjacent to the inpatient beds. This children’s hospital also contains the Garbose Family Special Delivery Unit, specifically designed so that neonates born with congenital heart disease can quickly access the necessary paediatric services.

It does need to be noted that few of the international centres identified face the same levels of remoteness and scattered populations that are part of the demography of Australia. A planning approach that addresses the Australian conditions is required.

5.1.4 Models of Care

*Planetree Model (founded in the USA, now international)*

Planetree is an international nonprofit organisation committed to improving medical care from the patient’s perspective (see http://www.planetree.org/about.html). There are 10 components of the Planetree Model that outline both psychological and physical requirements for health care organisations, including:

1. Creating organisational cultures that promote human interactions.
2. Encouraging the involvement of family and friends in the care experience.
3. Providing patients with information and educational resources so they can actively participate in their own care.
5. Providing delicious, healthful meals and making good food choices available.
6. Creating an atmosphere of serenity and playfulness through arts and entertainment.
7. Supporting patients, families and staff spiritually to connect with their own inner resources.
8. Using caring touch and massage to reduce anxiety, pain and stress in patients, families and staff members.
9. Expanding choice by offering patients access to complementary therapies.
10. Increasing the role of hospitals and redefining health care to include health and wellness of the community.

Most recently a relationship has been shown between those health service organisations demonstrating the Planetree Model and their outcomes in patient satisfaction (132).

5.1.5 Redesigning care initiatives

Many hospitals have recognised the benefit of process review and redesign to improve the patient journey through designated services. Common themes have been found in redesign initiatives: there are often variations in the care received that result from the many and varied pathways by which patients and their families access specialised hospital services; the patient length of stay is often variable and unpredictable making it difficult to plan for elective admissions and the typical care process comprises numerous disconnections and misalignments that are often uncovered during the diagnostic phase of redesign initiatives.

5.2 CHD care hubs

Based on international guidelines, with one paediatric cardiac centre serving a population of 4 to 6 million (112) and one adult centre serving a population of 3 to 10 million people, Australia would require five specialist CHD care hubs. Based on where the population resides and the distances
between major centres, the care hubs would be effectively located in Sydney, Melbourne, Brisbane, Adelaide and Perth, but this should be confirmed by the Paediatric and Congenital Council (PCC). It is essential that the designated centres establish effective mechanisms to ensure adequate support for CHD children and their families when they are not at the CHD centre, such as the provision of outreach services. This may be accomplished by the development of transitional centres in other parts of Australia.

5.2.1 Health professionals
A number of jurisdictions have outlined the need for health professional staff for paediatric and adult CHD centres. The table in the Appendix consolidates the information available at this time. In most centres in Australia there are currently fewer cardiologists, surgeons and other specifically training health care professionals than recommended by international standards. In addition, the cardiac specialists need to work within organisations with sufficient professionals within cardiac imaging, intensive care and neonatology. It will be important to receive clinical advice on the relevance of the recommendations in light of the specific needs in Australia.

In England, the standards require a named Children’s Cardiac Specialist Nurse for each child, working within the cardiac liaison team, who is responsible for coordinating the care and who acts as a liaison between the clinical team and the parent, carer and child throughout their care (94).

5.2.2 Facilities
Designated CHD centres require one operating theatre for 250 annual cardiac procedures, with an additional theatre made available for emergencies (112). The centre requires access to 6 to 8 intensive cardiac care beds per 250 surgical patients and 10 to 12 ward beds (112).

There is a need to ensure that there are sufficient, appropriately designed facilities for families within the designated CHD centres. There is an increasing evidence base linking facility design and patient outcomes that needs to be incorporated in future facility planning (133). It is recommended that accommodation be available for at least 2 family members to stay at the hospital and for parents/carers to stay with their child in the ward 24 hours a day (94).

5.2.3 Data collection
To assist future planning consistent and comprehensive data collection of the incidence of CHD and surgical and other procedures and outcomes is required. In other countries the necessary data is obtained through a designed congenital heart disease registry. In Australia it is difficult for clinicians to obtain funding for data entry and analysis staff, suggesting that a coordinated national approach to a CHD registry, with allocation of sufficient resource for data management would fill an important gap and assist in establishment of the underlying data infrastructure necessary for a world class research agenda. The CHD registry and associated infrastructure would also provide relevant information for health system planning and evaluation.

A database manager with nursing qualifications is essential.
Clinician interview

The German Competence Network of Congenital Heart Defects (www.kompetenznetz-ahf.de/en/research/) was created in close collaboration between government, clinicians and parent organisations. The German Federal Ministry of Education and Research and other sources (donors, professional organisations) fund the network. The German government keeps the database under close surveillance to prevent misuse, because only the federal government can assure safety and integrity of sensitive data.
The CONgenital CORvitia (CONCOR) national registry of patients (children and adults) with congenital heart disease (http://www.concor.net/nieuw2/achtergrond-1-E.htm) was established in the early 2000s to provide information about the epidemiology of CHD in the Netherlands. Currently the data base contains information on around 11,000 individuals and around 4,000 adults have provided DNA for further testing.

The European and American surgical databases are well established. The International Paediatric Cardiology Code (IPCC) comprises 5,600 diagnostic and procedural codes thus enabling international standardisation and comparison of CHD data, with additional categories for describing the complexity of CHD (i.e. RACHS-1, Aristotle Score) (134). It is suggested that the clinician and health authority driven database initiative should be able to make information available to user groups, such as patients, health authorities, HeartKids and the general public.

It has also been suggested that there is a need to track the rapidly growing adult population in Australia with CHD. A national registry would provide essential information on the epidemiology and morbidity of adult congenital heart disease.

5.2.4 Research

In recent years there has been substantial competition for research funding for various medical conditions. The interview participants outlined the need for greater public awareness of CHD and the associated impacts on the families in the hope that this would translate to additional funding for research in this area.

Throughout the interviews there were mixed opinions as to how best to build the necessary research infrastructure in this area. The Australia and New Zealand Children's Heart Research Centre (ANZCHRC) established in 2002 was identified by many interview participants as an effective model to enhance research in this area throughout Australia. However, there were concerns raised that the Centre had an over-emphasis on Melbourne-based research and had not to date been effective in the development of a comprehensive supported research strategy. But others suggested that through the development of the regional research strategy in 2004, and the growth in transparency in planning and funding research ANZCHRC was slowly becoming a more effective research collaboration. Good research infrastructure has also been developed at the major cardiac centres and these attract funding in their own right.

On the other hand, some felt that there was a need to coordinate CHD research through the auspices of the National Health and Medical Research Council (NHMRC). It was suggested that this would promote a greater national research focus, coordination, government funding sponsorship and priority in this vital area.

Many of the clinicians that were interviewed indicated that donations they had directly received in the past to fund research and associated infrastructure, were no longer being offered to individual institutions, but they believed were now being provided to HeartKids. The reported outcomes were that some key processes, such as data entry and analysis, ongoing funding for research assistants and PhD students had been lost to the individual programs. The clinicians indicated that these resources were essential to a coherent research program, but were not able to be effectively written up as a National Health and Medical Research Commission (NHMRC) type research project grant with an overall loss to the system. It was also suggested that it would be easier for the larger centres with established research infrastructures to access the NHMRC type grants to the disadvantage of the smaller centres.
A related concern was raised that HeartKids would weaken their abilities in community awareness and supporting parents and families of heart kids, because of the complex nature of operating a research granting process that would consume more of the organisation’s efforts and resources.

5.3 Involvement of the field
The evidence for a planned, regionalised and adequately funded CHD program throughout Australia is well accepted. The clinicians who were interviewed in the completion of this study all agreed that there were more effective ways of funding and structuring the system which would lead to enhanced patient outcomes. The PCC has committed to a leadership role in advising how best to improve the health care system for congenital heart disease.

The clinicians advised that HeartKids and patients and family members should also be participants in the planning processes. Interview participants spoke positively of the role of HeartKids, but many suggested the need for HeartKids to focus in the areas where they held the greatest expertise. Some suggested that they perceived that the HeartKids organisations in different states had different goals and thus made diverse contributions, which had the potential to lead to greater variance in access to services.
6.0 RECOMMENDATIONS

The first set of recommendations relates to the role of the Paediatric Cardiology Council (PCC) and associated clinicians in enhancing the system:

1) It is recommended that the Paediatric and Congenital Council (PCC) of the Cardiac Society of Australia and New Zealand, in consultation with the wider CHD community, develop a proposal for funding assistance from Government(s) to resource a collaborative and comprehensive planning process for clinical services and the establishment of a national congenital heart disease register.

2) Through this process it is recommended that the PCC develops an agreed plan for paediatric and adult congenital heart disease services and associated physical and human resources required to deliver the services in Australia and New Zealand. The current CSANZ guidelines for the provision of paediatric cardiologists on a population basis need to be reviewed in relation to Australian circumstances, such as the geography, indigenous population requirements, etc, as the guidelines were derived for UK needs. Following review, strategies need to be put in place to ensure the necessary capacity is achieved.

3) This process should also focus on enhancing services supporting better health for children, adolescents and adults with CHD, such as screening practices, neuro-developmental assessment, psychological support, access to allied health services, dental care and support for parents.

The three recommendations above need to be considered, implemented and aligned with the implementation of the following recommendations. This next series of recommendations relate to the Australian and State Governments:

4) It is recommended that the Australian Government work with the State and Territory Governments to consider the plan to be produced by the PCC above and to review the funding models for paediatric and adult CHD services throughout Australia, aiming for greater consistency across the states and territories.

5) It is recommended that the Australian Government, in consultation with the clinicians working in this area, develop, fund and implement an Australian congenital heart disease register to assist in tracking clinical outcomes and providing valid data for planning of future service needs. This register should also focus on capturing quality of life measures for people with congenital heart disease.

6) It is recommended that the Australian and/or State Governments ensure the designated care hubs have the required level of qualified staff and appropriate facilities to meet the population needs, including the required psychological care and social and neuro-developmental follow-up, supported by local health professionals.

7) It is recommended that the Australian and/or State Governments ensure links are established between all emergency departments and CHD care hubs for efficient transfer of patients.

8) It is recommended that functional performance indicators for heart disease outcomes, as recommended by the specialist clinicians and/or CHD network be included in the suite of health system performance indicators to be implemented by the National and State and Territory Governments (as per NHHRC recommendations).

9) It is recommended that the disparity in the performance indicators for Aboriginal and Torres Strait Islander health status be addressed through targeted health care initiatives and that the action plans for rheumatic heart disease include support of infants and children with CHD.
10) It is recommended that the Australian Government ensure mechanisms are put in place to improve detection of fetal cardiac malformations, with the establishment of target detection rate indicators. This will also require the development of additional service capacity to support greater detection.

11) It is recommended (as recommended by the NHHRC) that the Australian Government work with the State and Territory Governments to ensure the provision of more equitable coverage of the travel and accommodation costs for families required to travel to the designated CHD specialist centres.

12) It is recommended that the Australian Government work with the State and Territory Governments to trial a medical passport system for children, adolescents and adults with childhood heart disease. This could be intergrated into trialling or rolling out new e-health initiatives being funded as part of the Commonwealth’s national health reforms.

13) It is recommended that the Australian Government work with the State and Territory Governments to ensure the development of consistent national ‘Accelerated Care through Emergency’ (ACE) processes.

14) It is recommended that the Australian Government review disability and carer payments to ensure children and adults with congenital heart disease are not discriminated within the funding models.

The next recommendations relate to the potential role of HeartKids in addressing some of the issues raised in this Discussion Paper, and are conditional on sufficient funding being raised by HeartKids to support ongoing operations as well as strengthening the strategic planning and focus as it grows and defines itself as an organisation:

15) It is recommended that HeartKids, in consultation with the specialist clinicians and service providers, develops an effective strategy to create greater understanding and awareness of the needs of children with congenital heart disease and their families.

16) It is recommended that HeartKids considers broadening its funding base to enable the expansion of its family support services into the community (including regional areas and transition into the education system) and developing an appropriate and effective national support structure for families with CHD.

17) It is recommended that HeartKids works with the Aboriginal and Torres Strait Island communities to advise the Commonwealth Government on how best to provide family and healthcare support to the heart kids and their families in these communities.

18) It is recommended that HeartKids works with the specialist clinicians and service providers to identify information that is scientifically accurate and relevant to parents-to-be and heart kids families about the prevention of both congenital and acquired forms of childhood heart disease, and to disseminate that information to the community.

19) It is recommended that HeartKids works with hospitals, specialist clinicians, the National Health and Medical Research Council and the National Institute of Clinical Studies to develop, test, publish and disseminate relevant information on the causes, diagnosis, treatment and management of congenital heart disease including management of the disease and its complications throughout life. Where possible information brochures could be provided in languages other than English.

20) It is recommended that HeartKids considers partnering with the cardiac care hubs and bereavement experts to ensure that bereavement support is as available and sensitive to family needs as reasonably possible.
7.0 REFERENCES


45. Mellaor D. Incidence and Treatment of Congenital Heart Disease in Adults and the Need for a Coordinated treatment Service in NSW. 2007.
136. Canadian Congenital Heart Network. Managing Congenital Heart Defects.
8.0 APPENDICES

8.1 Appendix Care of Adults with CHD

From the Canadian Adult Congenital Heart Network Website (http://www.cachnet.org/managing_apps.html)

Types of patients who may be cared for exclusively in the community:

Valves:
- Isolated aortic valve disease
- Isolated mitral valve disease (except parachute mitral valve and similar anomalies)
- Mild pulmonic valve stenosis
- Isolated tricuspid valve disease (except Ebstein anomaly)

Shunts:
- Secundum atrial septal defect (closed, no residual shunt, no arrhythmia, no pulmonary hypertension)
- Ductus arteriosus after complete closure with no residua
- Ventricular septal defect (small and isolated, or repaired with no residual lesions)
- Repaired partial anomalous pulmonary venous connection

Types of patients who should be seen at national or regional ACHD centres (Alphabetical)

- Aorto-left ventricular fistula
- Atrioventricular septal defects
- Coarctation of the aorta
- Complete transposition of the great arteries
- Congenitally corrected transposition of the great arteries
- Coronary artery anomalies (except incidental findings)
- Criss-cross heart
- Cyanotic congenital heart patients (All)
- Double outlet ventricle
- Ebstein anomaly
- Eisenmenger syndrome
- Fontan procedure
- Heterotaxy syndromes
- Infundibular right ventricular outflow obstruction of significance
- Mitral atresia
- One ventricle (also called double inlet, double outlet, common, single, primitive)
- Partial anomalous pulmonary venous connection
- Patent ductus arteriosus (not closed)
- Pulmonary atresia (all forms)
- Pulmonary hypertension complicating CHD
- Pulmonic valve regurgitation (moderate or greater)
- Pulmonic valve stenosis (moderate to severe)
- Pulmonary vascular obstructive disease
- Sinus of Valsalva fistula/aneurysm
- Subvalvar or supravalvar aortic stenosis
- Tetralogy of Fallot
- Total anomalous pulmonary venous connection
- Tricuspid atresia
- Truncus arteriosus or Hemi-truncus
- Valved conduits
- Ventricular septal defect with:
  - Absent valves
  - Aortic regurgitation
  - Aortic coarctation
  - Mitral disease
  - Right ventricular outflow tract obstruction
  - Straddling tricuspid and/or mitral valve
  - Subaortic stenosis
### 8.2 Appendix Some human resource requirements

<table>
<thead>
<tr>
<th>Paediatric CHD centre</th>
<th>Adult CHD centre</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cardiologists</strong></td>
<td></td>
</tr>
<tr>
<td>Three or more specially trained cardiologists. It has been recommended that paediatric cardiologists are best placed to counsel parents in the treatment options for children with CHD, as cardiologists have more experience in longer term outcomes than other medical practitioners (135). One consultant paediatric cardiologist per half million populations served (94).</td>
<td>Requirement for two or more cardiologists with specific training (two or more years) in the medical management and investigation of adults with congenital heart disease (136).</td>
</tr>
<tr>
<td><strong>Surgeons</strong></td>
<td></td>
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<tr>
<td>Two or more surgeons with expertise in congenital heart surgery (112). The European Association for Cardio-Thoracic Surgery (EACTS) suggests that a full time surgeon should provide 125 operations per year and that the centre should complete over 100 neonatal and infant surgeries each year (112). A minimum of 4 full time consultant cardiac surgeons for tertiary centres (94).</td>
<td>The European Society of Cardiology stipulates that an individual surgeon should provide a minimum of 50 operations on adults with congenital heart disease per year (137-138).</td>
</tr>
<tr>
<td><strong>Electrophysiologists</strong></td>
<td></td>
</tr>
<tr>
<td>At least one electrophysiologist.</td>
<td>Adults with congenital heart disease have an increasing risk of arrhythmias (139), and international task forces have recommended at least one electrophysiologist (46).</td>
</tr>
<tr>
<td><strong>Radiologists</strong></td>
<td></td>
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<tr>
<td>At least one radiologist with specific expertise in cardiac imaging of infants and children with congenital heart disease</td>
<td>An adult congenital heart service requires at least one radiologist with specific expertise in cardiac imaging of adults with congenital heart disease (46).</td>
</tr>
<tr>
<td><strong>Paediatricians</strong></td>
<td></td>
</tr>
<tr>
<td>At least one consulting paediatrician.</td>
<td></td>
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<tr>
<td><strong>Obstetric and perinatal specialists</strong></td>
<td></td>
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<tr>
<td></td>
<td>It is recommended that high-risk obstetric care and genetic counseling services should be available for females with CHD who are pregnant or considering pregnancy (46).</td>
</tr>
<tr>
<td><strong>Nursing</strong></td>
<td></td>
</tr>
<tr>
<td>Nurses with specific training and skills are required. A minimum of 7 Children’s Cardiac Specialist Liaison Nurses are required in each tertiary centre (94). Sufficient cardiac clinical nurse educators to deliver standardised training and education competency-based programs (94).</td>
<td>Nurses with specific training and skills are required.</td>
</tr>
<tr>
<td><strong>Allied health</strong></td>
<td></td>
</tr>
<tr>
<td>Full complement of allied health professionals, including dieticians, occupational therapists, physiotherapists, psychologists, recreation therapists, social workers, speech therapists.</td>
<td>Recommendations from international studies of care of adults with CHD include access to psychologists, psychosexual counsellors and social workers (46).</td>
</tr>
</tbody>
</table>
NOTES:
Professor Sandra G. Leggat
Dr. Sandra Leggat is Professor of Health Services Management and Head of School of the La Trobe University School of Public Health located in Melbourne, Australia. Sandy has international experience in health system policy, organisation and management. She is editor of Australian Health Review, the leading Australian journal in health care policy and management, and is a member of the Northern Health Board of Directors. Sandy trained as a physiotherapist and has had substantial experience in health service management and consulting in Canada and Australia. Her research is focused on people and performance in health care.

HeartKids Australia
HeartKids is Australia’s only charity solely focussed on meeting the needs of Childhood Heart Disease.

As the public face of Childhood Heart Disease (CHD) and through active partnering with the medical community and Government, HeartKids hope is that Australia will adopt best practice in the intervention, treatment and support for all those affected.

This will result in a reduction of incidence, decreased mortality, significantly improved quality of life and best outcomes for those affected by CHD.

HeartKids:
- Employs Family Support Coordinators in each of the major children’s hospitals throughout Australia
- Runs Family and Teen activities
- Funds Research into CHD
- Provides equipment and facilities
- Assists families with travel and accommodation needs
- Advocates the needs of CHD to Government

www.heartkids.org.au

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