National Strategic Action Plan for Childhood Heart Disease

The announcement of the National Strategic Action Plan for Childhood Heart Disease (Action Plan) will help save lives and improve care for tens of thousands of Australians.

Minister for Health, The Hon Greg Hunt, launched the Action Plan with a total funding commitment of $26 million saying,

“The Australian Government is committed to supporting the Action Plan by providing funding towards seven key focus areas. This includes a significant amount towards research so that we can better identify the factors that cause congenital heart disease (CHD). It is important to recognise the burden of CHD and the acute mental health and socio-economic implications. I believe the HeartKids Project will be an enduring contribution towards saving and protecting the lives of these beautiful children with congenital heart disease.”

Eight babies are born with CHD in Australia every day. It is a lifelong condition that
will affect almost 6,000 new parents in Australia this year alone. It is one of the leading causes of death and hospitalisation in infants, affecting one in every 100 births according to the Australian Institute of Health and Welfare.

The Federal Government will provide $20 million for medical research into the genetic causes of CHD, prevention and treatment options. A further $6 million will help HeartKids implement the recommendations of the National Strategic Action Plan for Childhood Heart Disease.

The funding commitment coincides with findings from a new Australian survey of over 1700 people impacted by congenital heart disease, which has revealed that almost 80 per cent of parents whose children have CHD, experience profound psychological distress including anxiety, depression and post-traumatic stress disorder. The survey also revealed the lack of access to appropriate medical care, with many patients travelling more than 200 kilometres for specialist treatment, and facing significant out-of-pocket expenses.

HeartKids CEO, Rob Lutter said, “Congenital heart disease not only affects babies and children, but also more adults than ever before. This funding will make a significant difference to the delivery of specialist care so that every Australian CHD patient will be able to live life to the fullest.”

The Action Plan presents a comprehensive overview of the Australian CHD landscape, identifying needs, emerging challenges and includes a Framework for Action that will support those with congenital and acquired heart disease.

In acknowledging the many clinicians, researchers, ‘heart kids’, parents and carers of ‘heart kids’, policymakers and members of the community who contributed to the Action Plan, Jan McClelland AM, HeartKids’ Chair said “HeartKids is proud to have worked closely with the CHD community in developing the Action Plan.”

“The Action Plan is the first nationally-coordinated effort to tackle CHD and provides direction and guidance to transform care so that it is lifelong, holistic, person-centred and family-centred,” Ms McClelland said.
HeartKids CEO, Rob Lutter said, “The Action Plan highlights several serious issues that require urgent attention. The Framework for Action will allow us to start addressing these issues in our community. Disease awareness and education are also critical areas of focus, so families can have access to information, support and resources when and where they are needed.”

There is no known cure for CHD and those that survive often require a lifetime of highly specialised medical care. Sadly, four young lives are lost due to CHD each week.

Lisa Selbie, HeartKids Research Advisory Committee Chair, said, “The Action Plan and support of the Commonwealth government is critical to identifying the needs of the CHD community and key research investments will significantly transform diagnosis, treatment and management, improving the whole of life journey of those growing up with CHD.”

While congenital heart disease is diagnosed in babies and children, survival rates mean there are now more adults than children living with CHD. Unfortunately, more than 50 per cent of those impacted by CHD are becoming ‘lost to care’ as they transition from paediatric to adult cardiac health services.

**Click here to download the Action Plan.**

**About the Action Plan:**

The National Strategic Action Plan for Childhood Heart Disease 2019 - Beyond the Heart: Transforming Care (the Action Plan) aims to reduce the impact of childhood heart disease (CHD) in Australia and achieve the goal that people with CHD live longer, healthier and more productive lives through effective management of CHD across the life course.

CHD, which includes congenital heart disease and acquired heart disease, places a significant burden on the estimated 65,000 children and adults living
with CHD (‘heart kids’) and their family members and carers. [i] The disease significantly impacts Australia’s healthcare system, educational institutions, the workforce and the broader economy. CHD is one of the leading causes of death and hospitalisation of infants.[iii] [iii] [iv] CHD is a chronic condition that, for many patients, requires complex, specialised care across the life course.[v]

CHD survival rates have improved dramatically due to medical advances. Most people with CHD now survive into adulthood, and currently adults living with CHD outnumber children with the disease.[vi] [vii] [viii] [ix] The longer survivorship of people with CHD means we must now look beyond childhood and consider whole-of-life care and the cost to patients, the health system, workforce and national economy.

Despite prevalence and its significant impact on individuals, families, the health system and society, there is a lack of awareness of CHD in the community and among health professionals. There is also a lack of evidenced-based information and support for individuals with CHD.

Some sub-populations of Australians with CHD are disproportionately impacted by the disease, specifically: Aboriginal and Torres Strait Islander people; adolescents and young adults aged 15-24 years who are transitioning from paediatric to adult cardiac health services; and people living in remote, or rural and regional locations.

This Action Plan is the first nationally-coordinated effort to tackle CHD. It has been developed through close collaboration and consultation with clinicians, researchers, ‘heart kids’, parents and carers of ‘heart kids’, policymakers and members of the community. The Action Plan provides direction and guidance to transform care so that it is lifelong, holistic, person-centred and family-centred.
The Action Plan presents a comprehensive overview of the Australian CHD landscape, identifying needs, emerging challenges, opportunities for the CHD community and a Framework for Action. Implementation of the Action Plan will deliver:

- the first ever Australian standards of care for CHD, including world first neurodevelopmental and mental health standards;
- more specialist CHD health professionals and specialist CHD centres to provide access to CHD-relevant health and allied health services and support for all Australians impacted by CHD irrespective of where they live;
- increased awareness of CHD and its unique challenges and improved access to information, support and resources for all people impacted by CHD;
- research evidence that will inform earlier interventions and improved therapies to reduce the burden of CHD on all those affected; and
- monitoring and surveillance of the implementation of the Action Plan to ensure benefit for those impacted by CHD and the wider community.

The Framework for Action (Appendix 1) shows the link between the three priorities, seven focus areas, 29 recommended actions and desired outcomes of the Action Plan.

The priorities and focus areas are:

1. **Management, care and support**
   - Focus Area 1: Standards of Care
   - Focus Area 2: Infrastructure

2. **Supportive Communities**
   - Focus Area 3: Awareness and Education
   - Focus Area 4: Neurodevelopmental and Mental Healthcare
   - Focus Area 5: Priority Populations
3. Research

- Focus Area 6: Research Priorities
- Focus Area 7: Surveillance


National Strategic Action Plan for Childhood Heart Disease 2019
National Strategic Action Plan for Childhood Heart Disease:
- Word Version (DOCX 718KB)
- Pdf Version (PDF 1.7MB)

Compedia for the National Strategic Action Plan for Childhood Heart Disease (CHD) 2019
Compendium A - Consultation Summary and Implementation Partners

Word Document (DOCX 61.7KB)
Pdf Document (PDF 1.2MB)

Compendium B - Current Activities and Resources Stocktake

Word Document (DOCX 80.3KB)
Pdf Document (PDF 433.2KB)

Compendium C - Supporting Evidence

Word Document (DOCX 134.1KB)
Pdf Document (PDF 610.3KB)