NSW Paediatric Cardiac Services Model of Care Panel Recommendations
20 January 2021

This document summarises the outcomes from the Panel meeting held on 19 January 2021 for consideration of the Sydney Children's Hospitals Network (SCHN) Board as presented by the independent Chair, Professor Villis Marshall AC.

The draft Model of Care was endorsed by the Panel with agreement of the approach to deliver comprehensive, high quality cardiac services. The SCHN is responsible for incorporating Panel members feedback and redistributing the updated document. It was noted that there were no major concerns and the models of care should always be regularly reviewed to ensure they remain evidence based and contemporary.

There was detailed discussion and consideration of the RACS report (independent data and literature analysis), the Panel agreed robust data collection and analysis is required to inform the ongoing development of paediatric cardiac services and investment is required to support this.

The Panel Chair developed draft recommendations informed by the findings outlined in the RACS report for consideration of the Panel. There was consensus of the Panel for five of the six recommendations as follows:

1. The paediatric cardiac surgery service delivered by the Sydney Children's Hospitals Network (SCHN) is a statewide service providing care for the children of NSW. The service should work closely with the John Hunter Children's Hospital and local health districts across the state to establish comprehensive referral networks that ensure timely equitable access for all children in NSW.

   To support this goal the following recommendations from the RACS report are endorsed:

   - *Strong collaborative relationships with fetal maternal medicine services are necessary to ensure seamless care for newborns and their families and to ensure that the service can be responsive to innovations in prenatal cardiac diagnosis. This could be achieved through regular multidisciplinary care planning and case review through Mortality and Morbidity meetings.*
   - *If a transfer of an infant is required, processes must be in place to facilitate timely transfer once the decision to transfer is made.*
   - *An ECMO advisory service should be established with appropriate governance to allow early identification of patients who require ECMO, so that they are transferred at the earliest possible time. This service should have a single contact point to co-ordinate the required resources and manage the required 24/7 availability.*
2. The statewide service should operate as a single service across the two SCHN sites with a commitment from the SCHN to continue to strengthen existing teams and to build cross-site collaboration through a focus on the multidisciplinary team.

   To achieve this goal the following recommendations from the RACS report are endorsed:

   - *Surgeons who provide 24/7 emergency cover require appropriate rosters. The RACS and National Health Service (NHS) England have recommended roster frequencies. To support the number of cases with the required 24/7 roster, an appropriately skilled team of surgeons is required to treat congenital paediatric cardiac cases. The NHS England recommends that a team of at least four surgeons doing at least 125 congenital or paediatric cardiac cases per surgeon annually (paediatric and adult) is required. Consideration should also be given regarding the support required for children to transition to the adult service.*
   - *The SCHN needs to finalise and implement a model of care, including consistent and shared guidelines and pathways, as well as shared patient selection criteria.*
   - *There should be one service delivery model, which is provided across the two sites including: a coordinated and collaborative approach to waitlist management, joint multidisciplinary meetings pre- and post-surgery with both sites supporting each other, shared rosters (see following recommendation 14 below). Robust data collection and monitoring is essential.*
   - *Staff need to be appropriately trained/experienced medical and nursing staff. Rostering across the network for 24/7 cover will take into account staff sustainability, including paediatric surgery and interventional cardiology cover.*

- *Adequate support for cardiology interventions will be required to account for the predicated increase over the next decade for interventional treatment of atrial and ventricular septal defect closure and patent ductus arteriosus occlusion.*

3. The SCHN should continue to work closely with patients, parents, carers and families from across NSW to ensure the service is meeting their individual needs. The care provided should be a seamless experience for families regardless of which site they are receiving care. Similarly, for families being referred to SCHN from John Hunter Children's Hospital or other local health districts their experience should feel like a continuation of their care journey.
4. Monitoring and evaluation of the SCHN service will be essential to ensure the service is achieving the best outcomes for patients, their families and carers. To do this the SCHN should commit to collecting a standardised minimum data set which will include patient-reported and parent-reported outcomes and experience.

   To support this goal the following recommendations from the RACS report are endorsed:

   - *Data collection and data definitions should be standardised between all centres, and data should be collected at the procedure level.*
   - *There should be an independent audit of data to provide a quality assurance validation process to ensure that submitted data quality is of a high standard, being both accurate, pertinent, as well as ensuring all eligible patients are captured.*
   - *Data collection should ensure that patient details are fully recorded and that patient selection criteria is clear and transparent.*
   - *Additionally, all cases should be documented about whether or not they had surgery during that admission or if their case was delayed for any reason. Data needs to be collected on all aspects relating to a delay, whether it be in decision-making, transfer or treatment.*
   - *Economic sustainability needs to be looked at, as factors other than volume, such as length of stay and cost, should also be considered in the performance of services. The data collection needs to include items that can be used for such evaluations and for monitoring purposes.*
   - *Patient data should be collected so that the effectiveness of the service can be measured and the impact this has on patient outcomes understood. Additionally, patient/parent experience should be collected through surveys or other mechanisms.*
   - *Results of genetic testing should be included in data collected to improve understanding of their relevance and impact on preoperative and postoperative care.*

5. On the SCHN Board's acceptance of these recommendations, the SCHN will provide the NSW Ministry of Health with a proposal by 31 March 2021 for how they will use the $10 million already announced by the Government to support implementation. This funding 'of up to $10 million for equipment and infrastructure to ensure specialists are further assisted in delivering paediatric cardiac services' was announcement by Minister Hazzard in January 2020.

There was no consensus by the Panel for the recommendation relating to patient selection and site (refer below). There was discussion regarding the governance and decision making process for the recommendations where there is no consensus, this is ultimately a decision for the Board. There was agreement that the Panel Chair would reflect the discussion from the meeting with the Board including feedback regarding the data and literature review, consideration of resourcing impacts, equivalence of outcomes and the level of investment required.

The following recommendation is provided for the deliberation of the Board.

6. Appropriate patient selection will be essential to provide the best and safest care for children.

   - *For the highest complexity cases (assessed by complexity/STAT scores), the low numbers in NSW would not support operation at two sites.*
   - *Where procedures are of medium complexity, these could be safely conducted across two sites informed by a multidisciplinary team meeting (including the Divisional Network Director and clinical team members from both sites). This meeting would consider which site is best placed to manage each case based on various factors including, appropriate patient selection (e.g. age, comorbidities, previous history) and availability of resources (e.g. operating theatre, intensive care unit (ICU), specialist cardiac or allied health staffing).*
   - *Lower complexity cases should be conducted at both sites but with a decision made based on the best care for the patient (based on treatment in an appropriate timeline).*