Board Meeting

22 January 2021

Present: Elizabeth Crouch AM (Chair), David Nott, Jane Freudenstein, Emeritus Professor Les White AM, Jack Ford, Professor Donna Waters, Dr Abby Bloom, Jeremy White, Professor Louise Baur AM, Emeritus Professor Kim Oates AO, Dr Elizabeth McEntyre and Bruce MacDiarmid.

Guests: Professor Villis Marshall AC

In Attendance: Cathryn Cox PSM, Dr Joanne Ging, Rebecca Williams and Emma Cuell (Secretariat)

1.0 Meeting Opening

1.1 Acknowledgement of Country

The Chair acknowledged the traditional custodians of the land on which we meet, paying respect to elders past, present and emerging.

1.2 Apologies

Nil

1.3 Declaration of Interests

Nil

2.0 Matters for Discussion

2.1 NSW Paediatric Cardiac Services Model of Care Panel

The Chair welcomed everyone to the meeting and introduced Professor Marshall AC, Chair of the NSW Cardiac Paediatric Services Model of Care Panel (**Panel**). Professor Marshall provided an overview of the work of the **Panel** including the overarching principles and associated processes as follows:

- The **Panel** was established to develop a Model of Care, implementation plan and clinical outcomes evaluation that defines the delivery of high quality, effective and safe cardiac services for children and young people in NSW.
- The Terms of Reference provided the Model of Care was to be patient and family centred and define the delivery of health services based on best practice care to ensure children get the right care at the right time, by the right team and in the right place. With patients and families to be full partners in the co-design process.
- The **Panel** met on four occasions and it became clear at initial meetings that the **Panel** would need expert help to achieve these requirements and ensure they were evidence based.
- Two organisations were contracted to provide the external support the **Panel** needed:
    - ASERNIP-S a resource provided by the Royal Australasian College of Surgeons (RACS) was commissioned to review published literature, conduct an independent verification and analysis of SCHN data and review further data and analysis from other sources including the ANZ paediatric intensive care registry. Three independent expert clinicians reviewed the ASERNIP's report prior to finalisation.
    - Johnstaff was commissioned to work with the **Panel** to develop a model of care in consultation with key stakeholders.
- The findings from both of these organisations were provided to the expert **Panel** with a series of recommendations for consideration.
- As the paediatric cardiac service delivered by the Sydney Children's Hospitals Network (SCHN) is a statewide service it was noted that 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.

The **Panel** unanimously agreed to the following recommendations:

1. The paediatric cardiac surgery service delivered by the 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 were endorsed by the **Panel**:

   - *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 were endorsed by the **Panel**:

   - *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 predicted 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 were endorsed by the **Panel**:

- *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 following recommendation. The **Panel** agreed this would be provided to the **Board** for consideration and decision.

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).*

The concern for some **Panel** members with this recommendation was largely related to the level of evidence for paediatric cardiac surgery, the time periods considered and historical narrative.

The **Board** reviewed and noted the RACS independent analysis of SCHN cardiac surgery data and findings. The **Board** also noted that some **Panel** members who were concerned about the accuracy of the RACS data analysis, subsequently provided additional data. This additional data was further reviewed by RACS with confirmation and assurance that the data analysis provided within the report was correct.

The **Board** discussed and noted:

- The agreement by the **Panel** that the highest complexity cases should be done at one site. The **Board** noted data which confirmed that prior to all surgical work being done at CHW, approximately 2/3 of the cardiac surgical cases were performed at CHW and 1/3 at SCH. It was also noted that the majority of cases at SCH were less complex in nature.

- The findings of the RACS report highlighting the paucity of high quality evidence, including clinical outcomes associated with a single cardiac service operating across multiple sites. The closest example was from Canada with two hospitals in close proximity performing paediatric cardiac surgery with lower-level surgery performed at one site, although this was not a randomised control trial and other factors were not considered e.g. staffing.
- The importance of patient factors and resources and the need to carefully consider all factors in relation to the care of patients with varying levels of complexity as highlighted in the RACS report.
- As Professor Marshall observed, this presents an important opportunity for SCHN to fill this evidentiary gap and provide key data globally on patient outcomes across a single service.
- The impact of operationalising surgery on two sites and the number of surgeons required for sustainable rostering. The Chair noted that the **Board** needed to consider and discuss the recommendations from the **Panel** and resolve whether to support those recommendations; it was then up to the SCHN Executive and team to determine how to operationalise the decision of the **Board**. The **Board** was not expected to opine on issues such as "sustainable rostering" but should concern itself with how high quality services can be delivered safely and cost effectively.
- RACS had provided three categories for paediatric cardiac surgery and proposed site based arrangements:
    - Highest complexity – should be single site
    - Medium complexity – could be two sites
    - Lower complexity – should be two sites
- The **Board** noted there was not consensus by the **Panel** for the categorisation although there was support for highest complexity being at a single site. The **Board** also noted the other considerations identified in the RACS report related to quality and safety. The impact for emergency work if elective work was only conducted at one site.
- The Importance of keeping the child at the centre of decision making.
- Professor Marshall provided the following observations:
    - there remains a strong feeling from CHW representatives on the **Panel** that they wanted to retain present arrangements for cardiac surgery and were not prepared to contemplate any other structure.
    - there was evidence to support lower cases being done at other institutions with appropriately trained staff, and a roster system in place to ensure it is safe and workable as far as the patient is concerned.
    - the SCHN service could be one of the best in the country by adopting the Model of Care and could add significantly to the body of evidence regarding patient outcomes and service configurations.
    - it is reasonable and supported by evidence to have a single service and two site model; SCHN will need to work with key individuals to implement this model and contribute data more broadly on the outcomes of this model.
    - clinical governance is essential to ensure ongoing monitoring of quality and safety outcomes, with data collection and analysis to provide evidence and inform decision making.
- Paediatric cardiac surgeons currently work across other sites, working in other facilities for adult congenital and/or adult cardiac surgery.
- Since December 2020 SCHN has had a 1 in 4 roster for cardiac surgery.
- The **Board** Chair and Deputy Board Chair have had several discussions this week with CHW and SCH clinicians and the full **Board** was briefed on the nature of those discussions and the views expressed by individuals.
- The Minister announced in January 2020 there would be one cardiac service across two sites, this process is about the implementation of that decision. The Model of Care has been developed, the literature and data analysis has confirmed complex cardiac surgery should occur in one location, and for medium complexity and less complex surgery there is an opportunity to rebuild the service as a world class service across two sites.

- The background notes provided by Dr Yishay Orr and Dr Phil Roberts to the **Board** were noted. Dr Orr's subsequent email was also noted and reiterated that there was not support for a two site model. However, it did indicate that cardiac specialists will work with the Executive to operationalise the decisions of the **Board**.
- Considerations for operationalising the Model of Care included discussion regarding strategic and operational risks, the **Board** also noted:
    - The importance of data and system improvements required to capture and track morbidity and patient experience outcomes, data collection resources are also required at both sites and this would form part of the $10M from the Ministry.
    - The need for additional allied health and nursing staff for the SCH cardiology service, not to duplicate arrangements, but provide greater wraparound services and support for patients and families.
    - infrastructure requirements and availability of a bi-plane at SCH for cardiac catheterisation if required; discussions have commenced with SESLHD with opportunities identified through the Eastern Heart tender process.
    - clinical leadership appointments for SCH Head of Department – cardiac surgery and cardiology and a Network lead for fetal medicine.
    - the crucial importance of working with clinicians to rebuild the relationships and bring the teams together to develop confidence and trust.
    - there is agreement on a range of procedures that can be performed at both sites. There is a commitment from the cardiac surgery team to support trauma and emergency care at SCH, with consultation and onsite support for thoracic and oncology services.
    - a previous request has been provided to the Ministry of Health from the **Board** regarding funding to support cultural transformation work at SCHN. The Board acknowledged the continued importance of this work.
- The $10M from the Ministry is not recurrent. Whilst there will be some one-off infrastructure costs SCHN are working on an approach to distribute the funding over a three year period which will allow a better understanding of the annualised impact and requirements for the service. Following the decision by the **Board**, the SCHN will provide an outline for the $10M funding to the Ministry in March 2021.

The **Board** acknowledged the significant achievement in development of the Model of Care. It reflected the importance of keeping the patient at the centre of decision making and ensuring a high quality and safe service for NSW children and young people. It provides the blueprint for ongoing development of an excellent service and was unanimously supported by the Board.

The **Board** noted the importance of financial sustainability in the implementation of the Model of Care. To support this, the **Board** has requested the Chief Executive to provide relevant data and reporting as part of the operationalisation of the Model of Care over time including quality and safety, financial, economic and operational (including patient outcomes and experiences) data.

The **Board** accepted the five recommendations that were unanimously agreed by the **Panel** and with regards to recommendation 6 will finalise deliberations over the coming week regarding the arrangements for the one service, two site model for cardiac surgery.

Following the **Board's** decision, a communique will be developed and provided to the **Board** prior to distribution to the **Panel**, Cardiac Services Team, SCHN staff and all stakeholders.

The **Board** Chair thanked Professor Marshall and acknowledged his leadership and the work of the **Panel**, particularly the comprehensive analysis and work of RACS and Johnstaff to provide the Model of Care and inform the recommendations to the **Board**.

The **Board** thanked the **Board** Chair, Chief Executive and Executive Director Clinical Operations for their efforts and active engagement with key stakeholders throughout the Panel process.

3.0 Any Other Business – nil