



Special Commission of Inquiry into Healthcare Funding

Submission Number: 14
Name: Sydney Children's Hospital Network
Date Received: 31/10/2023



The Sydney
children's
Hospitals Network

Special Commission of Inquiry into Healthcare Funding

Sydney Children's Hospitals Network Response

October 2023

Table of Contents

Introduction	3
About the Sydney Children’s Hospitals Network	3
Quick facts	4
Innovative approaches to care.....	6
virtualKIDS (Item H)	6
Kids Early Years Network (KEYS) (Item B and H).....	8
Quiet Pathway (Item H)	9
Providing Enhanced Access to Health Services (PEACH) (Item H).....	9
Minderoo Children’s Comprehensive Cancer Centre (Item H)	10
Opportunities and challenges.....	11
Sustainability (Item A and D)	11
Research and innovation (Items F and H)	12
Aboriginal Health (Item A and B).....	14
Philanthropy (Item B).....	14
Redevelopments (Item A and H)	15
Partnerships (Item B).....	16
Workforce (Item F)	17
NSW Health-wide systems	20
System transformation and the future of healthcare (Item H)	20
Disability (Item H).....	21
Activity Based Funding (ABF) (Item A).....	21
Mental Health (Item A and F)	25
Digital (Item H)	26
Conclusion.....	26

Introduction

The Sydney Children's Hospitals Network (SCHN) is pleased to provide a response to the Special Commission of Inquiry into Healthcare Funding.

This response has been structured to provide details about the Network and examples of our innovative approaches to care for children and young people. Information is included on the issues associated with the provision of highly complex care in the paediatric setting. For ease of navigation alignment to the letters patent is indicated in the topic headings.

About the Sydney Children's Hospitals Network

SCHN is the largest paediatric healthcare entity in Australia providing tertiary and quaternary paediatric healthcare services. SCHN was formed in 2010 in accordance with the *Health Services Act 1997*.

Care for children and young people is a critical component of the NSW health care system. It is important to ensure that any changes to governance arrangements do not dilute the focus and need for care for children and young people, but rather broadens and strengthens the recognition of its importance, facilitates access, and promotes excellence of care for children and young people in NSW and Australia. Considerations include:

- The importance of investing in caring for children and young people who are our future.
- Creating a resource and support to all Local Health Districts (LHDs) from a centralised expert paediatric service in NSW.
- Facilitating strong service networks to support specialised care for children wherever they live in NSW.
- Standardising best practice care across like services, where possible.
- Strengthening paediatric workforce development through collaborative education and training programs.
- Embedding strategies and practices state-wide that contribute to combating adult ill health through childhood and adolescence health promotion and harm prevention activity.

SCHN comprises the following services:

- **Sydney Children's Hospital, Randwick (SCH)**, located in Sydney's east, providing specialist inpatient and outpatient services.
- **The Children's Hospital at Westmead (CHW)**, located in Sydney's west, providing specialist inpatient and outpatient services.
- **Bear Cottage** at Manly, providing care for children with life-limiting conditions and the only children's hospice in NSW. Bear Cottage provides paediatric palliative care 24 hours a day.
- **Kids Research**, a Network service with more than 600 researchers, support staff, and students, dedicated to discovering new ways to improve the health of children. The team undertakes cutting-edge research into childhood diseases, resulting in significant advances in the treatments of cancer, obesity, kidney, heart, and respiratory problems, diabetes, muscular dystrophy, and other childhood conditions.
- **NETS (Newborn and paediatric Emergency Transport Service)** is a statewide service, hosted by the Network, with its base at Bankstown, providing 24 hour a day clinical advice, coordination, and emergency treatment and transportation for sick babies and children across NSW and the ACT.
- **Children's Court Clinic**, located in Parramatta, undertaking independent clinical assessments for children to help magistrates and judges in NSW Children's and District Courts make decisions in the best interest of children.

We are committed to providing world-class paediatric healthcare in a family-focused, healing environment. Children and young people have access to speciality clinical services in areas including oncology, cardiac, neurosciences, respiratory, severe burns, ear, nose and throat, plastics, orthopaedics, vascular, gastroenterology, complex medical and surgical services, anaesthetics, pain management, gender, adolescent medicine, organ, bone marrow or cord blood transplants, advanced gene therapies, imaging and mental health.

Our patients range from newborns usually up to those aged 16 years. Our services care for the most complex patient cohorts, with highly specialised services to treat children and young people who are not able to be safely cared for in any other setting.

Some patients will visit us just once or twice, but for others our staff and hospitals become part of their childhood and our teams respond to the unique needs and goals of each individual. We hold 'graduations' for patients and families who have had a long association with our hospitals. It is a chance to recognise an important milestone in their healthcare journey and celebrate with their peers, family, and treating team as they transition to the adult system.

We also recognise that it can be daunting for young patients – and their parents – when the time comes for them to move to the adult health system. To support this next stage of care, our Trapeze service enables current and past patients (with a chronic condition) aged 14-25 from SCH or CHW to make a seamless transition to an adult based healthcare facility.

Children and families with life limiting conditions are offered palliative care and bereavement support.

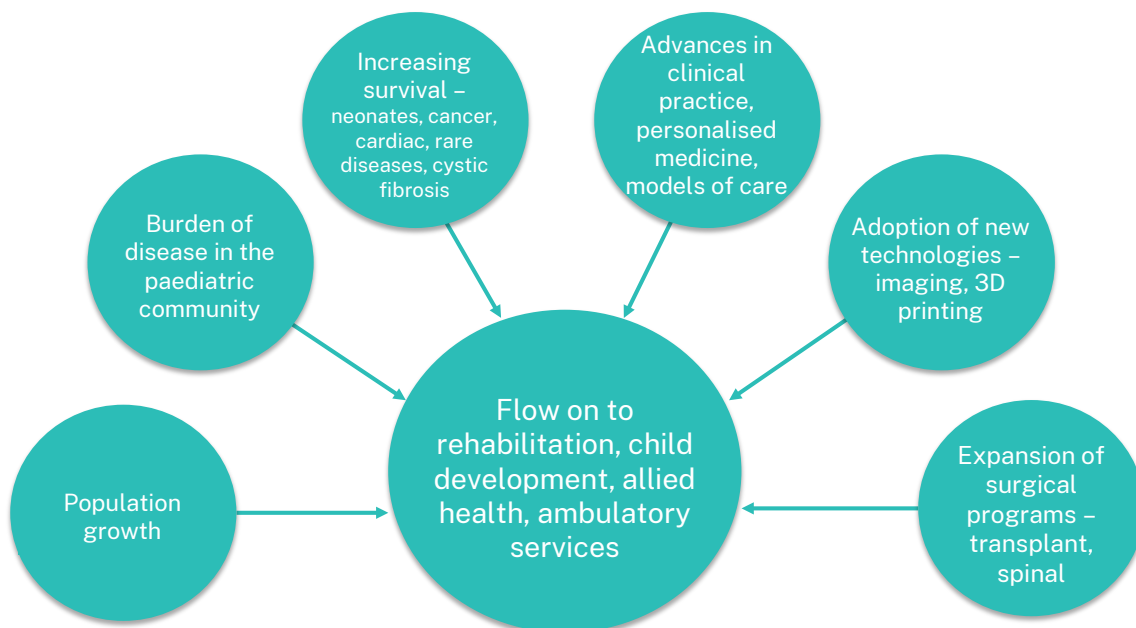
SCHN provides statewide tertiary and quaternary level services, relied upon by LHDs and other community health services for expert advice, support for workforce development, referral and retrieval arrangements, and models of care that support the best access for the children being cared for. The Network has strong relationships with John Hunter Children's Hospital to ensure services are planned collaboratively and are complementary, as well as with paediatric services provided locally across NSW and the ACT.

The SCHN organisational structure chart is available at https://www.schn.health.nsw.gov.au/files/attachments/exc7534_organisational_structure_0722_fa.pdf. The SCHN Board comprises up to 13 members who bring a broad range of skills and expertise in areas of health and clinical practice, management, finance, risk, and business leadership.

Quick facts

- From 2021 to 2041, the NSW population is projected to increase by 21%, from approximately 8.2 million to 9.9 million.
 - The paediatric population aged 16 years and under accounts for 19.5% of the NSW resident population and is projected to increase by 6% (around 100,000) from approximately 1.6 million to 1.7 million.
 - The population aged 0 – 4 years is projected to grow by 12% (approximately 70,000) from 480,000 to almost 550,000, and aged 5 – 16 years by 4% (almost 45,000).
- The local catchment for CHW comprises the Local Government Areas (LGA) of The Hills Shire, Cumberland City, and City of Parramatta. The local catchment LGAs for SCH are Botany Bay, Randwick, Sydney, Waverley, and Woollahra.
- The majority of inpatient activity for the Network in 2020-21 was for:
 - General paediatrics
 - Respiratory medicine
 - Orthopaedics
 - Gastroenterology
 - Haematology
 - General surgery
 - Neurology
 - Oncology

- Care and support are provided by more than 5,000 Full Time Equivalent (FTE) staff and more than 600 volunteers.
- Each year, across the Network there are:
 - approximately 59,000 inpatient admissions
 - about 105,000 emergency department presentations
 - over 1 million outpatient occasions of service
 - nearly 190,000 occasions of service delivered in the community or in the home
 - approximately 20,000 operations (elective and non-elective)
 - approximately 4,000 NETS retrievals from across NSW
 - around 260 Bear Cottage patient admissions.
- The past few years have seen significant changes to our models of care, with many services provided through ‘telehealth’ – there was an increase of more than 1,500% in telehealth appointments in the second quarter of 2020 (15,405) compared to the second quarter of 2019 (955). In 2019-20 this saved families more than 2.5 million kilometres in travel. SCHN is the second highest user of My Virtual Care in NSW.
- Major capital works are occurring at SCH and CHW, contributing significantly to the transformation of these hospitals and the services they provide, representing the single biggest investment in paediatric hospitals in NSW.
- There is a range of factors which contribute to the health and wellbeing of children and young people. Many of the diseases of adulthood have their start in childhood and so there is enormous potential to impact the health outcomes of adults by addressing these factors early. Some of these include overweight and obesity, disability, mental health, congenital conditions, acute infections, and injury and poisoning.
- Demand drivers for SCHN specialist clinical services include:



Innovative approaches to care

Health systems around the world are facing challenges such as attracting and retaining a skilled workforce, adapting to changes in technology, responding to changing community and patient expectations, and rising healthcare costs. This requires different ways of delivering care, thinking differently about our future workforce, and working with our communities to understand and support the significant changes that need to occur to achieve a safe, sustainable and resilient paediatric health system.

Examples of innovative approaches to care that the Network has implemented are highlighted below. Each of these can be scaled and adapted to meet local requirements.

virtualKIDS (Item H)

virtualKIDS is a 24/7 nursing-led service, with medical and administration support, providing a single access point to SCHN. It manages the information, communication, clinical advice, and logistics for children requiring tertiary paediatric care, in collaboration with local paediatric teams and other care providers.

The vision for virtualKIDS is to transform 'kids health' through choice, access, and digital healthcare. The following principles were developed to define our approach to virtual care:

- *Virtual first* – aiming for at-home intervention and support first. Connecting virtually to SCHN, and only coming physically to SCHN when absolutely required.
- *Choice* – empowering families to choose the healthcare that best suits them, including where and how they receive help.
- *Informed-care navigation* – providing families with options to make an informed decision on how their care is best delivered.
- *Family-led care* – empowering kids and families to take charge of their own health. This can be done by providing care, support and training tailored to their circumstances.



Through technology and virtual care, virtualKIDS delivers care for patients closer to their homes by working in partnership with local clinicians and building important relationships. This single access point is enabled through virtualKIDS' free to call 1800-phone number, available 24 hours a day, seven days a week.

virtualKIDS was implemented during the COVID response, launching in June 2021, and in less than four months 10,000 patients from across NSW were cared for through the service, with activity peaking in September 2021 with over 2,500 active patients. This showed the ability to rapidly implement change at scale.

The virtualKIDS service is continuing to expand into other areas of care and now includes:

- virtualKIDS Urgent Care Service.
- virtualKIDS Acute Review.

- Kids GPS hotline – 24 hour access for families with clinically complex children enrolled in the SCHN Care Co-ordination and Navigation Service Kids GPS (Guided Personalised Service).
- Rural and regional advice facilitation.
- Remote monitoring, including sleep studies at home.
- Support for day only procedures including knee surgery and tonsillectomy.

For patients transferred to SCHN from local services for care, 75% of families would prefer care closer to home when safe to do so. Importantly, nearly all (more than 99%) of our patients and families who have used virtual care have rated their experience as good or very good, with almost 95% saying their virtual care experience was better or as good as an in-person appointment.

Although this work started prior to COVID-19, the pandemic has demonstrated the innovation and adaptability of SCHN teams towards a virtual future, which has seen:

- More than 100 SCHN departments set up on telehealth.
- A 2,128% increase in telehealth service events.

SCHN's virtual care centre, 'Kids HQ', comprises staff from patient flow, nursing, integrated care, Kids GPS, virtualKIDS, and the Emergency Operations Centre, all working to support the smooth and coordinated movement of patients in and out of SCHN and accessing care closer to home. The physical space was completed at CHW in late-2021, and will be delivered at SCH with completion targeted in 2025.

Identified benefits and outcomes for this model of care include:

- Improved support for paediatric care teams to deliver care locally.
- Improved health system efficiency.
- Improved collaboration and communication with local care providers.
- Reduced movement of patients across the health system.
- Decreased travel and significantly reduced disruptions to work, schooling, and family life for our patients.
- Improved experiences for children and families navigating the health system.
- Improved environmental sustainability through reduced travel.

The vision for virtualKIDS is for a 24/7 innovative, digitally enabled health network and hub, supporting paediatric service delivery across NSW with:

- Supportive care - designed to remotely support families whilst residing in the community. The key focus is emergency department avoidance and reducing inpatient length of stay.
- Care closer to home - the scheduling, coordination, and facilitation of paediatric outreach services across NSW, considering the balance of face-to-face and virtual appointments.
- Advice and transfer coordination - managing the communication, clinical advice, and logistics for children requiring tertiary paediatric inpatient care. This is planned to be a step-based acuity approach utilising advice and virtual ward rounds prior to any decision to physically transfer.

virtualKIDS Urgent Care Service

SCHN has partnered with John Hunter Children's Hospital to provide a statewide, 'single front door' for families to access prior to presenting to an emergency department. In April 2023, it was announced that the virtualKIDS Urgent Care Service, then operating in only three Local Health Districts (LHDs) – South Eastern Sydney, Western Sydney, and Hunter New England – would be funded for two years and rolled out statewide by the end of 2023. South Western Sydney is now live, and Western NSW and Mid North Coast LHDs commence on 30 October 2023.

The Service works via HealthDirect. Children are assessed via video conferencing with a specialist paediatric nurse, who then determines the patient's best care pathway and care provider based on their specific needs. That might be a trip to the emergency department, a consultation with a paediatrician, ongoing management by the virtualKIDS service, or a visit to a local GP or urgent care centre. The Service seeks to keep children out of emergency departments and provide care closer to home, also reducing low acuity triage category 4 and 5 patients presenting to NSW-wide emergency departments. This is achieved by providing virtual consultations in the home and facilitating linkages to local services and primary care. The statewide expansion is also expected to provide specialist paediatric advice to clinicians in rural and regional hospitals and to paramedics in non-emergency situations. This recognises the workforce challenges for rural, remote, and regional areas in providing these services for their populations.

The virtualKIDS Urgent Care Service has managed over 2,000 calls since commencing in December 2022. Over 65% of the calls that have had access to this secondary triage have not required attendance at an emergency department for the duration of that illness. There are also many calls that have had 'red flags' identified by the team immediately and an ambulance has been dispatched to ensure the safety of those children. The children have then been referred for follow up by their usual GP if possible, or to a GP based urgent care centre, or managed by the virtualKIDS Acute Review Service. This has led to the parents being empowered with appropriate knowledge and supported to manage their children with their next illness.

virtualKIDS Acute Review Service

The virtualKIDS Acute Review Service has been operating since June 2022 and has managed over 4,000 children referred from emergency departments to prevent an admission or following early discharge to facilitate shorter lengths of stay or representations. The feedback from families shows over 95% are very satisfied with the service. This service was a finalist in the NSW Health Awards in 2023.

Kids Early Years Network (KEYS) (Item B and H)

KEYS is a collaboration between the Western Sydney Primary Health Network, NSW Department of Communities and Justice, SCHN, Western Sydney Local Health District, and the Department of Education. KEYS aims to promote partnership between services and share information respectfully and securely between providers, so that 'no family gets left behind'. KEYS commenced engaging families in May 2021 and currently predominantly serves the Western Sydney Local Government Areas of Blacktown, Cumberland, The Hills Shire, and Parramatta.

As provided in the KEYS Evaluation Report ¹, there is compelling global evidence that community-based system integration is urgently needed to improve equity of service access and address the social determinants of health for children and their families. The nature and impact of strengths and adversity in childhood is multifaceted and there are multiple trajectories over time from early adversity to children's developmental outcomes. By the time children begin school in Australia, clear inequities in health and developmental outcomes are already evident, driven by the circumstances they live in and the failure of health, welfare, and educational systems to work together to ameliorate these impacts.

In 2018, 15.4% of children living in the poorest areas of Australia were developmentally vulnerable on two or more domains of the Australian Early Development Census compared to the national average of 11.0%. Research studies have suggested that a child's development is impacted by multiple levels of the child's environment, and the impact over the life course. To be effective, responses to child inequities must be similarly complex, engaging diverse organisations, community supports, child welfare services and others to meet the complex needs of children and families.

¹ Kemp L, Donohoe K, Elcombe E, Bucknall N, Anderson J, Blythe S (June 2023). Kids Early Years Network (KEYS) Evaluation. Translational Research and Social Innovation, School of Nursing and Midwifery, Western Sydney University and Ingham Institute for Applied Medical Research. Liverpool NSW.

KEYS is a different way of working across agencies and has involved realignment of staff, centred on the family, with systems and resources supporting family-centred plans, aiming to provide effective consumer-led and person-centred integrated care, particularly to meet the needs of children and families. 617 families have been referred to the KEYS Network, with 419 of these families having now successfully exited the program.

KEYS works to navigate the complex governmental system for priority population families using KEYS navigators embedded in all the partner organisations who work together, and in addition there are specific navigators for disability, housing, and Aboriginal care. Brokerage funds are used to pay for services that are time critical to achieve family goals - for example, paying the bond for rent, or a childcare bond. The other main task for KEYS is to work with the Lead Service Providers in Western Sydney to revamp their services to meet the needs of these families.

The initial evaluation has indicated that KEYS is a healthy and effective collaboration providing a quality client-centred and client-led wrap-around service that assists providers to access needed services for families and improving family wellbeing. The evaluation also indicated that the program provides a considerable annual and lifetime return on investment. Further evaluation is ongoing and will assess developmental, educational, and health outcomes.

Quiet Pathway (Item H)

Children with complex anxiety, autism, and other behavioural and intellectual disabilities are challenging paediatric services across NSW hospitals to provide optimal care and support staff in often difficult and stressful circumstances for the child, family and staff.

The 'Quiet Pathway' is a successful perioperative program for children with severe anxiety, autism, and other behavioural and intellectual disabilities. This individualised stewardship program makes the perioperative journey safe and stress-free for these children. It involves early identification, avoidance of pre-admission visits, and pre-hospital anxiety management.

The program involves working with carers to tailor care to support the individual needs of the child. Collaboration between healthcare teams means several procedures can be carried out under one anaesthetic, reducing the need for multiple hospital admissions. When patients come to hospital they are admitted directly to an anaesthesia bay, avoiding crowded areas and distractions. Creating a safe and calm space reduces anxiety for the child and their family.

The program has radically changed perioperative care for this vulnerable group of children through innovative use of the building, clustered care, and pre-hospital anxiety-management. In this way, the experience of carers and patients has been streamlined and transformed.

Working in partnership with carers and multiple medical and surgical teams has been central to success. The program regularly involves collaboration with general and community paediatricians, local pharmacy services, and community disability service providers. Treatment goals are shared, and plans are tailored to suit the individual circumstances of each child. Openness to the experiences and insights of the carer is fundamental to the assessment. The program won the Transforming Patient Experience NSW Health Award in 2022.

Providing Enhanced Access to Health Services (PEACH) (Item H)

We know children and young people from priority populations have more difficulty accessing health services. Patients from priority populations have higher rates of non-attendance, spend longer on waitlists, and have poorer health outcomes, including higher rates of mortality for Aboriginal inpatients. The PEACH project aims to change this.

The PEACH concept is that if we are to reduce inequities in health outcomes, we all need to do things differently and advocate for our patients from priority populations to support their access to our health services. The project uses co-design with collaboration between consumers and staff, as well as quality improvement methodology and existing data to inform decision-making.

The project is focused on:

- The early identification of children and young people from priority populations.
- The provision of supported, enhanced, and equitable care for children and young people.

- The enhancement of systems and processes utilising technology-based solutions such as the electronic medical record (eMR).

The project is focused on providing care for priority groups:

- Aboriginal and/or Torres Strait Islander children.
- Children and young people in Out of Home Care.
- Refugee/asylum seekers.
- Children living with disability.
- Children and young people from Culturally And/or Linguistically Diverse communities.

Consumer engagement has been a key area of focus to understand the patient needs with over 40 individual consumer interviews undertaken across the priority groups to prioritise and explore key areas. The project has also brought staff and consumers together in co-design workshops to explore ways we can do things differently to support access and health outcomes for children and young people.

Minderoo Children's Comprehensive Cancer Centre (Item H)

The Minderoo Children's Comprehensive Cancer Centre (MCCCC), being developed as part of the Stage 1 redevelopment of Sydney Children's Hospital, Randwick, is a leading example of the future of medicine being demonstrated in NSW and a nationally leading model. SCHN, including the Kids Cancer Centre (KCC), the Children's Cancer Institute (CCI) and the University of NSW (UNSW) are partnering in the formation of the MCCCC.

Achievement of the vision of the new centre is also being supported by philanthropic funding through the Minderoo Foundation and Sydney Children's Hospitals Foundation and generous donors.

Traditionally, it takes many years for research to translate into clinical practice and change patient outcomes. By physically co-locating scientists, clinicians and educators in a collaborative multi-disciplinary environment, the MCCCC will enable accelerated care outcomes to inform and transform the treatment of childhood cancer and translate laboratory discoveries into clinical trials and clinical care. It will also enable clinicians to work with researchers on finding the answers to the questions challenging the optimal delivery of clinical care. That is, clinical care is both informed by, and informing, research endeavours.

The MCCCC will provide a home to precision medicine and support children with cancer and their families wherever they live in Australia. The centre comprises of purpose-built clinical, research and collaboration zones. The KCC clinical services and CCI's research endeavours will be fully co-located and bring together technologically advanced laboratory spaces, education zones, a public laboratory to engage the community and new inpatient cancer units.

The laboratory spaces will use ground-breaking technologies to foster innovation in biopsies, bone marrow transplants, 3D tumour printing, cell and genomics studies, the development of industry prototype, new drug discovery and clinical trials. Research and clinical facilities will be connected via multifunctional spaces, designed to maximise interactions and catalyse idea-sharing.

The MCCCC will provide a seamless integrated treatment approach enabling clinicians and researchers to work together.

SCHN and CCI are working together to navigate the operational, funding and governance challenges that establishment of the MCCCC has identified, acknowledging the unique situation of an embedded and integrated research institute with a clinical service. As part of exploring the future governance arrangements to support delivery of the MCCCC vision, a Ministerial determination of SCHN's functions was signed in January 2023 to include collaboration with CCI to establish and manage the MCCCC pursuant to section 53 of the Health Services Act. This was the first example of a Ministerial determination in this context.

This approach reflected the complex legislation, research governance and clinical service delivery within which it must operate. Introduction of such models which support new ways of working present a variety of issues which can be time consuming and difficult to resolve, especially in relation to current funding models.

Opportunities and challenges

The examples provided above demonstrate the Network's ability to innovate and change models of care. There are many opportunities to fundamentally transform care but current funding approaches, systems, workforce challenges, and industrial instruments often create significant barriers to realising the full benefit of these opportunities.

Sustainability (Item A and D)

The health sector across NSW contributes around 7% of the state's carbon emissions. Climate change will increasingly place significant risk on the health system's ability to deliver safe, high quality, equitable, and accessible care to patients.

Physical risks associated with climate change such as rising temperatures, bushfires, droughts, or floods place significant pressure on assets, infrastructure, and hospital resources. To use extreme heat as an example, CHW is located in the City of Paramatta. A Western Sydney University study benchmarked the streets surrounding the Hospital, identifying them as some of the hottest locations within the Local Government Area according to mean summer temperatures. Rises in hot weather increase youth mental health emergency presentations with suicidality. An increase in presentations places additional demand on staffing and staff wellbeing, as well as hospital beds. As temperatures rise, pressure on cooling systems increases demand for reliable power. Fundamentally, the health system needs to be resilient and agile in response to climate risks, act on the clear science of climate risk, and embed expertise across the health system.

The health system is reliant on whole-of-government contracts that supply necessary power to support the operations of the hospital. A stable grid that transitions away from fossil fuels is essential for ongoing service delivery and contributes to reducing health-generated greenhouse gas emissions.

SCHN has embedded the risks, opportunities, and financial impacts associated with climate change and the transition to a lower-carbon economy within the Network's risk management framework. Policy changes, reputational impacts, shifts in market preferences, norms, and technology have been considered to manage risks and identify opportunities for improved resource efficiency and the development of new technology. Key risks in transitioning to a lower carbon economy include the lack of available green energy through whole-of-government contracts, significant expenditure on offsetting rather than mitigation, and hurdles in upfront investment - for example, funding for electrification of building assets.

Climate change will disproportionately impact vulnerable populations and the obligation to act on climate change on behalf of future generations is mounting. SCHN services children and young people who are our future and will inherit the planet. Climate change presents a unique opportunity for engagement with local communities in the development of climate actions and future models of care that respond to changing illness patterns and demand.

It is vital for all tiers of government to collaborate on a coordinated approach that demonstrates leadership to deliver the actions required to limit climate change. SCHN is responding to this obligation by setting a net zero target of 2035 for emissions within the Network's direct control, and 2050 for those the Network has less control over.

The National Health Service (NHS) in the United Kingdom has made significant gains in tackling climate change, with experience that the NSW Health system can leverage. Through investment in teams upward of 200 strong, the NHS is the first health service to embed net zero into legislation and has progressed procurement strategies that ensure supply chain carbon emission reductions.

To act on climate change the health system needs to invest in and decarbonise high value care. Sustainability development needs to be built into funding models with upfront investment. SCHN is embedding environmental sustainability into decision-making processes with a particular focus on ensuring our models of care are fit for the future. Environmental sustainability education and resources are being built into existing educational programs such as the SCHN Quality Improvement Academy and Agency of Clinical Innovation Redesign School to build clinician capability to design sustainable models of care.

Recognition of climate risks across operational areas and the built environment presents opportunities for carbon and cost savings. Decision-making needs to consider carbon emission costs and opportunities alongside health and financial costs. A project by the Australian Sustainable Built Environment Council found 100% electrification with renewable electricity was the lowest cost, fastest emissions reduction pathway for Australia's built environment. If SCHN is to significantly reduce its operational greenhouse gas emissions in the built environment and meet net zero carbon targets, it is crucial to transition to fossil fuel free, primarily by eliminating the use of natural gas. Upfront investment is required by NSW Health to future proof infrastructure and assets.

Research and innovation (Items F and H)

An evidence-enabled healthcare system is one that places research and evidence at the centre of the organisation, enabling informed decision making for policy, planning, and clinical practice, ensuring the provision of cost effective services and improving patient outcomes.

There is considerable evidence that hospitals that run clinical trials have better patient outcomes and demonstrate economic benefits including increased efficiencies. Retrospective cross-sectional studies examining the relationship between measures such as standardised hospital mortality index and Care Quality Commission, which are used by the NHS to monitor performance in English hospitals and research activities, demonstrate that 'research activity is associated with more favourable hospital performance outcomes'².

Further, a 2020 paper by Jonker, Fisher and Dagnan³ demonstrates that 'clinical research activity in hospitals is associated with reduced mortality and improved overall care quality'. This means that hospitals that routinely embed clinical trials into models of care have increased rates of patient reported satisfaction and better patient outcomes. However, this also means that there needs to be appropriate time and processes that support this focus and effort.

The NSW health system will need to strengthen innovation if it is to continue to provide high quality services and respond to ongoing demand. Precision medicine and advanced therapeutics are already fundamentally changing the way that care is delivered and providing cure and treatments for previously unsurvivable conditions. The Network provides advanced therapies including Zolgensma for spinal muscular atrophy (\$2.5 million per treatment); Luxturna for inherited retinal disease (\$1 million per treatment); CAR-T therapy in oncology (\$500,000 Kymriah drug cost); and drug discovery and new treatments such as Trikafta for Cystic Fibrosis (\$250,000 per year) and Voxzogo for achondroplasia (\$330,000). These are all new and emerging therapies with very high costs and the need for ongoing monitoring and evaluation. Funding models that recognise the high fixed infrastructure costs to support safe introduction and delivery of these advanced therapies, as well as the per patient treatment cost, are required.

There is a requirement to work closely with regulatory authorities to establish frameworks that facilitate healthcare innovation while ensuring patient safety and privacy. There is significant opportunity to streamline regulatory processes, provide clear guidelines, and foster an environment that encourages the development and adoption of innovative healthcare technologies and practices.

There is a need to explore funding mechanisms, grants, and incentives to support healthcare innovation, start-ups, and the adoption of new technologies.

Case study - Spinal Muscular Atrophy

Spinal Muscular Atrophy (SMA) is a paediatric disorder similar to adult motor neurone disease, which affects the motor neurons of the spinal cord. SMA occurs in 1 in every 10,000 births and there is no cure. Patients with SMA are missing the gene on Exon 7 within the horn cells of the spinal cord which makes a specific protein called Survival motor neuron protein one (SMN1). This protein is responsible for neural cell growth and development. Without SMN1 the nerves atrophy and motor muscle death occurs, causing severe motor dysfunction and disability.

² Jonker, L., Fisher, S. J., & Badgett, R. G. (2022). Hospital clinical research activity, rather than staff motivational engagement, significantly links effective staff communication and favourable patient feedback; a cross-sectional study. *Journal of Healthcare Quality Research*, 37(1), 44-51.

³ Jonker, L., Fisher, S. J., & Dagnan, D. (2020). Patients admitted to more research-active hospitals have more confidence in staff and are better informed about their condition and medication: Results from a retrospective cross-sectional study. *Journal of evaluation in clinical practice*, 26(1), 203-208.

A medical breakthrough, Zolgensma, a novel in-vivo gene therapy used in the treatment of SMA, has transformed the lives of affected babies. SCHN was the only Australian site selected to participate in the global SPR1NT trial, which investigated the use of Zolgensma. The study, which followed each participant until aged 18 months, found that all children achieved the ability to sit independently, all were alive and free of permanent ventilation, and all had normal swallow function and were fed exclusively by mouth by 18 months of age.

Until a few years ago, SMA was the leading cause of death in infants under two years old, and as noted above occurs in 1 in 10,000 births. Untreated SMA prevents babies from being able to roll, sit up, crawl, walk and eventually breathe. For babies with the most severe form of the disease, average life expectancy was just nine months. Since the addition of SMA to the NSW Health funded newborn screening program almost four years ago, more than 330,000 babies have been tested for the condition free of charge and given quick access to treatment and support.

Digital systems that facilitate research and adoption of new evidence into care

More effective integration of current digital systems would facilitate and support research. The core systems for ethics and governance submissions are managed via the statewide ethics and governance system REGIS. The professional staff report that REGIS has variable data quality and limited reporting capabilities which has resulted in the need to run a parallel process.

Additionally, a NSW statewide Clinical Trials Management System (CTMS) was implemented by the Network two years ago. Although the CTMS produces reports, these reports are limited only to clinical trials, and are further limited by the accuracy of the data in the system. The different systems do not talk to each other, creating issues for the researchers in navigating the research processes and adding layers of complexity and risk.

NSW Health accounting policies and structures are not fit for the purpose of research. One of the biggest obstacles to embedding evidence into care is moving beyond the activity-based funding model. Setting up clinical trials has a high-cost and this is often seen as a barrier to implementation. However, through the establishment of governance frameworks, processes, and capacity building, these costs can be reduced. Further to this there are additional benefits of running trials, including enhanced research capacity and reduced downstream healthcare costs as a result of improved health outcomes for patients.

Research capacity and capability

There are several challenges that impact research and innovation from a workforce perspective:

- Turnover of research support staff is high due to people becoming overburdened, resulting in the loss of skills and expertise.
- Lack of professional development opportunities, mentoring, and career progression for research staff. There is no formal recognition for allied health and nursing professionals in clinical-research roles.
- There is vulnerability in the clinical trial workforce. There is no fit for purpose industrial award that provisions for research staff in the Network, and we are often competing with industry to attract staff. Clinical trials are conducted across the health system by a diverse workforce including clinical research managers, clinical research nurses, trial coordinators, and research assistants.
- The lack of an award or articulated pathway within the health system results in poor attraction and retention and the value of clinical trials within clinical practice is not maximised.
- The health translation advisory committee of the National Health and Medical Research Council delivered a report in December 2021 on the state of clinician researcher career pathways in Australia. There is a predicted high attrition rate among clinician-researchers, with a quarter of medical practitioner researchers, a third of midwifery and psychology, and a fifth of all physiotherapy clinician researchers indicating they want to leave the workforce in the next five years. Specifically, across allied health and nursing around 1.5% indicated they hold a clinical-research role.

This presents an important opportunity to provide a career pathway for allied health and nursing professionals to undertake research in their specialty, which is cited as a talent retention strategy that enables top of scope practice. This will set NSW Health apart from the non-government sector.

Aboriginal Health (Item A and B)

We know we need to do more for Aboriginal children and young people and are committed to increasing our Aboriginal employment. We recognise Aboriginal children and young people as a vulnerable and priority population.

It is well documented that Aboriginal children are at risk of poor health outcomes. We know that the health, development, and wellbeing of children is influenced by many factors including genetic, epigenetic, environmental, and experiential factors. Aboriginal populations throughout Australia experience adversity in social capital, education, employment, and housing⁴. This can have an adverse impact on child health outcomes as well as undermining parenting capacity⁵.

As part of our redevelopments at SCH and CHW we are working with our communities to ensure culturally safe and welcoming environments.

In 2020/21:

- Of the 97,425 emergency department presentations age 16 years and under, 2,520 (2.6%) were Aboriginal children. 261 were Triage Category 1, and 2,217 were Categories 3 and 4. 716 (28%) were admitted. 761 (30%) lived in Western Sydney Local Health District (LHD) and 747 (30%) in South Eastern Sydney LHD. 11 were residents of the Australian Capital Territory, 38 resided in Murrumbidgee LHD, and 58 in Western NSW LHD. 86 patients did not wait.
- Of the total 53,022 inpatient separations, 1,968 (3.7%) were Aboriginal children. 980 (50%) were aged 0 – 4 years. 1,148 had a length of stay of overnight and longer.

In NSW, the Aboriginal population is significantly younger than the non-Aboriginal population, with approximately 36.2% of the Aboriginal population under 15 years of age, compared to 18.8% of the non-Aboriginal population. The Network has developed programs such as KEYS and PEACH to provide more flexible, culturally appropriate and safe services, and is implementing recommendations from a consultation and engagement process in 2023 to position the Network as a culturally safe organisation and employer of choice for Aboriginal and Torres Strait Islander people.

There needs to be an ongoing focus on recruitment processes and industrial awards to provide recognition of the expertise and capability of Aboriginal health professionals, which is cited as a talent retention strategy that enables top of scope practice.

Philanthropy (Item B)

The Sydney Children's Hospitals Foundation (SCHF) has successfully raised significant funds and promoted the prevention and control of disease in children for SCH since 1986, and in 2018 became the single charitable entity supporting SCHN with the fundraising function of CHW, Bear Cottage, NETS and Kids Research transferring to SCHF.

SCHN is fortunate in having well established and significant philanthropic support. SCHF provides an important contribution to our financial position, including a \$75 million capital contribution to our two redevelopment projects as well as capital donations to support new and replacement major items of equipment throughout our facilities. As our exclusive fundraising partner, SCHF contributes approximately \$40 million to support redevelopment, equipment, clinical services, patient experience, and research across the SCHN each year.

⁴ Welfare AloHa. The health and welfare of Australia's Aboriginal and Torres Strait Islander people, an overview 2011. Canberra: AIHW; 2011.

⁵ Walker S. Child development: risk factors for adverse outcomes in developing countries. *The Lancet*. 2007;369(9556):145-57.

SCHN and SCHF agree that the role of philanthropic funding is to make a good children's hospitals network as great as possible. We jointly recognise that government funding can never meet all demands or all opportunity in children's health, and this is why the generous contributions from donors are so appreciated.

While recognising that government cannot fund everything that may be required, it is important to note that limited growth funding means a number of core clinical services across the Network are currently being funded by philanthropy. This is neither desirable from a philanthropic perspective nor sustainable long-term from a clinical perspective. While the Network is grateful for such philanthropic support, it does mean that core clinical services have uncertain futures, and their staff are on 'permanently temporary' engagements. For optimal clinical care and staff employment, it would be better for these core services to be supported by core funding.

Redevelopments (Item A and H)

Over \$1.3 billion is being invested in expanded and enhanced infrastructure in the Network. This comprises State, Commonwealth, and philanthropic funding.

At CHW over \$619 million is being invested to provide:

- A new paediatric services building, which will be co-located with the new emergency department, medical imaging, and short stay unit and delivered through Stage 1 of the redevelopment. The new building will provide new and expanded critical care and acute healthcare services and comprise:
 - Operating theatres and perioperative suite
 - Cardiac catheterisation and interventional laboratories
 - Neonatal Intensive Care Unit
 - Paediatric Intensive Care Unit
 - Expanded cancer services
 - Pharmacy
 - Additional inpatient units
- A new multi-storey car park will also be constructed to provide additional parking to address the growth in healthcare services and replace parking lost in freeing-up the site for the project.
- A revitalised forecourt and refurbishment of some areas within the existing hospital.

Over \$658 million is being invested at SCH Stage 1 and Minderoo Children's Comprehensive Cancer Centre to provide:

- The Minderoo Children's Comprehensive Cancer Centre, the first facility of its kind in Australia. Including the Children's Cancer Institute and the Network's clinical services, the facility incorporates state-of-the-art technologically advanced wet and dry laboratory spaces, education and research spaces, new oncology inpatient units, patient and family focused retreat areas, and a new day oncology unit.
- The Neurosciences Comprehensive Care and Research Centre, that will deliver integrated specialist care for children with neurological disorders including complex epilepsy, brain tumours, neuromuscular disorders, and traumatic brain injury.
- A new children's Emergency Department and Emergency Short-Stay Unit with direct links to new and existing services.
- A new children's Intensive Care Unit.
- A new paediatric Virtual Care Centre that will transform children and young people's health through better access, and digital healthcare, delivering coordinated and efficient services that can be accessed 24/7 by patients and their families so they may receive care closer to home.
- New inpatient units for medical and surgical specialties.
- A new medical short-stay unit.
- New front of house and High Street drop-off.

- A new pharmacy, kitchen, back of house and logistics services.
- Over 3,000 square metres of publicly accessible green space for patients, families, staff and the community.
- Optimised shared services across the Randwick Health and Innovation Precinct, including medical imaging and logistics.

Financial impact of redevelopments

Financial Impact Statements (FIS) have been prepared for each redevelopment as part of the Business Case Process. Each FIS was informed by projected growth in staffing to accommodate increasing demand and cost of running the new and expanded facilities.

The operating funding gap of the two projects is approximately \$80 million per annum once commissioned. As well as a staffing uplift of approximately 20% to support the additional services and clinical capacity, the facilities will require a significant step up in funding for operations, given an increase in floor space and fixed costs relating to staffing, maintenance, and Information and Communication Technology. At present, both facilities are scheduled to open in the 2025-26 financial year, adding additional financial pressures for the Network.

An additional 80,000 square metres is being delivered with the two new redevelopments, which will increase the footprint of the Network from 110,000 square metres to 190,000 square metres – a 73% uplift in floor area.

Partnerships (Item B)

Alignment of strategic partnering relationships to deliver health care improvement with key partners, such as universities, medical research institutes, and Advanced Health Research Translation Centres will need to evolve with a clearly understood and articulated value exchange to ensure that the investment of resources (time and funds) is contributing to optimal health outcomes. There is no direct funding from NSW Health to support engagement with these precincts and this warrants consideration at a system level. SCHN is part of two major health and innovation precincts.

Randwick Health and Innovation Precinct

The Randwick Health and Innovation Precinct (RHIP) brings together government, the University of New South Wales, Health Infrastructure, four hospitals and associated health services (Prince of Wales Hospital, Sydney Children's Hospital Randwick, the Royal Hospital for Women, Prince of Wales Private Hospital), preclinical facilities, and nine institutes spanning neuroscience, mental health, cancer, biomedical sciences, robotics, and next generation technologies.

Since its inception in 2016, RHIP has continued to evolve, with ongoing investment in redevelopment and partnership initiatives. It is the crucial anchor of the Greater Cities Commission Randwick Collaboration Area Group. Over \$1.5 billion is being invested into RHIP's physical assets, with three major redevelopments due to be completed by the end of 2025 as part of the Randwick Campus Redevelopment project.

RHIP brings together researchers, start-ups, and corporates to work and live in open ecosystems. The partnership is connecting experts with each other and breaking down barriers to collaboration in order to make new discoveries to improve clinical practice, and create a destination where people want to work, study, and socialise.

Westmead Health Precinct

The Westmead Health Precinct comprises four major hospitals, five world-leading medical research institutes, and two university campuses. The Precinct is part of the larger Westmead Health and Innovation District (WHID).

With a focus on innovative models of health care enhanced by emerging technologies, data analytics and industry partnerships, Westmead will house new industries and research partnerships. Among the first projects for development is a viral vector advanced manufacturing facility to provide ground-breaking trial therapies for infections, cancer, and genetic diseases.

As the WHID health leads, SCHN with Western Sydney Local Health District are responsible for:

- Leading governance for the Westmead Health Precinct.
- Working with the Ministry of Health to inform and guide planning for the broader District with other government agencies.
- Leading development of precinct-specific research information to inform industry partnerships and economic development strategies.
- Supporting achievement of broader government priorities for economic and employment growth in western Sydney.

Workforce (Item F)

SCHN has embarked on an extensive program of organisational development initiatives designed to enhance the Network's capacity to attract, develop, and retain talented and motivated people. The program of work, including the appropriate investment in leadership development, is expected to deliver on a range of people and culture improvements while creating a unified organisation – as one Network providing quality healthcare. Other elements include initiatives designed to enhance the employee experience through recognition and acknowledgement, a safe and respectful working environment with a focus on wellbeing, and multiple opportunities via career development pathways and succession planning across all professional and clinical streams.

The SCHN's newly created and dedicated workforce planning function plays an integral role in supporting the two new redevelopments with a Network-wide approach with strategies to attract, engage, retain, and deploy staff in line with service delivery requirements. The goal is to guide the Network's senior leaders and clinicians to secure the required workforce into the future within a tight and competitive market. In particular:

- Focusing on the effective alignment of the workforce with changing clinical and operational requirements.
- Adopting sound processes for forecasting the supply and demand of talent and skills, and analysing current and future workforce needs and gaps.
- Adapting to changes in the external and internal environment, including health system complexities around funding models and government priorities and requirements.
- Addressing any inefficiencies and improving productivity and quality as part of the workforce planning function.
- Focusing on employee attraction and retention.

Nursing (Item F and G)

Nursing is NSW Health's largest workforce with diverse roles and responsibilities across all aspects of clinical care, research, education, training and management.

Capacity and capability considerations for nursing include:

- Rostering and recruitment tools that reflect the business requirements and workflows. There is an opportunity to review these systems to ensure they are user friendly and support the work and service delivery requirements.
- Simplifying processes to attract and employ overseas trained staff when a skill set is not readily available in Australia. For example, AHPRA (Australian Health Practitioner Regulation Agency) registration could be simplified for overseas nurses.
- Increasing the scope of practice to undertake advanced procedures with appropriate training would assist care delivery. Examples could include Registered Nurse cannulation and prescribing.

Education and training program considerations for nursing include:

- Increasing paediatric placements and embedding students into wards for longer to assist the development of staff. Universities to look at a specific paediatric stream.
- Simplifying processes for visiting international professionals to enable greater sharing.

- Reviewing mandatory training according to role specific and business requirements, recognising prior learning and reducing repetition.
- Reviewing functions and interactions in medical training between universities, colleges and health facilities.
- Strengthening educational capacity to enable rapid upskilling and supportive development of staff.
- Reviewing rostering practices to identify more flexible work patterns to optimise the efficient utilisation of the workforce.

New models of care could include increased use of Nurse Practitioner (NP) models. These include outreach services, early discharging from wards, Nurse led services, and NP's performing procedures reducing surgical and potentially anaesthetic requirements.

Medicine (Item F and H)

Highly specialised tertiary and quaternary paediatric hospitals play a crucial role in providing the best care for children and young people, particularly those with complex medical and surgical conditions. A range of services provided at SCHN are not provided anywhere else in NSW (and some not provided elsewhere in Australia or the southern hemisphere).

Junior doctors, training and rostering

SCHN provides training for junior doctors in all paediatric medical and surgical subspecialties. These junior doctors are rotated to paediatric units of hospitals across NSW, providing care to children. This in turn creates close links between NSW hospitals, enhancing the consistency of the care of children.

The number of junior doctors training in paediatrics is not keeping pace with the numbers needed to provide paediatric services across NSW. Training requirements are also limited in availability. A significant reworking of the junior medical role with increased digitalisation of tasks and broad inclusion of assistants in medicine and administrative support is needed to maintain services.

Specialist medical workforce

Our services require a high degree of sub-specialty training, expertise and close teamwork between medical, allied health, and nursing staff. The specialist medical workforce is limited, with increased reliance on overseas training of Australian and international doctors. The specialised care of children also requires more direct involvement of specialist doctors in all levels of care when compared with the care required for adult patients. This in turn impacts on the specialist medical workforce required to maintain a sustainable 24/7, 365 days a year roster for services with high complexity.

Contemporary industrial instruments which reflect the way that health services are being delivered and optimise retention and recruitment would be strongly supported.

Allied Health (Item F and H)

As with the other professions and specialty areas, there are critical workforce shortages in Allied Health professions for Australian hospitals. This includes physiotherapists, occupational therapists, speech pathologists, and radiographers. These shortages can impact patient care and lead to longer waiting times for services.

Due to the tertiary and quaternary services provided at SCHN we have a highly specialised Allied Health workforce. Attracting and retaining qualified Allied Health professionals in paediatrics can be challenging due to competition and workforce shortages.

Examples of Allied Health-led initiatives at SCHN are provided to demonstrate the high degree of further subspecialisation in the field due to the specific requirements in paediatrics.

Example - Genetic counselling

There are population-based reproductive genetic screening tests which, according to The Royal Australian College of General Practitioner guidelines, should be discussed by General Practitioners (GPs) with all couples planning a pregnancy/in early pregnancy. These include reproductive carrier screening (which can be offered to couples prior to or during pregnancy) and non-invasive prenatal screening (which is offered to women during pregnancy). Many GPs report to us that they feel underconfident and do not have the time to provide suitable pre and post-test counselling. Genetic counsellors have the appropriate training and expertise and could free up GP time with pre-test discussions and provide support to GPs with post-test follow up and information about appropriate on referral where needed.

The main challenges to implementing this at the moment is resourcing. Public hospital genetic services do not currently have the genetic counselling resources to provide this population wide service. Furthermore, genetic counsellors working in private practice or attached to primary health care facilities are very limited. Genetic counsellors do not have provider numbers and there are no Medicare item numbers for genetic counselling sessions. There are also currently no Medicare item numbers for either of these genetic laboratory tests. Establishment of a Medicare item number for genetic counselling services was reviewed by the Medicare Benefits Schedule Review Advisory Committee who declined the request.

The Mackenzie's Mission research project, led by Australian Genomics (for which Genetic Services across the Network participated), demonstrated the effectiveness of a potentially centrally funded and administered, nationwide, expanded reproductive carrier screening program with a genetic counsellor hotline for pre and post-test counselling and on referral to tertiary hospital based genetic services where needed. This type of service, if it was established, could potentially assist GPs, at least in the reproductive carrier screening space.

Example - Orthoptics

Orthoptics at SCHN is working in an advanced scope of practice in the field of electrophysiology and insertion and removal of contact lenses in babies.

CHW runs the largest paediatric electrophysiology service in Australia. We are also the only dedicated paediatric service in NSW. There are four skilled orthoptists at CHW in this service. We are now so successful at performing these tests in clinic that we no longer do them under anaesthesia.

It is well known that babies with cataract are best to remain aphakic (without a lens) until the age of approximately two years. In order to correct their refractive error, we fit them with soft contact lenses (glasses are too thick and too heavy most of the time). This involves detailed education with the parents as well as follow up visits to ensure they fit correctly. This is across Randwick and Westmead campuses.

Other workforce considerations

This submission overviews the transformational clinical opportunities related to digital systems that facilitate research and adoption of new evidence into care and support system transformation. In order to achieve these outcomes, the workforce profile required is dependent on embedding new expertise in health in the form of informaticians, biostatisticians, health data scientists and health economists. In collaborating with clinicians, these resources will release the power of the immense clinical data that is collected across the health sector to transform health care outcomes. Through projects such as 'Zero Cancer', 'Big Data for Little Kids', and the 'Learning Health Initiative', SCHN can demonstrate the impact of data utilisation on life outcomes.

Activity Based Funding across the health sector is dependent on a small cohort of clinical coders. While there is currently great demand for clinical coders, this has driven a significant variance of grade and pay rates across NSW Health entities, resulting in significant impacts to timeliness and quality of cost related data. A redefined statewide approach that utilises machine learning/artificial intelligence with human expertise offers an opportunity for a more robust and future-proof solution.

NSW Health-wide systems

Many of the corporate systems are no longer fit for purpose nor aligned with leading industry practices. Inefficient recruitment, selection, and onboarding processes unnecessarily lengthen the time to fill vacancies, that then flows onto operational pressures through increased overtime, absenteeism, use of agency staff, and general ineffectiveness experienced through sub-optimal service delivery. The recruitment system requires simplification and streamlining to improve the efficiency and effectiveness of the end-to-end process.

The health system has recently been impacted through service contracts where agencies have been exposed to higher-than-normal fee increases. Proactive and robust service agreements and approaches with suppliers protect agencies from significant fee increases.

HealthRoster time capture for back-office staff who work a standard fortnight is inefficient, and out of step with other leading like organisations and private sector organisations who operate under auto pay/by exception systems. The current rostering practices consume significant resources.

System transformation and the future of healthcare (Item H)

There has been exponential growth internationally in the use of advanced therapeutics in recent years. There are currently close to 4,000 therapies in the developmental pipeline from preclinical through to early and late phase clinical trials, with a total of 113 gene, cell and RNA therapies already approved for clinical use. This pace of therapeutic development is unprecedented.

A barrier to successful development and implementation of these advanced therapeutics is the lack of a cohesive, centralised, and integrated pipeline of technologies and expertise that spans all stages of therapeutic product discovery, development, and clinical implementation along the entire pathway. Health system readiness and translation of these transformative therapies is complex and resource intensive. There is a need to build capacity and capability that will sustainably support the clinical delivery to meet the exponential growth in Advanced Therapeutics locally and nationally over the next decade.

There is an initial increase in clinical activity when these therapies are approved for clinical use. Treatment decisions surrounding clinical trial and clinical implementation of these therapies require experienced multidisciplinary teams of scientists, clinicians, nurses, and allied health professionals. Specialist knowledge of the technologies, regulatory, and facility requirements are required to facilitate the transition into clinical delivery.

NSW has a competitive advantage nationally for implementation of Advanced Therapeutics because of the capability and investments undertaken by our research partners and the Ministry of Health. We collectively can lead the nation in ground-breaking therapies for children with rare genetic disorders, musculoskeletal disorders, genetic metabolic disorders and those with cancer.

In response to the increasing activity in the area of advanced therapeutics, and recognition of the challenges these therapies pose to healthcare systems, the United Kingdom has made investments to establish a network of Advanced Therapy Treatment Centres (ATTC) (<https://www.theattcnetwork.co.uk/>). The ATTC aims to support growth in this area through building capacity and capability within the UK healthcare system. A similar response in Australia warrants consideration to facilitate health system uptake of these therapies both within our local network and nationally.

Case study – Advanced Therapeutics

The direct translation of gene therapy trials to mainstream clinical services was unprecedented. The provision of onasemnogene abeparvovec (Zolgensma) and voretigene neparvovec-rzyl (Luxturna) to eligible patients posed a challenge to the NSW Health system. The pace at which regulatory approval was achieved and imperative to provide this therapy nationally exposed a vulnerability in our system to respond to new and emerging technologies.

The clinical trial pipeline is growing rapidly and as these trials achieve favourable results, the health translation challenges will continue to grow. Downstream impacts that have been observed include new scope of practice, such as pharmacy service to deliver these therapies and coordination with clinicians and suppliers to ensure safe and timely preparation of dose for administration. This requires compliance with the Gene Technology Act given that many of the advanced therapies in question are genetically modified. Clinical space is required to deliver these therapies in either an outpatient or inpatient setting (dependant on the therapy) and close follow up conducted in the weeks and months following treatment administration.

Planning for the preparedness of the system for the scale and impact of advanced therapeutics, both in relation to training of our future workforce, financing and system impact is critical.

Disability (Item H)

We know that 7.6% of Australian children aged 0 – 14 have a disability and 4.5% with a severe or profound disability (Australian Institute of Health and Welfare Australia's Children 2022 Update). We also know there are long waits for children with behaviour and autism disorders, and early diagnosis programs are being implemented but with no easily accessible treatment system to support early diagnosis, intervention, and the care required. SCHN continues to attempt to address these through several multidisciplinary collaborations (including the Quiet Pathway, as previously mentioned), and with the Kookaburra Centre in the Westmead redevelopment being a direct and different way of treating patients with complex needs. Due to the high intensity of time and resources required, as well as funding limitations, to care for this paediatric cohort SCHN is now in beginning phases of trialling being a National Disability Insurance Scheme (NDIS) provider in Orthotics.

The complexity of the intersection between health and disability is across the lifespan. This is particularly poignant within a paediatric landscape as growth and development of a child can mean consistent changes in function for children, sometimes at a rapid pace. Between the Early Childhood approach and NDIS access, systems for accessing equitable, adequate care and support can be complex both for families and health services. One example of this is the recent transition of children with long term ventilation, with management of care transferred from EnableNSW to NDIS where there has been variation in assessment practices and changes to available hours of care from what some children were previously receiving. These system complexities can have significant additional impact for families with lower socio-economic status or from culturally and linguistically diverse backgrounds. The Network will work with NSW Health regarding the recommendations from the *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*.

Activity Based Funding (ABF) (Item A)

In NSW Health, Activity Based Funding (ABF) was introduced to enhance the effectiveness and efficiency of public health funding. It allowed health service management to allocate their share of available State and Commonwealth funding based on real levels of patient care, which in turn ensured greater accountability and transparency for expenditure. However, over the past four to five years, due to added cost pressures in the Health system in the form of COVID response, wages, redevelopments and increased cost to procure goods and services, there has been limited discretionary growth funding to sustain and support hospitals across the state.

As at October 2023, SCHN has been consistently over activity targets over the past three financial years. The increase in activity has been a result of increased respiratory presentations in the emergency department and increased acuity, driving medical and intensive care unit bed demand. SCHN has not received discretionary growth funding (for the same period) which has meant there has been a disproportionate allocation of inputs and outputs.

The full time equivalent (FTE) staff level over the last three years has grown at 2% and activity funding has grown at close to 0%. This mismatch in activity and FTE growth will continue to increase as SCHN generates more activity than it is funded to perform. This structural funding deficit will require a re-baselining of activity funding to ensure appropriate and transparent activity-based funding.

While ABF can work well in some healthcare settings, there are some challenges when applied to paediatric settings for several reasons:

- Variability in paediatric care - paediatric care is highly variable due to differences in the age, size, and health status of children. This makes it challenging to standardise and accurately quantify the 'activity' in paediatric care.
- Long-term outcomes - paediatric care often involves long-term monitoring and interventions to ensure healthy development. ABF may not account for the long-term ongoing care, leading to underinvestment in these critical services.
- Vulnerable population - paediatric patients include vulnerable populations, such as premature infants and children with complex medical conditions. ABF may not adequately address their unique needs, potentially leading to disparities in care.
- Resource intensity in SCHN is significantly higher when compared to adult hospitals in the state due to specialised staff, equipment, and facilities required for providing complex care to paediatric patients.
- SCHN's role in providing highly complex care at low volumes without large volumes of low complexity, lower cost care to offset these costs.
- An analysis of all Diagnostic Related Groups (DRGs) for the past five years for SCHN indicated that there is a significant cost-price mismatch in the activity based funding of services.
- Funding for the uplift in costs associated with the two major redevelopments cannot be accommodated within an ABF framework alone.

Specific examples where current funding approaches are not fit for purpose are provided with the following examples for the Neonatal Intensive Care Units and Newborn and paediatric Emergency Transport Service.

Example - Neonatal Intensive Care Units (NICU)

The funding model for ABF is not suitable for high complexity, low volume paediatric services. There is also a mismatch between ICU coded medical records, as this is very different for paediatric and neonatal intensive care units (ICU). The ABF NICU model has been established on a gestational NICU model of premature babies without surgical complications. CHW has a surgical NICU, and as per the Queensland and Victorian models, the funding model does not properly represent the surgical ICU work in the NICU.

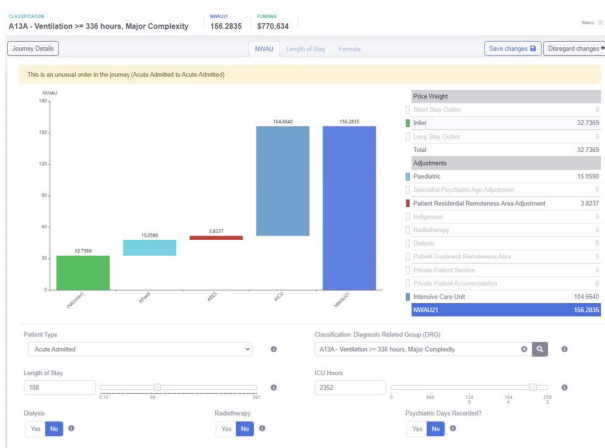
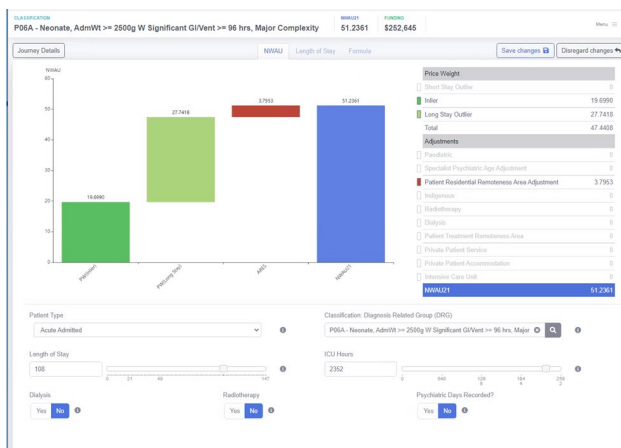
SCHN has analysed the difference between DRGs for the same procedures performed in a Paediatric ICU (PICU) versus NICU with the following findings:

- There is significant funding difference of similar case mix between both versions of Australian National DRG (ANDRG). Modelling of SCHN samples for patients with age 28 days or more showed a significant impact on National Weighted Activity Units (NWAUs) not only in V9.0 as used by Queensland, but also significant variation between Version 9.0 and V10.0 of ANDRG.
- P06A DRG is derived by patient admission weight (has to be equal or more than 2500gm) and also ventilation of equal or more than 96 completed hours.
- 96% of SCHN P06A DRG case mix for FY 2021 is for patients aged 27 days or less.
- The NWAU impact was seen in majority of cases where patients had mechanical ventilation and tracheotomy procedures in ICU. However, with 28 days and above age modelling not all P06A DRGs had an NWAU gain.
- Unbundling of the ICU component of the DRG price for Newborns and Other Neonates would provide consistency for all patients treated in an ICU and create a more transparent and equitable model.

The following examples are provided to demonstrate the same care for non-premature baby in a PICU will receive three times more funding than in the NICU, all other things being similar except the NICU babies are more complex.

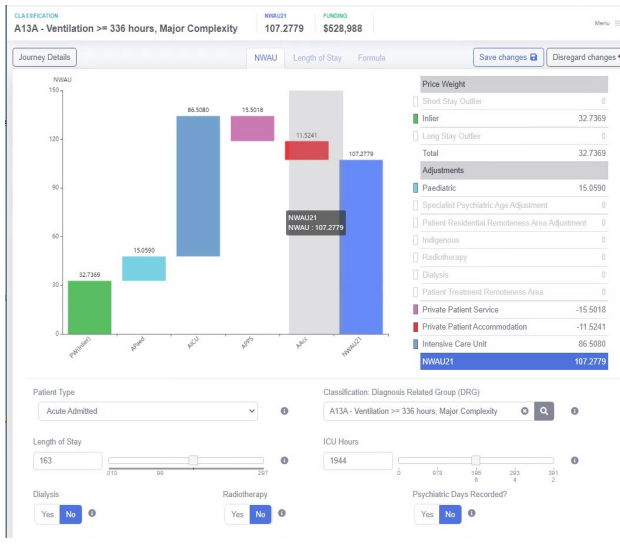
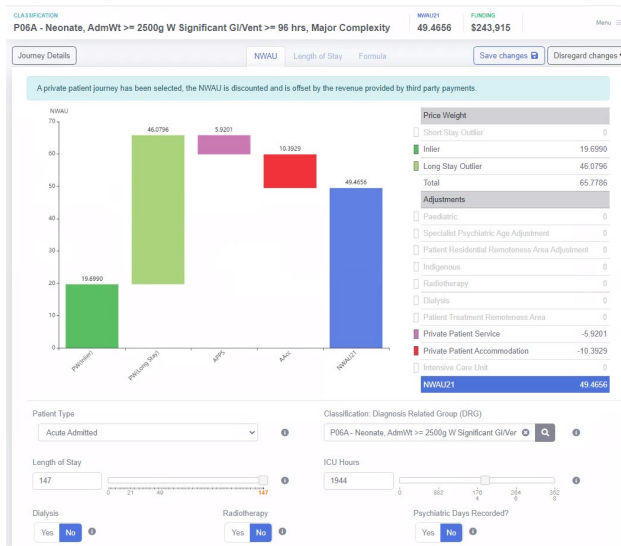
Case study 1 – baby <27 days old:

- Age on admission: 3 days
- Principal Diagnosis: Coarctation of aorta and respiratory distress
- Length of Stay (LOS): 108 days
- ICU hours: 2,352
- NICU funding \$252,000; if care was provided in PICU in funding would be \$770,000.



Case study 2 – baby <27 days old:

- Age at Admission: 0 days
- LOS: 163 days
- Principal Diagnosis: Congenital Tracheomalacia
- ICU hours: 1,944
- NICU funding \$244,000; if care was provided in PICU funding would be \$529,000.



Example - Newborn and paediatric Emergency Transport Service (NETS)

NETS provides specialist inter-hospital retrieval services for critically ill neonates, infants and children aged up to 16 years within NSW. NETS was established in 1979 and became the single statewide service for neonatal and paediatric retrieval services in 1995. It was incorporated into SCHN in 2011 and has been block funded since that time.

As a statewide service, the main NETS base is at Bankstown Aerodrome (with satellite services in collaboration with other entities at Newcastle (NETS Hunter) and Canberra (NETS ACT)).

NETS services over 250 hospitals within NSW and the ACT and provides transports interstate. NETS is staffed by a dedicated team of doctors, nurses, emergency vehicle drivers, technical and other support staff to provide a 24-hour a day, 7-day a week service.

Calls from hospitals into the NETS coordination centre are answered by specialist nurses and managed by retrieval consultants who provide advice, determine the appropriate response, and task selected teams. A key feature is telephone conferencing and linking specialists from tertiary and regional hospitals in NSW, the ACT and across state borders. NETS coordinates and supports reliable patient movement across health districts and network services across NSW and the ACT.

NETS usually receives over 4,200 calls for assistance per year (2021) approximately 11 per day from health professionals across NSW, the ACT and interstate. This increased significantly to over 5,000 calls with the introduction of non-emergency back transfers. During 2022 calls increased further as infants with bile stained vomiting require transport for investigation. Each case can involve dozens of calls to coordinate the clinical and logistical expertise needed to meet patient needs across NSW.

The average outcome of the 11 calls per day can be summarised as follows:

- Seven are moved by NETS;
- Two are moved by other services, including to regional centres closer to the patient; and
- Two are not transferred and continue to be cared for in the local hospital after careful clinical consultation.

In 2021, there was a total of 5,810 calls which resulted in 3,691 retrievals that were funded through transport billings, however it also resulted in 2,119 calls which were primarily consultations and coordination. There was no mechanism to bill these calls as they did not result in retrievals, leading to a funding gap.

Retrieval cost vs price

The Independent Pricing and Regulatory Tribunal determines the service rates, which are a callout fee and a per kilometre charge (IB2021_026) through a cost recovery model. These rates do not align with the cost for NETS and do not consider the cost of clinical coordination, ICU level work and consultation, which can take considerable time to discuss with clinical specialists at the base hospital and ensure beds are available at the receiving hospital. In some cases, no retrieval is required after discussions with clinical specialists and does not generate revenue.

Other components over and above the retrieval costs include:

- Consultation and clinical coordination.
- Additional resources required for complex situations, e.g. using nitrous oxide on babies and super specialty treatment such as ECMO (extracorporeal membrane oxygenation).
- Additional costs in managing regional transport.
- Specialised training and education required, particularly for fixed wing or helicopter transport.
- Quality and safety monitoring, including feedback to referral hospitals across NSW.
- Increases in fixed costs.
- Long distant travel – costs are by distance (kilometres) and not by time (minutes).
- Delays and lack of availability of aircraft.
- Usage of Careflight consultants to fill medical roster gaps.

Mental Health (Item A and F)

In mental health, recent funding has involved important specific funding allocations for teams. Examples are 'Safeguards', 'Safe Haven', 'Towards Zero Suicides', and virtual and community mental health. Some of this funding comes with very specific requirements of staffing and operation, including models of care. This is problematic in terms of creating locally sensitive, continuous care which integrates with other service elements. While warm handovers are important, continuous care, where and when possible, provides greatest consistency, quality care, and respect for the experience of consumers and their carers.

Short term funding envelopes with specific requirements lead to enormous difficulties recruiting and retaining quality staff in contract positions which may only be 2-3 years duration. This is a problem at SCHN where the Mental Health service is small and contract positions cannot be covered as permanent without significant risk.

Mental Health services at SCHN have experienced rapid staff turnover in the past three years. This is impacting retention and recruitment in all skills areas and across the service landscape. It is most significant on inpatient Mental Health Units where recruitment for nursing positions is constant and allied health retention rates are extremely poor. The impact is that staff constantly require upskilling and training, temporary and agency staff are frequently part of the skill mix and may not understand all standard operating procedures of the unit, and high levels of burnout and low morale for staff who persist in roles. High staff turnover reduces efficiency and effectiveness of the services. This all significantly impacts on care of patients and the capacity to develop sustainable models of care.

As with many areas in health, mental health has serious workforce shortages in the public health system. We have had two vacant staff specialist child psychiatry positions for over two years. This represents two of twelve positions for our Network. Locums have become a necessity when they can be identified. SCHN has experienced higher levels of turnover for allied health and nursing staff in the past two years – the feedback from separating staff includes challenges financially, with better awards working either privately or through agencies and the rising costs of living in Sydney. Burnout and the challenges of increasing complexity and risk also play a part of the complexity which is disincentivising working in public health.

As a tertiary hospital network for children, SCHN (identified as a Level 6 service in the role delineation of NSW services) needs to consider what balance of services is provided locally versus the statewide remit to provide tertiary health care services and education, research and capacity building for NSW. Understanding best allocation of resources to enhance equitable access for priority populations is essential.

This issue is currently concerning to the Mental Health services for children and young people at SCHN in determining the balance between patient care for the local populations, care for medically unwell paediatric patients, and subspecialty care and capacity building at a state level. Statewide mapping of service pathways for psychological care of young people from the Primary Health Networks and Headspace to Child and Adolescent Mental Health Services locally and through to subspecialty mental health care services is needed.

Central leadership at a Ministry level, with statewide service planning, would help delineate our service scope, roles and responsibilities, enhancing the power of Memorandums of Understanding between organisations, and informing resource priorities. It could be based on the analysed data available through InformH at the Ministry of Health, which has data on current patient diagnoses and activity. The National Mental Health Service Planning Framework might assist with anticipated population needs and growth predictions. This would support the work of Local Health Districts and Specialty Health Networks such as SCHN by helping to establish clear positions around care pathways and will benefit patient care through the system enormously. For SCHN it would identify the mental health need types and level of priority for subspecialty service provision, such as the eating disorders, functional neurological disorders, and Intellectual Disability Mental Health Hub services.

Digital (Item H)

Patient focused, comprehensive, agile, powerful, connected and secure digital systems will shape the delivery of healthcare and optimising patient outcomes into the future and are inextricably linked to supporting the future models of care and breakthroughs in clinical treatments.

Currently digital services across NSW Health are provided in a hybrid model across the LHD/Specialty Networks and eHealth. While this approach has significant benefits related to program standardisation across the state such as RIS-PACS (Radiology Information Systems and Picture Archiving and Communications System, NSW Health's medical imaging system) and the upcoming Single Digital Patient Record, as well as the project based support around implementation, the ongoing resources required to manage the systems need to be identified.

The Network has a proud track record of being digitally agile in response to emerging clinical practices and enabling clinical innovation. This was demonstrated during the COVID response where SCHN was managing more than 2,500 children remotely by a rapid pivot in its service delivery that was enabled through an aligned digital response. A focus on agility and streamlining of processes will be essential to enable digital innovation and ability to respond quickly to clinical developments.

As the system increasingly moves to a digital future, workforce requirements need to be carefully considered and the essential skills and capabilities needed for the future identified. Unexpected or prolonged outages and downtimes now have major impacts on service provision, and system redundancy and responsiveness need to be at the forefront of planning for the future. Long timeframes for delivery of new systems also result in functioning across different systems and impact continuity of record keeping and functionality.

Solutions for populations such as children also need to be planned, scoped, and implemented with a 'kids first' lens, as opposed to retrofitting or reconfiguring systems.

Cyber security is a complex, expensive and critical element that allows health services to provide care in a contemporary manner, while ensuring protection of sensitive patient data. eHealth provides cybersecurity for the state 'crown jewels' with a team dedicated to this critically important task, while growing its Essential Eight maturity to continually improve its performance in this important area.

Each of the LHDs/Specialty Networks is tasked with replicating cybersecurity functionality for the remainder of their local systems, which requires individual hardware and software, and highly specialised expert human resources which, in the current market, are difficult to attract and retain. In addition, each LHD/Specialty Network develops standalone information security plans and duplicates the resources to implement and maintain these plans. This approach is cumbersome, duplicative, and adds significant cost across the health system, while also bringing significant risk as a result of workforce challenges. There could be considerable benefit in a more coordinated and centralised response to cybersecurity.

Conclusion

The Network is proud of the services provided by highly skilled and committed staff, and grateful for the financial and other support from the broader community.

It is considered that opportunities to re-align our activity baseline, address areas of significant price and cost mismatches, and consider the appropriateness of ABF, all supported by modern and contemporary industrial instruments, will provide the ability to best provide care for sick and injured children and their families.