



## Special Commission of Inquiry into Healthcare Funding

**Submission Number:** 185  
**Name:** Medical Staff Council Executive, Children's Hospital Westmead  
**Date Received:** 28/11/2023



Medical Staff Council Executive  
Children's Hospital at Westmead  
Sydney Children's Hospitals Network  
Chair: Dr Angus Alexander  
Secretary: Dr Greg Kelly  
Councilors: A/Prof Kathryn Browning Carmo  
Dr Rachel D'Cruz, A/Prof Justin Skowno  
Dr Melanie Wong & Dr Jacqui Dalby-Payne

[REDACTED]

To: Mr. Richard Beasley SC  
Commissioner, NSW Special Commission of Inquiry into Healthcare Funding

**Re: Special Commission of Inquiry into Healthcare Funding  
A Response by The Children's Hospital at Westmead's Medical Staff Council**

Dear Mr. Beasley SC

The Medical Staff Council (MSC) represents the 500 senior medical staff who strive to provide the best possible care for our paediatric patients. Given the broad experience of our clinical practice, we are in a unique position to highlight the impact of inadequate funding on our patients, their families and the communities they come from.

The Children's Hospital at Westmead (CHW) provides clinical services to 80,000 sick and injured children every year. It is staffed by 3,500 people dedicated to the care of children. It is a quaternary referral centre and the largest paediatric hospital in NSW. It provides healthcare to the children and families of Western Sydney and important statewide services to children across the state and country. As a Local Government Area, Western Sydney has a population of over 2.7 million and is an area of significant population growth at 1.36% compared to Greater Sydney at 0.78% (Western Sydney University, .idcommunity: demographic resources 2022). It has a rapidly growing immigrant population with 49.8% of residents being born overseas. (Western Sydney Data Profile 2018). Uniquely, 27.2% of the population are under the age of 19. Within the Aboriginal and Torres Strait Islander community this number increases to 44% (Western Sydney Profile Data 2018).

In its role as a referral centre, CHW provides tertiary and quaternary care to the sickest children from greater Sydney, NSW, Western Australia, South Australia and the Pacific Rim. This care includes liver transplantation, burns care, cardiac surgery and bone marrow transplantation, to mention only a few.

The forecast population growth and the high proportion of young people creates a significant, incremental burden on CHW, chronic underfunding compounds this problem.

To present the information we have requested of our senior medical staff, we have taken select questions raised in the letters patent and will address them individually. Where appropriate, we have included submissions from departments and individuals in their original form. Some of these submissions will have been sent directly to the commission.

**A. The funding of health services provided in NSW and how the funding can most effectively support the safe delivery of high quality, timely, equitable and accessible patient-centred care and health services to the people of NSW, now and into the future.**

When our hospital opened in 1995, it opened at capacity, and the subsequent 28 years have been a continuous resourcing challenge. The MSC has, for many years, clearly articulated concerns about the need for more resources in the face of a growing paediatric population, sicker patients, more complex care and expensive new therapies. We have made this representation to the hospital executive, the hospital Board, the ministry, and state leaders.

In 2018, the MSC became so deeply concerned by our inability to consistently provide the highest level of care to the children and young people of NSW, that they developed a compendium of submissions on the subject from virtually every department within CHW. This was subsequently presented to the then NSW Minister for Health, Brad Hazzard. This compendium is attached at appendix 1.

In support of this growing concern, came The Alexander Review of 2019, which found *“significant differences between the Australian States in the level of funding for paediatric care, with SCHN being 14% lower in cost than its nearest counterpart interstate.”* Despite this, little meaningful change has occurred. The Alexander review is attached at appendix 2.

At least part of the problem with chronic under-resourcing CHW is the Activity Based Funding (ABF) model. ABF was formulated to fund hospitals in Australia based on the number and mix of patients they treat, considering the complexity of the treatments provided. This funding model came into effect in 2011, with the goal of establishing a transparent, fair, equitable, and predictable approach to hospital funding, informed by the cost of care delivery. The Independent Health and Aged Care Pricing Authority (IHACPA) was established in the same year to develop and implement ABF for Australian public hospitals. Under ABF, the annual National Efficient Price (NEP) for public hospital services is determined, which in turn determines the level of Commonwealth funding for these services.

The introduction of ABF aimed to provide a clearer and more efficient way of allocating funds to hospitals, based on the workload and types of services provided, thus encouraging hospitals to offer services more efficiently. The ABF model was a central feature of the Rudd hospital reform plan, titled 'A National Health and Hospitals Network for Australia's Future', showcasing its importance in reforming the healthcare sector in Australia. However, this model is not well-suited for tertiary and quaternary paediatric hospitals and especially Sydney Children's Hospitals Network due to several factors:

**Resource Intensity:**

The resource intensity in tertiary and quaternary paediatric hospitals is significantly higher due to the specialised nature of the care provided. The well-documented, long-term, financial challenges that the Children's Hospital at Westmead (CHW) experiences, signify the inadequacies of the ABF model to meet the resource-intensive nature of care in our paediatric settings. Under ABF, hospitals are paid a pre-defined amount for each patient based on the patient's condition, which does not adequately cover the higher resource needs in specialised settings. Moreover, as the Sydney Children's Hospitals Network is managed under the NSW Health umbrella, the Network gets funded at the State Efficient Price which is lower than the cost of providing services in a specialised paediatric network.

Tertiary and quaternary paediatric hospitals provide specialised care for complex cases, often requiring multidisciplinary teams made up of specialists spending a disproportionate amount of time diagnosing and managing complex patients. Specialised equipment is frequently required, which in turn mandates extra staff to support, run and train clinicians on the equipment. Patients frequently require extended hospital stays. Many of our smaller patients require admission for sedation or general anaesthesia for relatively simple diagnostic and therapeutic interventions. This extra resourcing is not captured by ABF, with its fixed reimbursement rates for specific conditions. A good example is an MRI scan in a three year old for a suspected brain tumour. In

adult practice the patient would walk in for the scan and walk out two hours later, having interacted only with a radiographer. Our three year old would require a family member to take time off work, be kept nil by mouth for six hours, get admitted to hospital on the day of the scan, have a preanaesthetic medication and then a general anaesthetic, the child would be intubated and put on a mechanical ventilator for the procedure and kept for four hours in the post anaesthetic care unit to recover before being discharged. This scan would involve a radiographer, anaesthetist, anaesthetic nurse, registrar and recovery nurse at an absolute minimum. ABF does not adequately capture this extra activity associated with this relatively simple paediatric patient.

**Complex and Variable Care Needs:**

Similarly inadequate is the ABF model for surgical procedures requiring neonatal intensive care units (NICU). The activity based funding was modelled around premature babies without surgical needs, but a significant number of our neonates require surgery and CHW is experiencing an enormous funding gap as a result. An analysis was done comparing the funding for procedures carried out in paediatric intensive care units (PICUs) and NICUs. The analysis highlighted that for diagnostic related groups with complex care needs (e.g. coarctation of the aorta, respiratory distress and congenital tracheomalacia) there is a funding gap that exists between \$285 000 and \$518 000 per patient.

**Patient Volume:**

ABF incentivises hospitals to treat more patients faster, to avoid procedures that do not attract adequate funding and to promote ones that do. This not only compromises patient care but adds significantly to the burden of hospitals like ours that “cannot say no”. A good example of this is a diagnostic procedure called a Micturating Cysto-Urethrogram (MCUG) which is commonly performed to check for reflux of urine up into the kidneys that can cause kidney failure and need for kidney transplant or dialysis. It is a very resource intensive procedure, often requiring sedation, a radiographer, a nurse, radiologist, registrar and at times a consultant surgeon. The procedure can take hours as the team engages with the patient and family to get the least stressful and optimal imaging. Most adult hospitals will have the ability to do the study but it is not well funded and consequently many of the paediatric patients are referred to CHW for their MCUGs. Performing highly resource intensive, poorly remunerated procedures like MCUGs for a large proportion of the paediatric patients in the state who need one places an additional burden on our already under-resourced hospital.

The above points underline the mismatch between the principles of ABF and the operational, financial, and clinical realities of tertiary and quaternary paediatric hospitals. The fixed reimbursement rates and volume-driven incentives of ABF fall short in addressing the complex, specialised, and resource-intensive nature of care that CHW and the Sydney Children’s Hospital’s Network provides.

**Chronic Underfunding:**

The Network has been consistently over its activity targets for the past three financial years as shown in the below table. The increase in activity has been a result of increased respiratory presentations in the ED and increased acuity driving medical and ICU bed demand. The long tail to winter has meant that SCHN has started FY24 at 4.2% over activity without any additional funding.

SCHN (Activity Performance)	Targets	Actual	Variance	%
FY21 (NWAU20)	114,754	119,719	4,965	4.3%
FY22 (NWAU21)	111,768	134,681	22,913	20.5%
FY23 (NWAU22)	114,483	123,195	8,712	7.6%

Source: CHIMP

The Network has not received discretionary growth funding for over 3 years which has meant there has been a disproportionate allocation of inputs and outputs. FTE 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 grow as the Network generates more activity.

**Nuanced funding:**

The allocation of ABF funding uses several proxies that are related to population and ageing as factors for growth at the state level. This creates more challenges in the way paediatric health services are funded. The below table shows a snapshot from the budget allocation model in 2021/22 which highlights the increased funding made available based on population growth and ageing. Ageing as a proxy for complexity reflects the increased needs of healthcare as people age but no such weighting exists to recognise the increased complexity that comes for caring for children, especially the very young, and their families.

This has been one of the key factors that has seen reduced funding for paediatric care over many years in NSW.

Health Entity	2021/22	
	Population growth	Ageing growth
Sydney Childrens Network	0.10%	0.10%
St Vincent's Network	1.20%	0.20%
Sydney	1.50%	0.30%
South Western Sydney	1.30%	0.50%
South Eastern Sydney	1.00%	0.00%
Illawarra Shoalhaven	0.80%	0.40%
Western Sydney	1.40%	0.50%
Nepean Blue Mountains	1.10%	0.50%
Northern Sydney	1.30%	0.40%
Central Coast	0.70%	0.30%
Hunter New England	0.80%	0.40%
Northern NSW	0.90%	0.40%
Mid North Coast	0.90%	0.50%
Southern NSW	1.00%	0.50%
Murrumbidgee	1.00%	0.50%
Western NSW	0.90%	0.50%
Far West	0.60%	0.20%
<b>Grand Total</b>	<b>0.97%</b>	<b>0.36%</b>

**B. The existing governance and accountability structure of NSW Health, including:**

- 1. the balance between central oversight and locally devolved decision making (including the current operating model of Local Health Districts);**
- 2. the engagement and involvement of local communities in health service development and delivery;**

Having a clear vision for paediatric health in NSW is essential. This vision must resonate with the health workers at the “coal face”, align with community expectations and be funded appropriately. Within reason, our vision and ambition for excellence in paediatric healthcare should be informing the funding we receive. Traditionally we have been unambitious, our aspirations having been seriously hampered by a budget that by all measures is inadequate.

- 3. how governance structures can support efficient implementation of state-wide reform programs and a balance of system and local level needs and priorities;**
- 4. the impact of privatisation and outsourcing on the delivery of health services and health outcomes to the people of NSW;**

Collaborative care (public surgery occurring in private hospital) has served a purpose at CHW. It has ensured a steady stream of relatively well patients were getting their surgery in a timely manner. The scheme could have had better uptake with a more consistent and equitable acknowledgement of the extra work required to move these patients into private and in our case, take on the additional stress of ensuring that the private hospitals had the necessary and unique equipment required to perform the anaesthetics and surgery on children. The inconsistencies are a definite barrier to generalised uptake. As an example, full time staff specialists were not paid for any extra surgery performed unless they took leave. Part time specialists and Visiting Medical Officers (VMOs) were, however, paid. Consequently, the surgeons with the biggest public waiting lists were disincentivised to contribute to the scheme.

This theme of health funding being allocated because of press or radio coverage of an issue is not unique in NSW. CHW had access to four additional theatres that had been built and moth-balled because of a lack of funding to staff and equip them. It was only once this situation made it into the news that funds became available. Adding insult to injury, the funds were offered on a “use it or lose it” basis with a near impossible task of having them operational within a few months before the funding was withdrawn.

Other good example of healthcare funding allocated by pressure from “shock jock diplomacy” was the funding assigned to support the development of heart transplantation at CHW. Frustratingly, no amount of clinician advocacy, over many years, was as effective as a radio host in unlocking this funding. The Close Observation Unit, a step down facility for intensive care patients, was similarly funded following negative press. These, and many other, examples significantly undermine our notion that paediatric healthcare is supported by a clear vision and ambition and is prioritised above politics. Further, these incidents feed the narrative that the press is a very effective way to get additional funding from NSW health.

**E. Opportunities to improve NSW Health procurement process and practice, to enhance support for operational decision-making, service planning and delivery of quality and timely health care, including consideration of supply chain disruptions;**

**Central Services and unsustainable Growth**

The intention of ABF was to create a more transparent and efficient system of funding. However, it has fallen short in respect of funding for paediatric services, as outlined above. In addition, there are issues with the funding of central services.

As you will know, the IHACPA set the National Efficient Price for 2023-24 is set at \$6,032 per national weighted activity (NWAU23). The State efficient price is set at \$5,207. The difference between the National Efficient Price and the State Efficient Price is \$825 per NWAU23. This amount of \$825 per NWAU is used to fund central services used by all LHD’s such as eHealth, HealthShare and Ministry. The total estimated value of this centralised funding for NSW Health is estimated to be \$2.6 billion which is funding provided for frontline clinical services being pulled to the centre.

**eHealth**

eHealth has grown at around 20% per annum over the last 5 years compared to growth of front line services at single digit increases or no growth at all. In 2018 eHealth had a budget of \$400 million which has now ballooned to over \$800 million. The expenditure growth at this rate for information and technology services seems incongruent given the pressure on clinical services.

Financial Year	eHealth (In \$'m)	Growth
2018/19	403,012,758	
2019/20	566,448,948	41%
2020/21	628,510,783	11%
2021/22	711,965,884	13%
2022/23	819,275,160	15%
<b>Avg. Growth</b>		<b>20%</b>

eHealth is now the sole technology provider for NSW Health and has effectively become a monopoly whose services cannot be contested. This has led to a bloating of resources with an inadequate accountability for impact on outcomes. With procurement restrictions in place, health entities are forced to hire through eHealth. The daily rates for eHealth resources are now not competitive with open market rates. As an example, a desktop support manager from eHealth costs \$1,100 a day compared to \$900 in the open market.

Systems that have been implemented do not have full functionality and most projects are over time, over budget and yet under-deliver on scope and functionality. An example is the ERIC project in the ICUs at the Children’s Hospitals. The previous system used by ICUs had functionality for integration that ERIC does not. The SCHN has been forced to use this system even though the clinical risks have been highlighted with the claim that the business processes need to change in the clinical setting. Moreover, this new ICU system does not integrate with the Statewide Digital Patient Record which was designed to afford patients a single clinical record across NSW. This had the noble intention of allowing the patient record to be accessed at the point of care rather than being trapped in a particular Hospital’s computer system. This is particularly important for referral hospitals like CHW, that receives patients referred from across the state and transitions all our patients to adult hospitals once they are 18 years old. The implication of different patient management platforms in the same hospital is highlighted by ICU patients discharged from ICU into the wards. Once in the wards, their record exists on a different platform and any ICU notes cannot be accessed outside of the ICU. This is a significant risk to patient care.

**HealthShare**

HealthShare provides centralised shared services for NSW Health such as Patient Transport, Food, Linen, Procurement, Supply Chain, Financial Services and Payroll. The aim of the service is to provide standardised, cost-efficient, shared services to Health entities.

HealthShare total expenditure has grown at 13% per annum over the last five years as demonstrated in the table below. The growth in costs have far outweighed the growth in funding for Health services, which have been single digit increments over the same period.

Financial Year	HealthShare (In \$'m)	Growth
2018/19	1,244,438,614	
2019/20	1,214,483,018	-2%
2020/21	1,448,369,295	19%
2021/22	1,999,054,913	38%
2022/23	1,906,779,280	-5%
<b>Avg. Growth</b>		<b>13%</b>

Once again these entities have effectively gained a monopoly, where services provided by HealthShare cannot be contested by the health entities, even if there are better options available in the open market. A prime example of this is food services. Food services costs has gone up by over 25% per annum over the last two years for the Network without any significant volume increases in admitted patients. Another example is transactional services, which are back-office accounting and procurement functions provided by HealthShare, the costs of which have also increased by over 25% over last financial year.

Significant funding has gone into growing these centralised services, yet the objectives of delivering a higher quality product in a more cost effective and efficient way have not been met. The services have instead become significantly more expensive and arguably captured funding intended for core health services.



**F. The current capacity and capability of the NSW Health workforce to meet the current needs of patients and staff, and its sustainability to meet future demands and deliver efficient, equitable and effective health services, including:**

**i. the distribution of health workers in NSW;**

NSW health should look to attract health care workers to rural and regional areas. The positions need to be incentivised to make the practice more appealing. In addition, job descriptions for substantive posts in major metropolitan areas could have a fractional appointment in regional NSW. This would increase the available health workers in these areas, increase skill levels, create an easy referral pathway for patients that need to be referred into regional centres, where the clinicians are based

**ii. an examination of existing skills shortages;**

**iii. evaluating financial and non-financial factors impacting on the retention and attraction of staff;**

**iv. the use of locums, Visiting Medical Officers, agency staff and other temporary staff arrangements;**

There are major ongoing concerns with the present remuneration awards in NSW.

Safely delivering high quality care to sick children requires highly specialised medical staff. Medical specialists at CHW have trained for a minimum of 15-20 years before becoming a consultant (specialist). Almost all of the members that the MSC represents have repeatedly uprooted ourselves and our families to move around the country and the world for training.

Our hospital runs on staff numbers that are barely coping with the existing clinical workload let alone the forecast increases with population growth, novel therapies, complex care, management, teaching and research commitments. It is an incredibly fragile balancing act that does little for staff morale.

Our medical subspecialists are in demand all around the world and are constantly being offered roles at other hospitals that have equally rewarding work alongside far better conditions. We have lost a sizable number of top-quality clinicians and researchers to private practice, other states and internationally over the years.

The employment conditions that the NSW public hospital system offers are not competitive with our national or international peers and have not been reformed as the nature and volume of our work has evolved.

At present there are two main mechanisms of remuneration that include the Staff Specialist Award and the Visiting Medical Officer Award.

Concerns can be summarised in the following points:

1. Remuneration packages for NSW staff across a wide range of health care sectors are significantly less than that clinicians enjoy in other states and territories.
2. The numeric value of the award is less of an issue than the gross inequity that exists between colleagues performing the same function across the country.
3. This inequity must be seen in the context of an increased cost of living in urban areas of NSW.
4. The above are all "push factors" that have made recruitment and retention of quality health workers very challenging. I refer you to the submission by our anaesthetic colleagues who had a staff turnover of 42% which is a very high figure in any clinical service, but is a critical issue in such a pivotal department where training and experience can have a significant

impact on outcomes. Another example is that paediatric ICU specialists in NSW earn between 20 and 70% less than people with the same qualifications working in smaller, less complex units in other Australian states and territories, a matter which is currently before the NSW Industrial Relations Commission.

5. It is generally agreed that the Staff Specialist Award is not fit for purpose and needs reviewing, in the words of the NSW Industrial Relations Commission “there is broad consensus that the Award needs to change.” This process is underway and being driven by ASMOF. Glaring inconsistencies in the award include the lack of ability to recognise overtime and the fact that hours between midnight and 7am are completely ignored by the award – making it impossible to recognise, let alone remunerate, work performed in those hours. This is a major issue for those specialties that bear the burden of being called back to the hospital after hours and on the weekends and who routinely do critical work after hours
6. Adding further to the inequity of the present remuneration is the scenario where a VMO and a Staff Specialist can be operating together after hours. In this circumstance, the VMO is paid an hourly rate while the staff specialist gets no remuneration for this time.
7. Training education and Study allowances are now at \$38 000 per annum under a use it or lose it agreement allowing accumulation period of only two years. It is a sizable portion of the salary allocation but it has become increasingly difficult to access these funds for their stated purpose. This effectively ensures a significant portion of a level one staff specialist salary is returned, unused to NSW health
8. Understandably clinicians and craft groups have at various times agitated for a change to their remuneration and on many occasions “special deals” have been made. This has often been a very acrimonious process with clinicians pitted against their executive and NSW health, in court. This has been at considerable cost to basic clinical services, time, effort and staff morale. Not to mention the material cost of court to both parties.
9. “Special deals” have further compounded the existing inequity by bringing interstate remuneration inconsistency into individual hospitals and departments. To the point where clinicians in the same department, performing the same tasks can have salaries varying by \$75000.
10. It is obvious how the above leads to ongoing battles between the executive and clinicians and will undoubtedly see further court appearances in the future. This is a situation that will ultimately effect patient care.
11. Most of the VMO contracts are remunerated purely on the basis of billable hours. Essential components of tertiary care including reading around complex patients, research, teaching and administration are not remunerated, making all but the very best of us less inclined to contribute significant time and energy to the holistic needs of academic practice.

**v. the relationship between NSW Health agencies and medical practitioners;**

There appears to be a uniquely antagonistic relationship between NSW Health agencies and medical practitioners. We frequently see parties in the Industrial Relations Court, we see negative press statements and we have seen several votes of no confidence in the hospital executives of late. Disagreements are inevitable but the degree of acrimony that some disagreements create seems to suggest an underlying frustration with the system, the institutionalized mediocrity, the apparent lack of ambition, clear vision, progress toward a common goal of health care excellence... leadership.

**vi. the role of multi-disciplinary community health services in meeting current and future demand and reducing pressure on the hospital system;**

There is an undue burden on the Emergency Departments of CHW. This is due to a number of factors that include:

- A lack of community based facilities capable and confident enough to handle basic acute paediatric care and after hours consults.
- Present funding models are a disincentive to establishing meaningful facilities capable of providing acute and after hours paediatric care.
- The lack of paediatric capacity in smaller hospitals has led to a lack of community confidence in paediatric care outside the teaching hospitals.

- Consequently a significant number of patients who do not need tertiary services (e.g. minor lacerations, urinary tract infections, respiratory infections, gastroenteritis) are presenting to the major teaching hospitals
- This in turn puts huge pressure on the capacity of the teaching hospitals and unless adequately resourced, leads to prolonged waiting times to be seen, prolonged waiting times in ED, bed block, ambulance ramping and potentially poorer patient outcomes.
- Developing basic, acute paediatric care capacity must be a priority.

**The Following submissions are from senior clinicians and Heads of Departments at CHW. They represent examples from across our hospital of how chronic underfunding and unfunded growth in demand inhibit the safe delivery of high quality, timely, equitable and accessible care to the children of NSW.**

### **The Paediatric Intensive Care Perspective**

The population of Brisbane and Gold Coast with a population roughly half the size of Sydney has access to 46 staffed paediatric intensive care beds. The population of Sydney has access to 40 or less, once staffing shortages are accounted for. The population of Western Sydney has access to only 25 beds at CHW. This is not a sufficient number of beds to manage the needs of our community let alone all the referrals we are getting from around the state and overseas. The consequence of this is that we frequently do not have ICU beds available to proceed with the day's operations. Patients are frequently cancelled, more than once, on the day of their surgery. The impact of this on the patients and families of our sickest children is beyond measure. Imagine a child from Dubbo who has a cardiac abnormality that requires open heart surgery. The parents have taken time off work, the family and the child have prepared themselves for the surgery. The child has not been able to have breakfast, they make the 5 hour trip to Sydney. They sit for half a day while our staff desperately try to manage a bed crisis in PICU. At midday we appreciate there is no way we are going to get a bed in ICU and cancel his surgery for the second time, the family return to rural NSW with disappointment, anger and frustration. This is a very regular occurrence and is well below the standard of care we should be providing yet funding and capacity are not rectified in response. This has now become the standard of care we provide.

### **A Report by Dr Andrea Christoff MD, FRACP, FCICM Medical Director Paediatric Intensive Care Unit, CHW, SCHN**

Dear Commissioner,

I am the Medical Director of the Paediatric Intensive Care Unit (PICU) at The Children's Hospital at Westmead (CHW) and an active member of the medical staff council (MSC). My colleagues and I consider ourselves privileged to work as specialists in the PICU at CHW where we get to help approximately 1400 children and their families each year at a time when they are at their most vulnerable.

Providing optimal care for these sick infants, children, and their families, is a vital objective, and we would be failing our patients if we felt their care was potentially compromised due to inadequate staffing and we did nothing. Inadequate nursing ratios and understaffing of intensive care specialists, however, is a real safety concern that places these infants and children at risk and as such, must be brought to your attention.

### **Recruitment and Retention for specialized workforce**

The working conditions for critical care specialists and nursing staff at CHW has changed dramatically over the past two decades due to the steady increase in patient numbers, acuity, and complexity which has occurred in parallel with a community expectation that consistent high-quality care must be provided 24 hours a day. This has resulted in the need to provide on-site presence of an experienced and trained paediatric intensive care specialist day and night to ensure that the sickest babies and children in NSW receive the highest quality care.

The after-hours work that used to be extraordinary in critical care is now becoming routine. There are currently 13 PICUs in Australia and New Zealand competing to attract the best talent among the approximately 80 medical specialists with the skills, training, and qualifications to provide such care. Over the past decade or so, it has become increasingly challenging to recruit and retain paediatric critical care specialists to work in NSW due both to the intensity of the work and the fact they can earn up to 50% more working in PICUs interstate. In fact, a newly graduated junior consultant in Adelaide earns approximately \$100k more than a senior staff specialist in Sydney. While junior doctors, nurses and nurse practitioners are invaluable and essential members of the team, as patient acuity and complexity increases, so too does the need

for well-trained qualified paediatric intensivists for the delivery of high quality, innovative, safe, and reliable care to critically ill infants and children.

In May 2022, a letter sent to the Health Minister signed by 50 specialists working in anaesthesia and intensive care at CHW highlighted the chronic understaffing over a number of years and the departure of a number of staff specialist for interstate or the private sector to pursue better working conditions and remuneration. With the support of ASMOF, we pursued the issue of working conditions for specialists being in breach of the current Award before the Industrial Relations Commission in July 2022. This matter is ongoing.

### **Critical Care Service Delivery**

According to the SCHN 2023/24 Service Level Agreement, the PICU at CHW has 25-beds, however, we are not resourced with adequate nursing staff to sustainably staff >23 beds. Despite this, the PICU census is consistently above capacity with pressure daily to admit planned surgical cases when the staffing in PICU is inadequate to accommodate the demand. In fact, in July 2023 the PICU surged up to 29 admitted patients to accommodate unplanned admissions. This required us to utilize alternative nursing staffing models which places patients at risk of adverse events.

The Children's Hospital at Westmead is responsible for providing statewide services including complex cardiac surgery, liver transplantation, and burns care which is relied upon by infants and children across New South Wales. It is also the busiest center for newborn surgery in the state.

To ensure ongoing provision of these statewide services at a world-class standard, a commitment to permanent recurrent funding for services and resources is required to open and staff more PICU beds.

There are plans to move into a new acute care services building in mid-2025 with 45 PICU beds. However, the current budget does not incorporate growth funding to enable the growth of critical services, and we are currently unable to sustainably staff more than 24 beds due to lack of funding available for nursing staff and junior medical staff. The lack of parity with employment conditions interstate for staff specialists negatively impacts recruitment and retention for the highly specialized group of critical care physicians.

Without a strategy to support recruitment and retention of critical care medical and nursing staff, many of the PICU beds currently under construction will remain unused due to lack of staffing, as a PICU bed without staff is just an empty bed.

### **What do we require?**

Guaranteed recurrent future funding for resources to enhance the bed base at CHW PICU to enable sustainable and safe delivery of critical care services for the sickest infants and children of NSW.

Staff Specialist Award reform that remunerates specialists who work onerous and anti-social hours to safely provide critical care services. Parity with other states in Australia is needed to enable recruitment and retention of paediatric intensivists and develop a sustainable highly skilled workforce into the future.

Sincerely,



Andrea Christoff MD, FRACP, FCICM  
Medical Director Paediatric Intensive Care Unit, CHW, SCHN

**Intensive Care Unit Budget and Activity**

The purpose of this is to provide information regarding safe and sustainable medical rostering and to enable future workforce planning which includes a 24/7 dedicated outreach service.

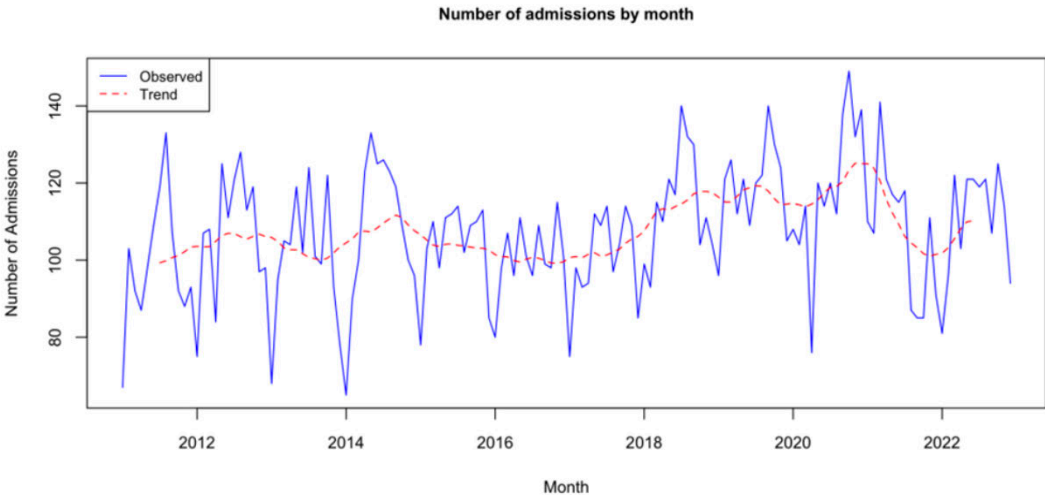
**Inpatient Activity**

Figure 1. PICU/COU Discharges by Discharge Financial year

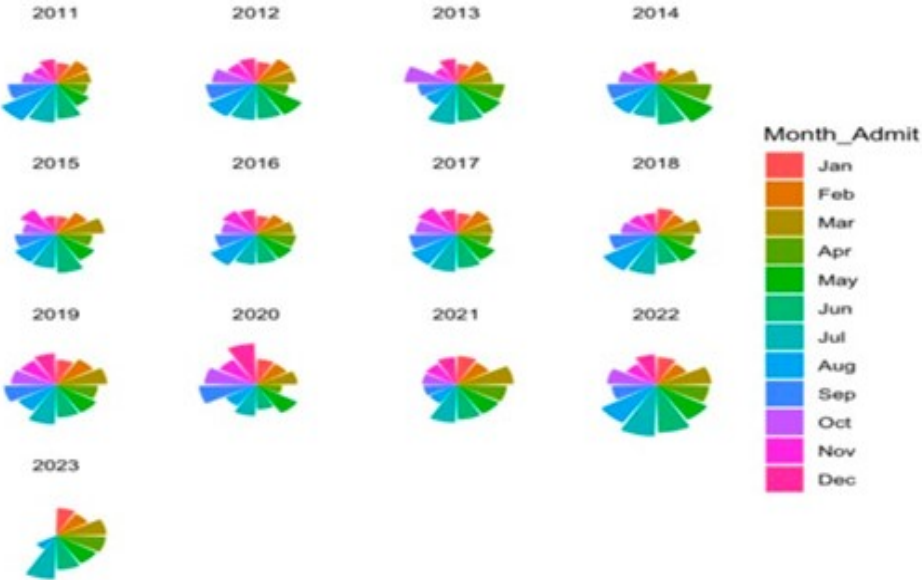
Values	2017	2018	2019	2020	2021
No Separations	1,039	1,117	1,274	1,223	1,305
NWAU for icu_adj	5,865	5,817	5,928	5,090	5,381
NWAU20	16,257	17,675	17,419	17,160	16,555
Length_of_stay	20,157	21,476	22,658	22,555	21,822
Hours in PICU/NICU/COU (ICU1)	193,743	189,244	182,559	167,537	183,958
Avg LOS	19.4	19.2	17.8	18.4	16.7
Avg ICU/NICU (bed type ICU1 only) LOS of those who have been through PICU/COU	7.8	7.1	6.0	5.7	5.9

Average length of stay in ICU has reduced to 5.9 from 7.1 days since 2018. However the complexity and acuity of patients admitted to intensive care has increased. 10% of our patient cohort makes up 60 % of bed days

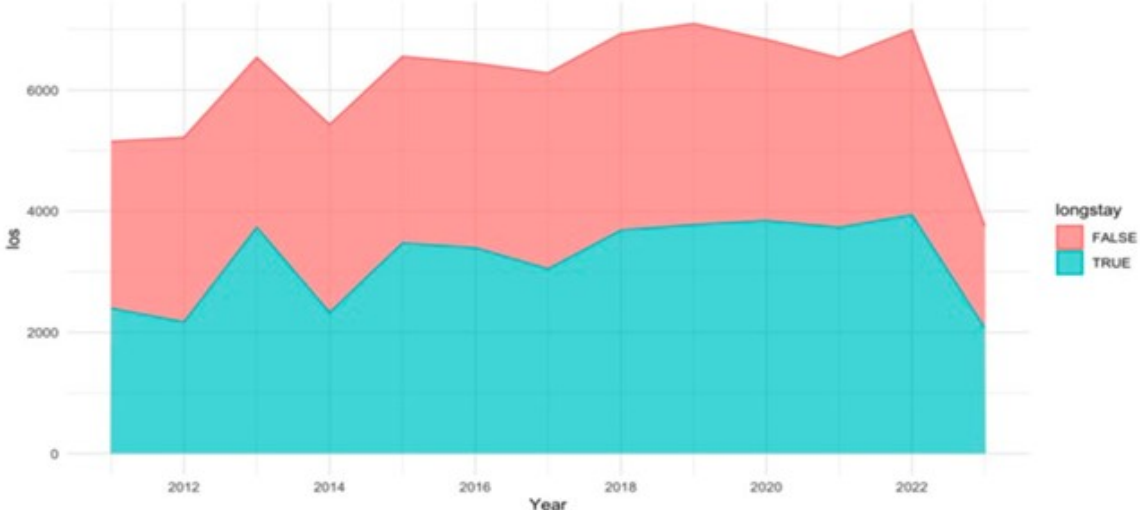
**Monthly admissions**



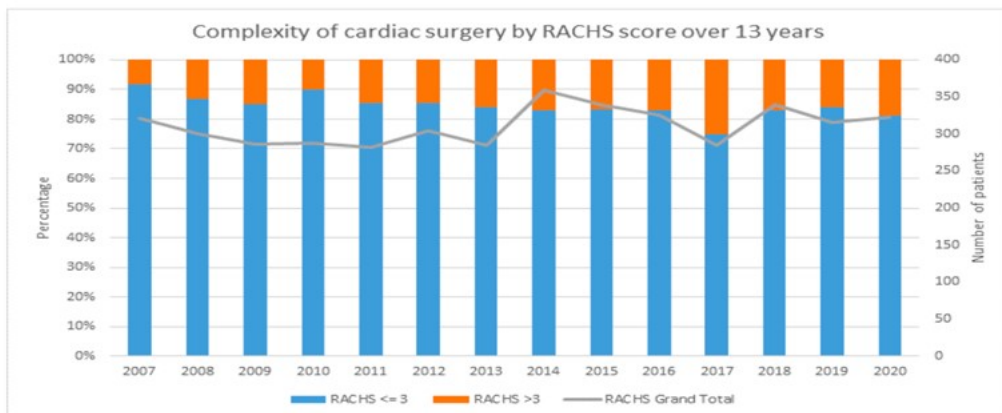
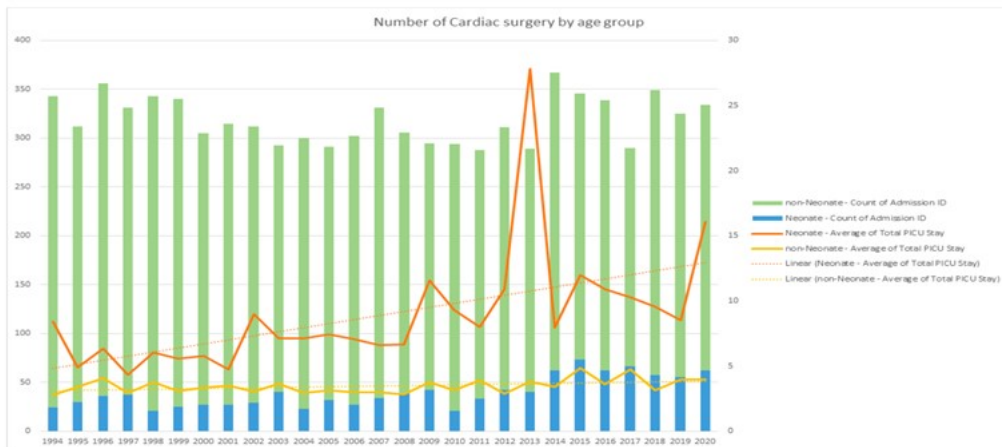
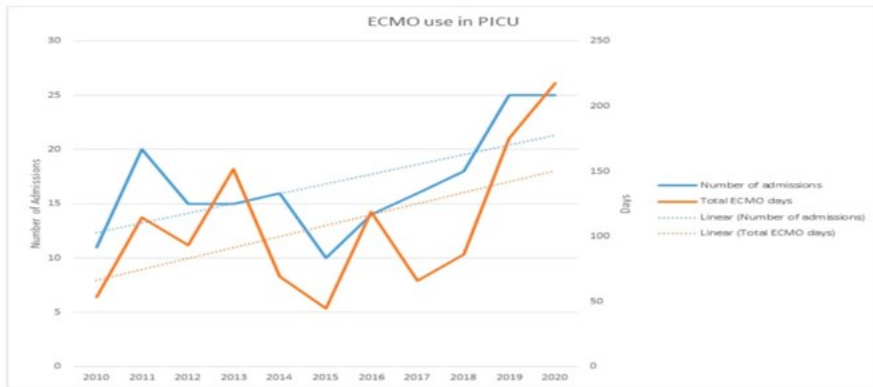
**By emergency**



**10% of our patients contribute to up to 60% of our total bed days**

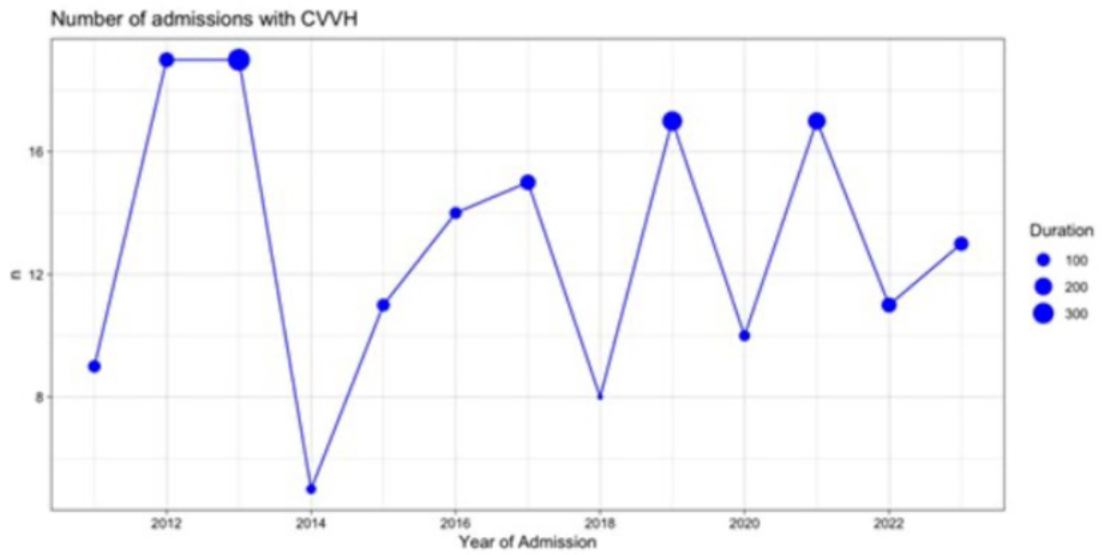


2. ECMO days have doubled from 2018 to 2020, requires 2 nurses per patient 24/7.

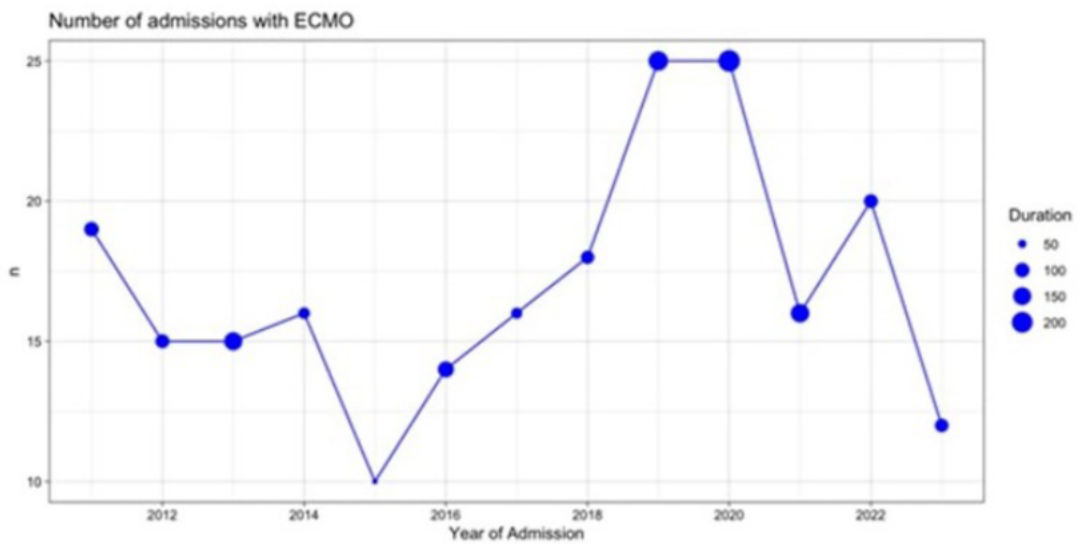




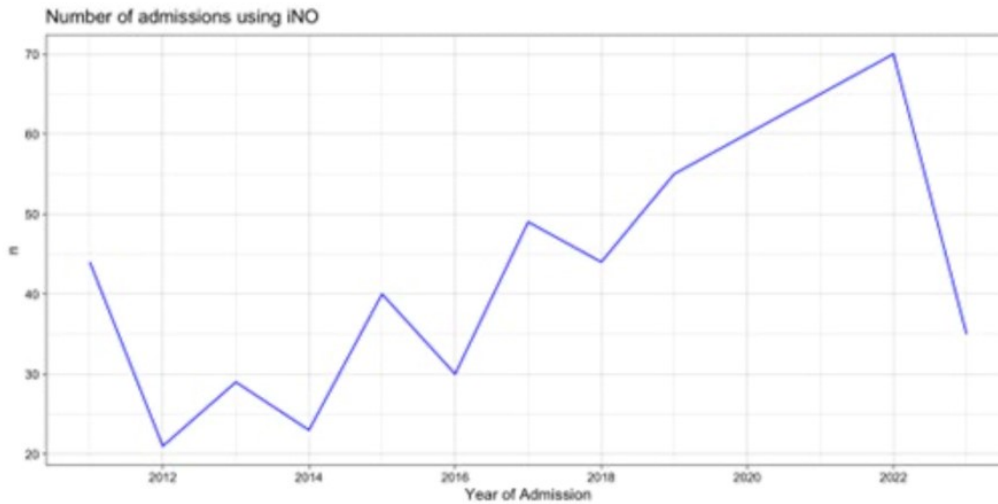
## CVWH use



## ECMO use



## iNO use over the years



### NCOS Trend

FY	NCOS Actual	% Actual increase from previous year	NCOS Budget	% Budget increase from previous year	Actual to Budget Variance
2014	18,316,254		18,673,902		- 357,648
2015	18,156,685	-0.9%	19,212,548	2.9%	- 1,055,863
2016	19,684,266	8.4%	19,660,720	2.3%	23,546
2017	21,152,027	7.5%	19,746,842	0.4%	1,405,185
2018	21,944,604	3.7%	20,664,951	4.6%	1,279,653
2019	26,766,333	22.0%	25,145,177	21.7%	1,621,156
2020	28,743,578	7.4%	26,924,921	7.1%	1,818,657
2021	29,899,650	4.0%	27,457,557	2.0%	2,442,093
<b>Overall Increase</b>	<b>11,583,396</b>	<b>63.2%</b>	<b>8,783,655</b>	<b>47.0%</b>	<b>7,176,779</b>

The unit's unfavourable budget variance has doubled since opening close observation unit (4 beds) in 2018. \$2.4m in 2021 as FTE have increased over the years to try and manage the unit activity, increased complexity of patients and outreach service (PICOS)

FTE Trend required to staff PICU, staffing enhancements have not occurred and currently only able to service 23 beds as failure to provide recurrent permanent funding to support positions.

FY	680261 Nursing CC	680660 JMO CC	680315 SMO CC	Grand Total
2012	104.8	15.4	11.3	131.6
2013	109.3	15.6	11.3	136.1
2014	115.1	16.3	11.0	142.3
2015	119.7	14.7	10.5	144.9
2016	126.6	17.1	11.1	154.8
2017	126.8	20.2	11.5	158.5
2018	132.3	20.6	11.4	164.2
2019	154.8	25.0	13.0	192.7
2020	158.5	26.8	13.4	198.7
2021	164.7	27.9	15.5	208.0

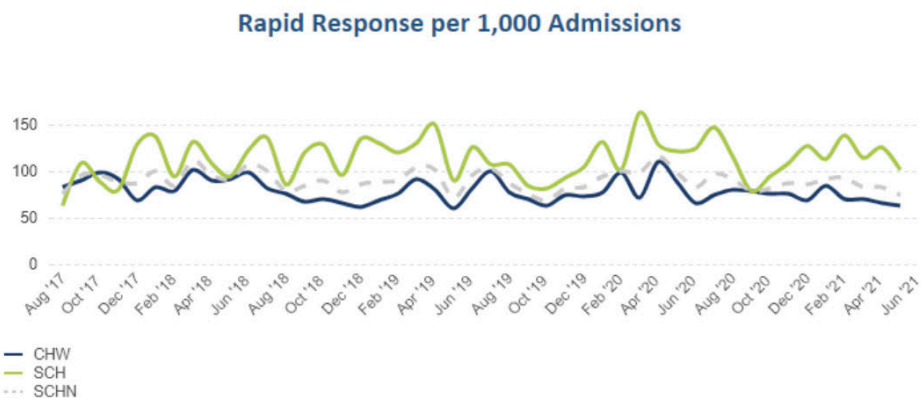
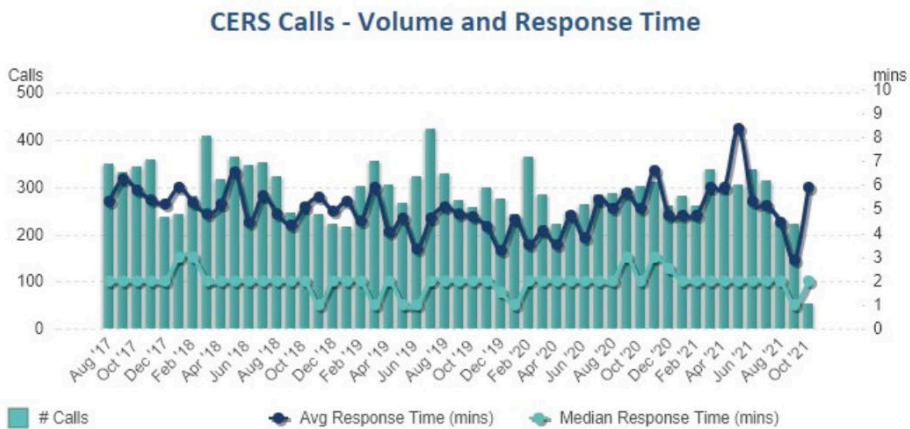
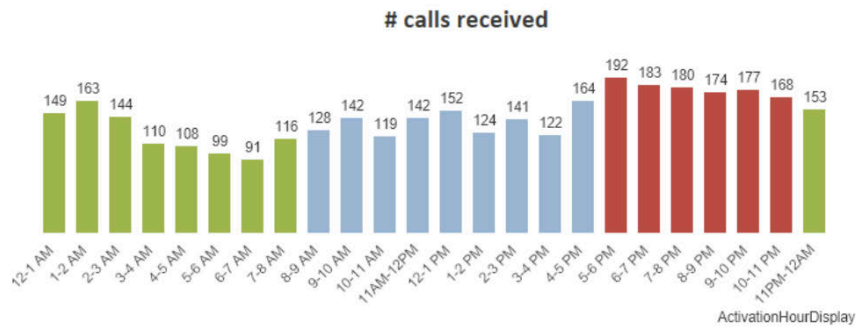
**Outreach Activity**

Number of Activations (i.e. PICU outreach urgent attendances) per 1000 hospital separations. Outreach workload has significantly increased, it should be noted there is a relationship between dose and patient outcome.

Year	Activations	Separations	Dose/1000
2009	480	27791	17.3
2010	779	29559	26.4
2011	951	29033	32.8
2012	1025	29623	34.6
2013	1361	30872	44.1
2014	1404	32201	43.6
2015	1537	32243	47.7
2016	1466	32831	44.7
2017	2449	33140	73.9
2018	2942	32947	89.3

PICOS- paediatric intensive care outreach service. The PICU provides a service to the hospital to respond to deteriorating patients and support the wards and emergency department. This service has never been funded and the resourcing has been reliant on existing staff to manage nursing and medical without enhancement in staffing. It is projected that PICOS activity will continue to increase with increasing patient complexity and ICU capacity. The relocation of the emergency department and medical short stay unit (Acute Building Stage 1 in 2020) will add further pressure on PICOS with a requirement to respond to deteriorating children located in two different campuses.

The graphs below display increased activity overtime. Over the past 12 months the PICU staffing has not been adequate to staff PICOS and we have adapted an alternative tiered model of care – the PICOS service is not available to the patients 24/7 and this places infants and children at risk not having the response team available to attend to deteriorating children outside of PICU



**A Report by Dr Soundappan S.V. Soundappan  
Head of Department, Trauma Unit  
The Children's Hospital at Westmead**

**Introduction**

Trauma remains the leading cause of death for Australian Children, accounting for 33% of all fatalities among those aged 1 – 14 years (Australia Institute of Health and Welfare - AIHW 2020). From AIHW's most recent data update, 62,121 children were hospitalised due to injury between 2019 and 2020, and 502 children (0-14) died as a result of injury during 2018 to 2020. Despite improvements in mortality rates over the last 3 decades, the burden of paediatric trauma persists and continues to outpace other causes of childhood mortality including childhood cancer. This disease often remains overlooked and disregarded at all levels of the system. However, delivering timely, coordinated, and multidisciplinary care is essential to minimising mortality, mitigating long-term disabilities, and maximising quality of life for all injured children, especially to polytrauma patients who are complex to deal with.

This clinical service plan for The Children's Hospital at Westmead (CHW) aims to assess current trauma service capabilities, activity trends, gaps, and initiatives to ultimately inform strategies for better meeting the trauma needs of Western Sydney's growing paediatric population. With projections indicating a 44% increase in the local child population by 2036, substantial enhancements to paediatric trauma services will be imperative.

An effective trauma system encompasses the full continuum of care from acute care through rehabilitation and community reintegration, with integrated education, quality improvement and research. Although the existing trauma program at CHW serves patients across these domains, several gaps exist that continue to compromise the consistency and sustainability of quality care. By quantifying patient volumes, injury patterns, and outcomes over a multi-year period, this plan provides evidence-based support for the resource investments and infrastructure upgrades critical to keeping pace with rising demand.

The subsequent sections analyse trauma activity and trends at CHW, highlight achievements of the service to date, identify persistent care challenges, and, most importantly, propose recommendations to address these gaps. The overarching goal of this clinical plan is to further develop a robust and proactive trauma clinical service aligned to the needs of the Greater Western Sydney now and into the future.

**Role and structure of Trauma Department at CHW**

The Children's Hospital at Westmead (CHW) is a designated Level 1 Paediatric Trauma Service for Western Sydney and Western NSW in accordance with NSW Trauma Service plan, providing the highest level of definitive care for injured children across the region.

The trauma service at CHW provides 7/24 coverage of resuscitation, surgical management, critical care, and multidisciplinary coordination of patients, especially those with complex and severe traumatic injuries. This encompasses the full spectrum of care from emergency response through discharge/transfer planning and rehabilitation.

Core multidisciplinary capabilities of our service in conjunction with the other specialised medical specialties include Emergency Medicine, Trauma/Acute Care Surgery, Neurosurgery, Orthopaedics, Plastic Surgery, Critical Care, General Surgery, Ophthalmology, ENT, Psychiatry, Rehabilitation, Allied Health, with long-term collaborations with Nursing, Radiology, Pathology Laboratory and Blood Bank. The overarching aim of our service is to provide the highest standard of care to paediatric trauma patients and their families.

Our service engages closely with referring hospitals and prehospital transport teams throughout the Greater Western Sydney and NSW to facilitate transfers and promote bidirectional learning. We collect and collate patient information from all trauma patients admitted to CHW as a local clinical trauma database which is also part of the NSW Trauma Registry. The database is used

for monitoring service delivery and performance, as well as generating quality improvement projects and audits.

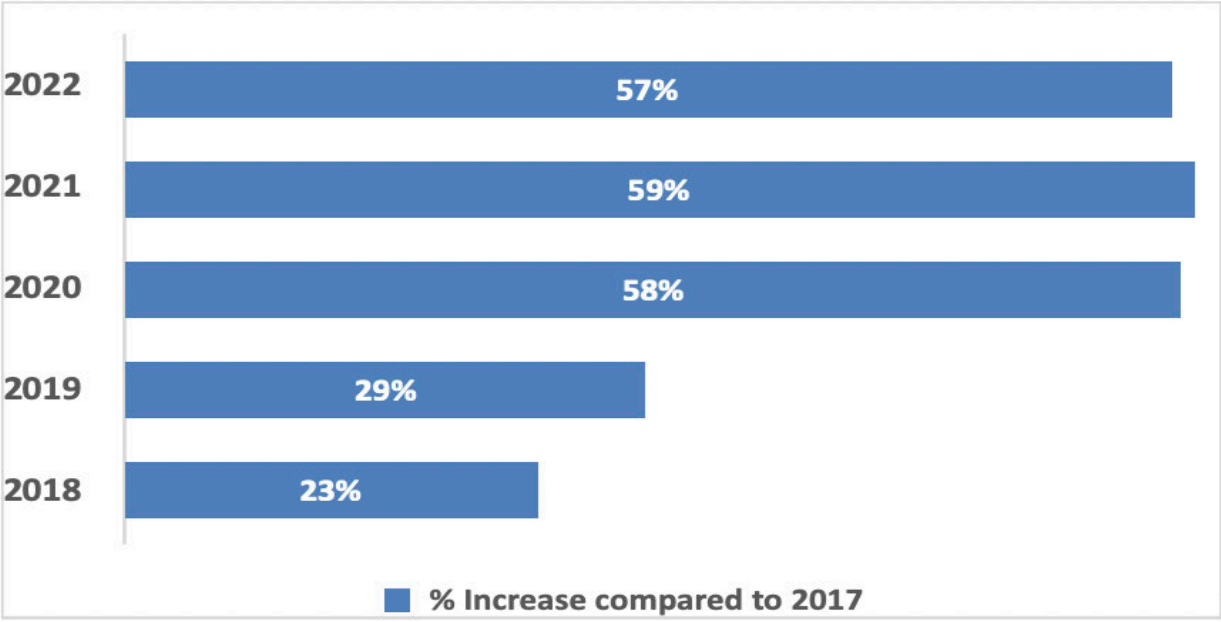
As the regional paediatric trauma leader, CHW provides consultation services, education, prevention programs and research collaboration with multiple partners and stakeholders. Our collaborators span across NSW, including trauma services in both adult and paediatric hospitals both in urban and rural area.<sup>3</sup> Trauma presentations at CHW.

**Trauma presentations at CHW**

Injuries account for 25% of CHW’s Emergency Department (ED) presentations annually, i.e., approximately 58,000 children with injuries are admitted to CHW every year.

Over the last 5 years, trauma patient volume grew by at least 23% from 2017, with 485 trauma calls per year on average (Figure 1). Specifically, the last 3 years have seen a strong and steady increase of greater than 50% in the trauma admissions into our service, with no additional increases in resources to meet the increasing challenges and demands.

2022 saw 617 trauma patients, including 502 trauma team activations plus 115 patients that did not have a trauma call activated but fitted the trauma criteria and still required a multidisciplinary team approach in the management of their injuries. As of November 2023, trauma team activations reached 543 already. This rising volume reflects both population growth and increased injury acuity.



**Figure 1:** Trauma Calls at CHW over a 5 year period between 2018-2022.

The current (2023) population in Greater Western Sydney is 2.6 M, containing about 50% of Sydney’s population (GWS; <https://profile.id.com.au/cws>). Based on census projections, the Greater Western Sydney child population will surge by 44% to 731,600 by 2036 (Table 1; <https://www.westir.org.au/new/images/CPGWS.pdf>). With trauma comprising a substantial portion of CHW’s paediatric patient base, substantial service growth must begin now to meet future demand.

**Population Projection for Greater Western Sydney**

	<b>2016</b>	<b>2036</b>	<b>% Increase</b>
<b>0-4 years</b>	183700	249200	35.7
<b>5-9 years</b>	167150	244150	46.1
<b>10-14 years</b>	156250	238250	52.5
<b>Total</b>	<b>507100</b>	<b>731600</b>	<b>44.3</b>

**Table 1:** Projection of population in GWS for 2036. A comparison of population size in differing childhood age groups ranging 0-14 years.

**Morbidity and Mortality rates**

Injury Severity Scores (ISS) is an established medical score to assess trauma severity:

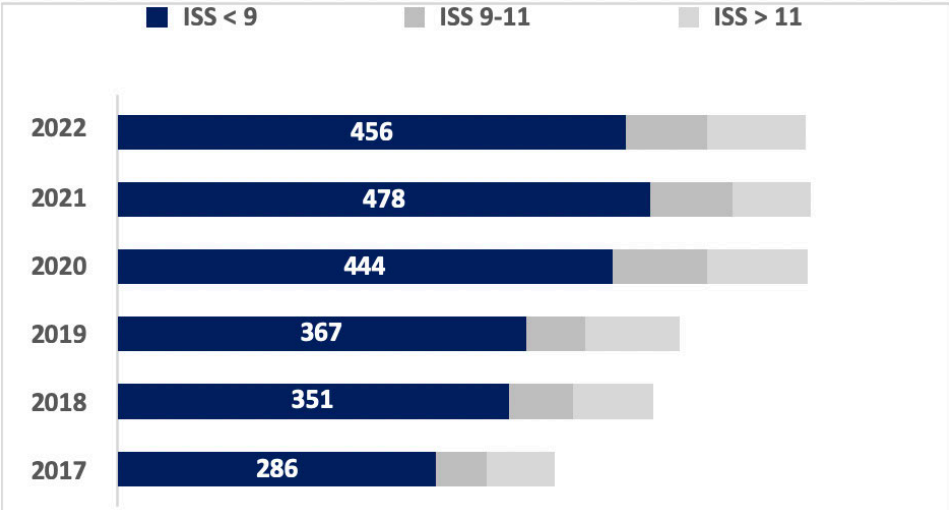
Minor: ISS < 9

Moderate: ISS = 9 – 11

Severe: ISS ≥ 12

Not only have the trauma presentations to CHW increased but also the severity and the acuity are also on the increase.

An ISS < 9 is minor injuries which can be managed with less specialised resources in a variety of clinical settings. Over the past 5 years, minor trauma admissions increased 50% since 2017 (Figure 2).



**Figure 2:** Trauma Presentations at CHW with ISS < 9 over a 5-year period.

An ISS 9-11 is classified as moderate injuries that require significant resource utilisation for their management. In 2020 moderate injury cases rose significantly as well, by upwards of 89% compared to 2017, and has since remained high (Figure 3).

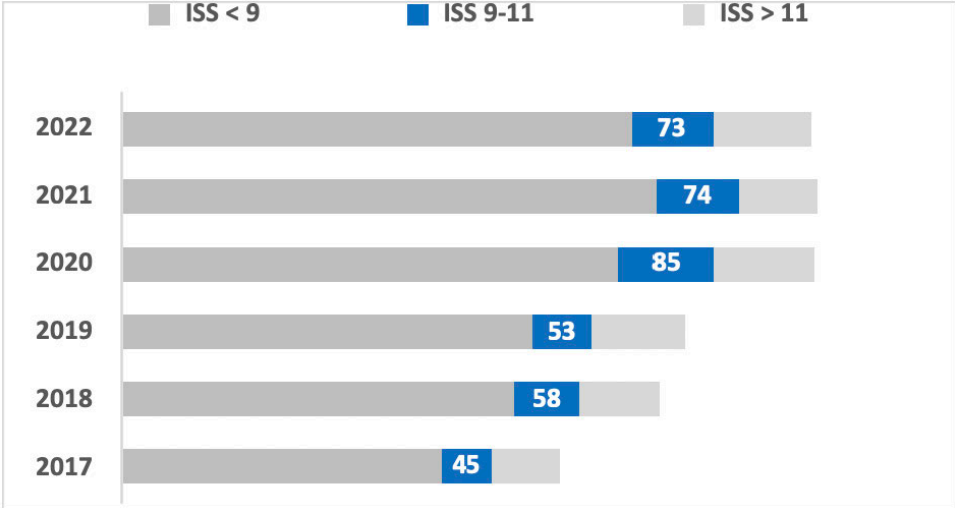


Figure 3: Trauma Presentations at CHW with ISS 9-11 over a 5-year period.

Finally, an ISS ≥ 12 is classified as severe injuries with a significant risk of mortality, and those that do survive will have significant morbidity. There has been a 44% increase in number of severe trauma patients between the years 2022 and 2017 (Figure 4).

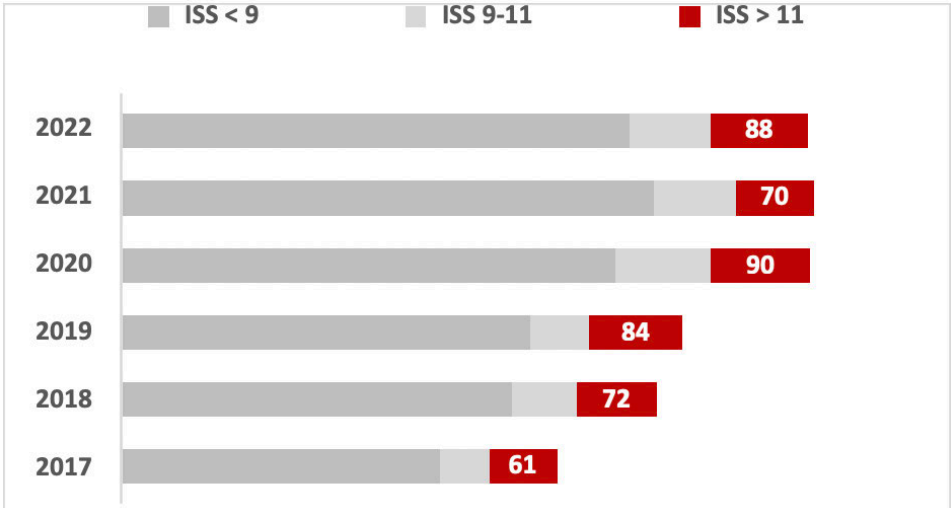


Figure 4: Trauma Presentations at CHW with ISS >11 over a 5-year period .

**Challenges with the Current Model of Care and Recommendations for Improvement**

The population in Greater Western Sydney is projected to grow by 12.1% by 2021, with a 2.4% growth in Western NSW. As most of these individuals are young families, we anticipate a proportional increase in the paediatric population and a potential rise in trauma-related presentations to CHW. Despite this, and the increasing workload, our service has not seen any increase in staffing for nearly two decades. Based on the above data and analysis, we have identified several gaps that limit our ability to meet current and future demand. In response, we stress the need for relevant intervention to ensure the sustainability and comprehensiveness of our service.



### 1. A Lack of Designated Trauma Beds:

#### *Recommendations:*

- Establish 6-8 dedicated trauma beds to centralise care of trauma patients before admission into a sub-specialty services.

### 2. Absent Injury Prevention Support:

- Injury prevention is an important aspect of our service. Currently there is no centralised staff who could collaborate with appropriate agencies for community education and safety programs.
- It is difficult to operationalise prevention initiatives within clinical teams.

#### *Recommendations:*

- Funding for a dedicated injury prevention officer/coordinator.
- This officer/coordinator will focus on the development and implementation of consumer-centered education and preventative programs through close consultation and collaboration with schools, community centres and local agencies across the Greater Western Sydney district.
- This position will facilitate the shaping a district/state wide model of care framework for injury prevention services, ensuring the delivery of high-quality care to the district.

### 3. Minimal Integrated Mental Health Services:

- Post-traumatic Stress Disorder (PTSD) is a well-documented mental health risk factor for children sustained trauma/injuries. A recent longitudinal study demonstrated that children treated in NSW following an injury have reduced quality of life and in particular, reduced emotional well-being at 12 months post-injury, regardless of injury severity (Curtis et al., 2020a).
- Our service has had no routine follow-up support services post-discharge for our patients or their families, due to the lack of staffing and resources.

#### *Recommendations:*

- Funding for a dedicated trauma social worker, who is trained in paediatric trauma, to assist patient follow-up and targeted mental-health related screening.

### 4. Gaps in trauma Education and Simulation:

- There has been a lack of sufficient training in paediatric trauma management in the current workforce, especially those in regional or rural NSW.
- Over the last two years, our service has conducted a full day simulation education session (Tiny Tots) twice in our network hospitals. These two sessions were very well received and there has been an on-going demand for future offerings. However, there has been no funding to support this education initiative.

#### *Recommendations:*

- Adequate funding to support:
- The development an in-house, high-fidelity, simulation program.
- Conduct regular multi-disciplinary simulation scenarios.
- Offer training sessions to regional/rural hospitals.
- Build a dedicated simulation centre for all specialities to impart their unique knowledge and skills.

## Conclusion

Analysis of CHW's trauma volumes, patient complexity, and capacity constraints reveals a system stretched by rising caseloads without proportional expansions in staff, infrastructure, or care coordination pathways. Addressing such gaps will require investment in key areas:

- **Staffing:** funding an dedicated injury prevention officer/coordinator and a mental-health focused trauma social worker.
- **Infrastructure:** Establishing trauma beds/ward and simulation facilities.
- **Care Models:** Implementing injury prevention coordination and mental health services into our service. Operationalising a simulation-based education curriculum for state-wide health workforce in paediatric trauma.

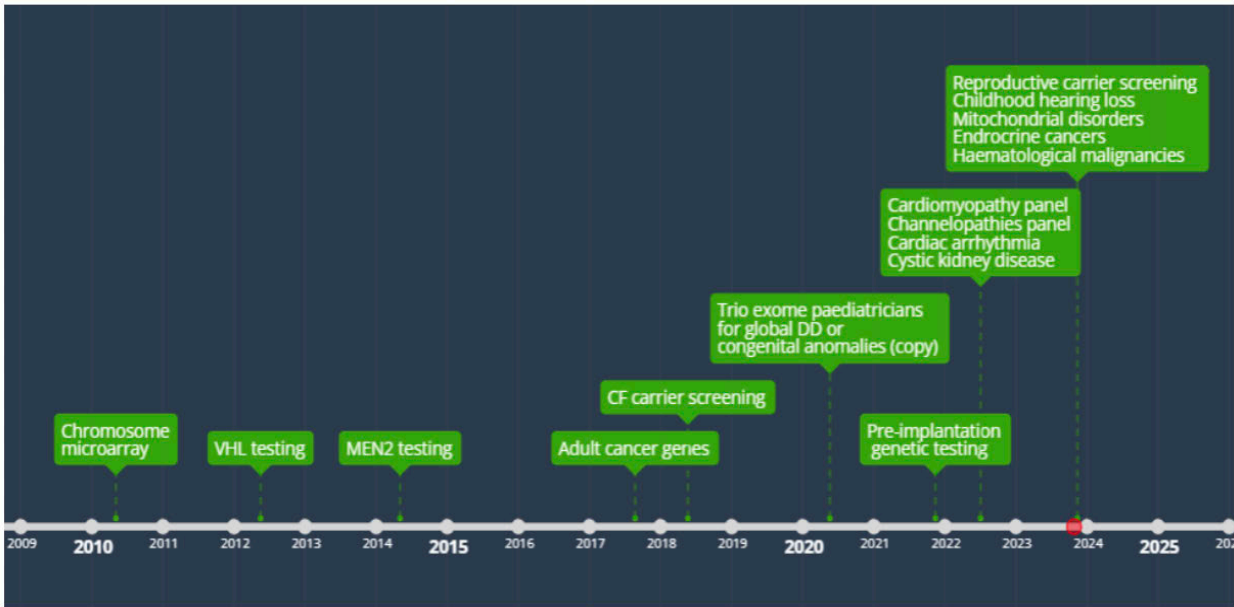
Executing such initiatives will allow CHW to fulfil its role as the regional leader in paediatric trauma care, promoting quality, continuity, and accessibility for all children requiring urgent injury care across Greater Western Sydney.

Trauma continues to be the leading cause of preventable death and disability for Australia children. Trauma presentations to CHW are increasing, along with the acuity. As both population growth and injury severity place an increasing demand on CHW’s paediatric trauma service, substantial clinical service enhancements are essential to sustain, let alone maintain the service into the future.

**A report by Dr Kristi Jones  
Head of Department  
Clinical Genetics  
The Children’s Hospital at Westmead**

The impact of advances in genomics has been far reaching in paediatrics - spanning every sub specialty and across all facets of health care.

There has been a significant increase in workload for clinical genetics services in Australia over the last 10 years, particularly the last 5 years, reflecting increased availability and complexity of genomic testing. This graph shows the exponential increase in Medicare funded genomic tests, which is going to continue. These are only the ‘tip of the iceberg’. Each of these require input from clinical genetics to determine the appropriate test to order, upskill in the consenting process, interpretation of complex results, and ‘next steps’ into research and treatment pathways. The introduction of Medicare funding for reproductive carrier screening and expansion of the newborn screening program will bring a dramatic increase in demand for clinical genetics expertise.



Genetics at SCHN has dual responsibility and there is ongoing tension between them:

- Servicing the genomic needs of our highly complex patients from all over NSW.
- Providing ‘district general’ genetic care to residents of Western Sydney LHD

We currently run or contribute to 15 different clinics and more than 20 subspecialty multidisciplinary team meetings. At present, we are failing to meet the Agency for Clinical Innovation’s Clini-

cal Genomics, model of care metrics for time to see patients. For our 'General clinic' alone, there are currently at least 40 patients on the waitlist that have been triaged to be seen in less than 6 months, and a further 133 having been triaged to be seen in 6-12 months, who have been waiting more than 2 years to be seen. We have no more appointment space this year and we are receiving at least 10 referrals per week for this clinic alone.

The demand for teaching from our colleagues and peers, as well as students, to upskill and mainstream genomics across the SCHN, the broader paediatric community and primary health care providers is huge.

Research is fully embedded in our daily practice, as most of our patients could and should be linked in with an appropriate research pathway, be it at the diagnostic or therapeutic level. This process is complex and time consuming and requires a high level of specialized knowledge.

One area that we should be national leaders is the provision of ultrarapid turnaround genetic testing (results <3 days) to the most unwell and complex babies and children in NICU/PICU. This is considered standard of care, but is not currently provided to CHW patients. Testing was offered at CHW as part of a MRFF-funded research project from 2018 to 2022. This testing is available as a diagnostic test and is funded and offered by other states. These cases require intensive involvement by Clinical geneticists, genetics fellows and genetic counsellors, requiring hours of clinician time. They require staff to be immediately available when consulted. The CHW clinical genetics service is not currently able to offer this testing, as our clinical service is not resourced to provide this testing: the estimated time involvement for each of these clinicians for a single case is a minimum of 4-6 hours, including the initial consultation, liaison with other clinical teams, consent, organising sample collection, MDT variant assessment and return of results. Depending on the outcome of testing, clinicians from our service are often then involved in further discussions with members of the multidisciplinary team and with families, on treatment options and management decisions.

This testing:

- Provides a genetic diagnosis in approximately 50% of patients
- Results in a change in management in approximately 75% of those with a genetic diagnosis, resulting in access to targeted treatments, shorter hospital admission and reduction in invasive procedures, including major surgeries
- Enables patients and families to make informed decisions on clinical care, based on accurate information, available in a clinically-relevant timeframe.

We have applied for enhancement funding for this service, and have not been successful.

We as a service are well equipped with the clinical expertise to achieve excellence in clinical service provision, provide education to colleagues and students (directly and through contributions to the uni) and contribute/lead the many aspects of research within SCHN and nationally. Whilst we have constantly reviewed our practices, streamlined, mainstreamed etc ultimately no enhancement in 20 years leaves us unable to safely keep up with the number of referrals much less implement new complex services (such as ultrarapid turnaround genetic testing) and support mainstreaming.

**A report by Dr K. Prelog and Dr N. Caplin  
Department of Medical Imaging  
The Children's Hospital at Westmead  
MSC SUBMISSION 2023:**

**Executive Summary:**

- There is increasing complexity of imaging in the tertiary/quaternary setting.
- Paediatric radiology staffing does not match equivalent services in other states.

- Demand for extent and type of services should be referrer driven with radiology providing estimates of costs.
- Currently, funding for paediatric imaging is directed to local services, but complex and time-consuming cases diverted to SCHN.
- Funding should follow the patient.
- Increasing expectation/ requirement for secondary consultation of imaging performed external to CHW.
- Demand for radiology registrar training not met by staff specialists available to do the training.

### **Background:**

Medical Imaging at CHW provides primarily a tertiary/ quaternary level of specialisation. Imaging at CHW supports inpatient and outpatient medical and surgical services. CHW medical imaging is almost exclusively responsible for the paediatric imaging training and experience for radiology trainees in New South Wales.

Some demand is driven by patients of other LHD's where local imaging services deem the imaging procedures to be too specialised to offer locally.

Staff at CHW are specialised in paediatric imaging. As paediatric imaging is a relatively small field, there is little demand for paediatric imaging specialisation in the private sector.

The demand for imaging is generated by clinicians at CHW, 24 hours per day. The number of clinicians asking for diagnostic and interventional imaging and the complexity of this imaging has substantially increased in the last 5-10 years.

Funding for staff specialists is partly from the department budget and partly from private practice billing. Funding for staff, other than staff specialists is via the department budget.

Funding for equipment is partly from donations and partly from the department budget. The life-span of equipment is largely determined by eligibility for MBS rebates rather than technological advances.

### **Challenges:**

The department of medical imaging does not drive demand for services or have meaningful control over referrals. As such, a fixed budget is required to meet variable demand, with demand usually exceeding available resources. Budget allocation and monitoring needs to be matched with and assessed against demand, preferably on a department-by-department model. Overall, the medical imaging department at CHW is relatively small by comparison to the children's referral centres in other states, when considered on a per capita basis.

Consultation with referring departments is recommended when imaging budgets and resourcing requirements are assessed. Specifically, which outpatient tests they would prefer to be available at CHW and what access they desire for inpatient in and out of hours imaging.

Medical Imaging can provide input into the costs associated with delivering the desired demand.

Limited availability of specialist paediatric imagers at other LHD's and in the private sector should be considered in funding decisions. Specifically, not all paediatric imaging tests are available outside the SCHN and there are many tests that other LHD's and the private sector, do not perform. *In some cases, specialist paediatricians and paediatric surgeons require paediatric imaging specialists.*

Where funding is provided to other LHD's for paediatric imaging, with policies aiming for patient care "close to home", there needs to be a better understanding of how this funding is utilised. There also needs to be a better mechanism for diversion of this funding to CHW when the imaging occurs at CHW rather than locally.

Examples of tests that are routinely referred to CHW include:

*Fluoroscopy tests*, almost all of which are time consuming, require significant staff resources and are poorly remunerated by the MBS. These are usually declined by LHD's outside SCHN, with patients routinely referred to CHW.

*CT and MRI* requiring sedation or anaesthesia is offered by few other LHD's and in limited number where they are offered. MRI or CT in younger children requires anaesthesia or sedation. This increases the time and resources needed to do these studies. Even when sedation is not required, performing these studies on children is usually far more time consuming than the same test in an adult patient.

### **Second Opinions:**

Imaging performed at other LHDs or in private, that is abnormal, often requires a second opinion from a paediatric radiologist. This daily occurrence is not accounted for, or resourced, in the routine department workload.

### **Diversion of imaging to the private sector**

The fact that imaging can be performed sooner in private practice than it can in our over-stretched department has led patients who have the means to seek imaging in private centres. This seems like a good option to unburden the public system but in reality it has problems:

- It denies CHW of a valuable revenue source
- It does not take into account the ability or willingness of the private sector to perform the imaging
- It erroneously assumes the private sector has the knowledge and experience to conduct the imaging
- It is often associated with poor/inaccurate reporting, consequently we are frequently asked to review the images and reports by our clinicians.
- It confounds clinical care because access to reports and particularly the images is not always possible
- It can lead to inappropriate recommendations based on adult protocols (CT scans for suspected appendicitis) or unnecessary recommendations for additional or follow-up imaging.
- The loss of revenue to the department compromises income and the ability to recruit and retain staff specialists. It also limits our ability to maintain a well staffed administrator, nursing and radiographer workforce
- The practice reduces the availability of teaching cases for radiology trainees.

### **Paediatric Radiology training:**

Radiology Trainees require exposure to a volume of cases, spanning normal to abnormal and rare cases.

Trainee radiologists are rotated through CHW to gain valuable paediatric experience in a formal paediatric facility. The number of trainees on rotation to CHW has risen in the last 10-15 years, currently 21 per year, and is expected to rise significantly in the near future, due to increasing number of training positions at the adult hospitals. The capacity of the department to incorporate the increased trainees is limited at present.

### **Paediatric Radiologists:**

Recruitment and retention of radiologists deserves special mention. As described above, staff specialist salary is partly derived from Medicare billing and is subject to a high "facility fee" of almost 50%, compared to 20% for most other staff specialists. A high and increasing proportion of the work of CHW staff specialists is not billable.

There is a large and increasing discrepancy between the salary of a public hospital staff specialist radiologist and a private practice radiologist. This discrepancy makes recruitment and retention of radiologists challenging. It significantly reduces the willingness of trainees to undertake a career in paediatric radiology. Consideration should be given to this disparity when recruiting staff specialists to a referral centre where experience and expertise should be highly valued.

Because of our resource constraints, our radiologists spend the vast majority of their time performing clinical duties and relatively little, if any, on teaching and research. This is not a sustainable formula for an academic referral hospital. There has to be adequate resourcing to allow time for academic pursuit.

Consideration of overall department size is important. Currently CHW, has less FTE than Queensland Children's Hospital and the Royal Children's Hospital in Melbourne. Both of these referral centres have more fellows (qualified radiologists undertaking further training) and less registrars.

With emerging technologies, imaging becomes progressively more integral to patient care. Newer and faster, and often superior, imaging options will likely become more central to the work-up of paediatric patients in time. This will require additional resourcing.

A small department makes it difficult to cover on call rosters. The volume of radiology performed after hours has increased significantly. More patients, sicker children, new hospitals, less capacity in the community and higher fidelity imaging are all going to place additional strain on an already under resourced hospital.

### **Paediatric Studies Referred to CHW**

Whilst the health department ethos maintains that studies should be performed as close as possible to home, studies are often "diverted" or refused by other LHDs. These hospitals state that the equipment or expertise (or both) does not allow these to be done locally. Fundamentally, these imaging studies on children are more time consuming, use more resources and sometimes are more complex while being very poorly remunerated.

### **Micturating cystourethrogram (MCUG)**

This study requires a patient to have the bladder catheterised and contrast injected via the catheter, whilst concurrently taking X-rays. This is performed with the parent present. The study is rarely performed on children in private practice.

Additional staff and equipment are required to perform this procedure and incur costs:

- Cost for Radiology nurse (additional nurse if sedation required)
- Cost Radiographer/ Technician to monitor the radiation/procedure.
- Cost for Radiologist to perform the procedure (this may include a radiology trainee in the teaching hospital)
- Cost for the procedure equipment (contrast and sterile equipment)
- Cost for maintenance of the fluoroscopy X-ray machine.

The maximal MBS rebate is \$127. This does not cover all the required personnel and equipment.

### **Magnetic Resonance Imaging (MRI):**

Performing MRI on children requires different techniques and strategies to adults for the patient to cooperate. Fast and simple studies (usually normal) are commonly performed in private practice. General hospitals and private practices appear to not have the time, expertise or resources for many of the MRI's and thus their paediatric patients are "referred" to CHW. This is especially true for the youngest children. Many studies require a degree of sedation or general anaesthesia for completion, which is not an option in private. Studies performed at CHW are often more complex and time consuming than the "routine" studies performed outside the hospital setting.

### **Summary:**

The radiology department at CHW is under resourced for the work it has to do.

## **A report by Dr Himanshu Popat**

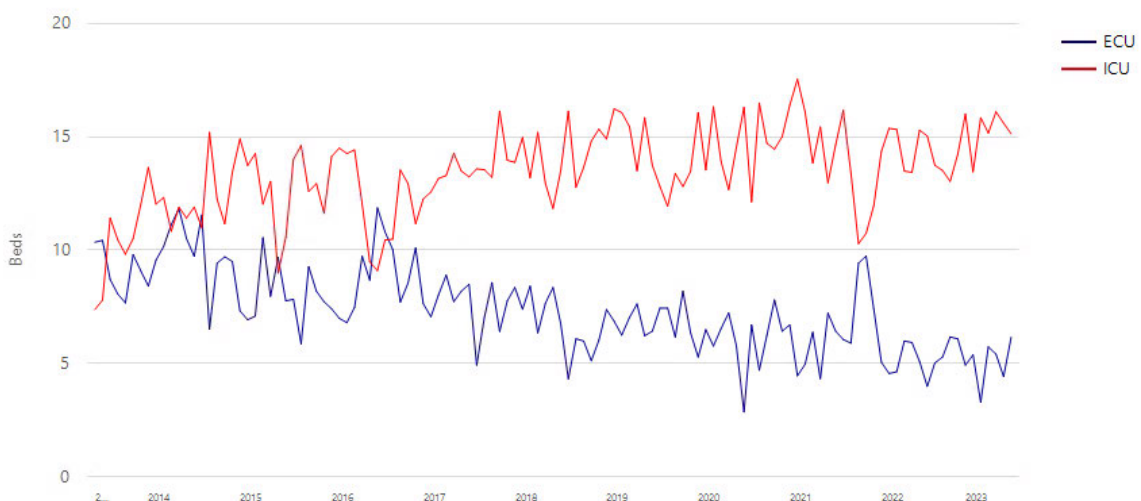
## Head of Department

### Grace Centre for Newborn Intensive Care Unit and The Grace Development Clinic The Children's Hospital at Westmead

**The Grace Centre for Newborn Intensive Care (NICU)** is a 23 bedded, quaternary referral unit for babies with medical and surgical conditions. The NICU accepts babies from across New South Wales, interstate and from New Caledonia (Noumea). It accepts newborn babies who have complex medical conditions or congenital malformations most of which are diagnosed in-utero and many require major operations within the first few days of life. In recent years, the unit has seen a sustained increase in the survival of these babies to over 95%.

This survival rate has been achieved despite our patients presenting to us sicker and with more complex problems. (Figure 1) In order to accommodate this increase in acuity and number, we now average an occupancy of 15 ICU beds. Only 10 of these beds are fully funded. Despite the figures presented below, there has been no parallel funding to accommodate the increasing pressure the unit is experiencing. This has had a significant impact on our ability to continue to provide high quality, safe care to the sickest babies in the state.

### Grace NICU Intensity



**The Grace Development Clinic (GDC)** provides multidisciplinary neurodevelopmental follow-up services for newborn babies admitted to the NICU and identified as being at high risk of later neurodevelopmental problems. Developmental assessments performed in the clinic are highly evidence-based, recommended as standard of care and enable diagnosis of serious movement disorders, such as cerebral palsy, within the first five months after birth.

Currently, the GDC receives no public health funding and is entirely reliant upon donated funds for operation. If donated funds were to cease, the opportunity to diagnose problems and intervene in this unique period of brain neuroplasticity will be lost. We know that missed opportunities in this period will have significant implications for the rest of these children's lives.

Additionally, current research strongly suggests that the rate of neurodevelopmental morbidity at school age for some of these children is significant, and follow-up into school age is increasingly advocated. This is currently not possible with our present resourcing. The Australian National Standards of Care for Childhood-onset Heart Disease, will outline standards of care for neurodevelopmental follow-up in those children with cardiac disease in Australia, and it will likely highlight the extent to which NSW is currently falling behind.

### A report By Dr J Mervis

## Paediatric Interventional Cardiologist The Children's Hospital at Westmead

Paediatric Cardiac Services run a state wide unit offering cardiology, cardiac surgery and interventional cardiology for all children of New South Wales.

Services include

- Outpatient reviews
- Echocardiography
- In patient care for children with congenital and acquired heart disease
- Care of children in PICU and NICU

Cardiac Surgery:

- Bypass and non bypass surgery
- All paediatric cardiac surgery is performed at CHW

Cardiac intervention

- All cardiac intervention for NSW performed at CHW

Electrophysiology

- All cardiac electrophysiology (EP) procedures are performed at Westmead Adult Hospital
- Currently there is no facility for EP procedures at CHW

Physiological testing:

- This includes: 12 lead ECG's, 24hr holter monitors, ambulatory blood pressure monitors, exercise stress testing, Cardio-pulmonary exercise testing, Stress echo cardiography, 6 minute walk testing.

Cardiac imaging testing:

- Cardiac CT scan
- Cardiac MRI scan

Outreach clinics:

- The unit functions with a hub-and-spoke model
- Cardiologists service: Canberra, Wagg Wagga, Orange, Armidale, Tamworth, Coffs Harbour, Gosford, Wollongong, Nowra, Dubbo.

Evidence of a significant increase in workload:

- Increase in catheter directed interventional procedures
- Significant increase in Neonatal and complex interventions.
- Increase in number of outpatient clinics and patient encounters.

The Figures 1, 2 and 3 clearly demonstrate the increasing workload of the cardiology service and particularly demonstrating the increased demand for interventional cardiology.

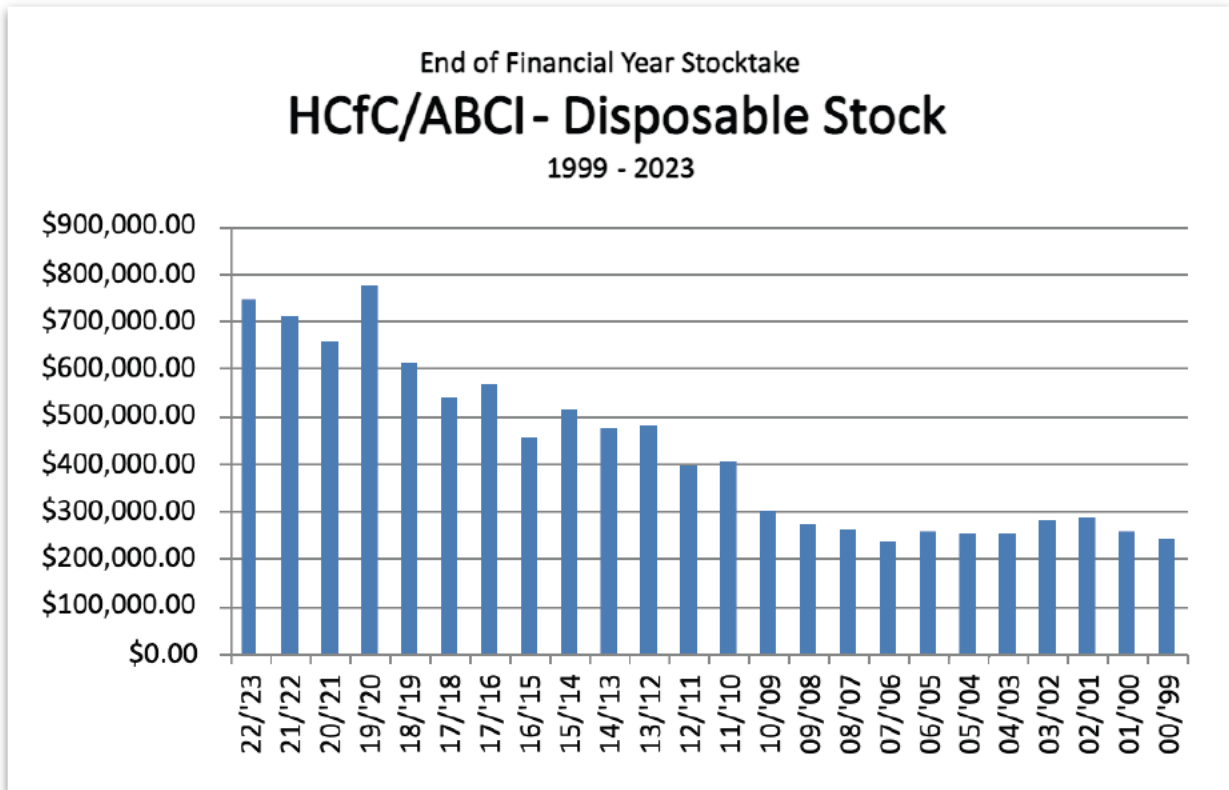
**Figure 1:** Number of patients visiting the CHW cardiology clinics each year.

Note: 2014/15 numbers are incomplete

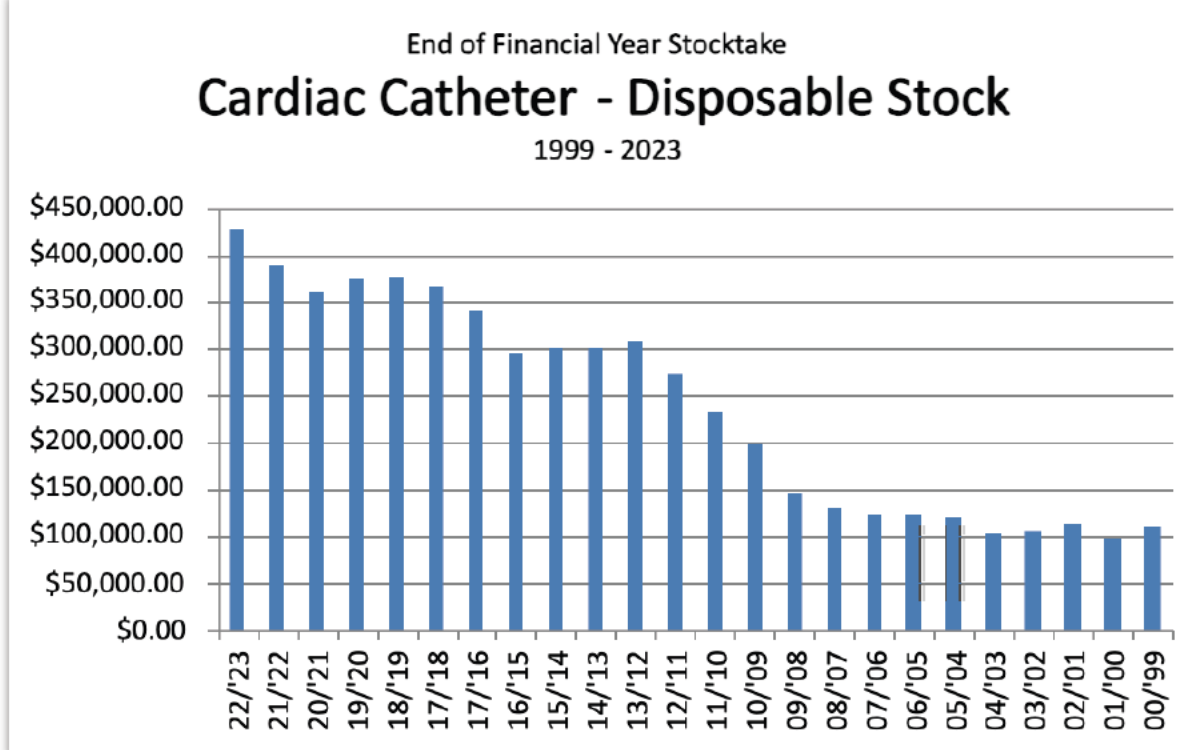
CHW	2014/15	2015/16	2016/17	2017/18	2018/19	2019/20	2020/21	2021/22	2022/23
Cardiac Outpatient (Consultant)	2,075	5,078	5,228	5,261	5,583	4,700	6,379	6,079	8,034
Cardiac Outpatient (Nursing)	0	0	476	251	356	421	2,805	2,002	1,816
Cardiac Outpatient (Psychology)	300	500	608	636	361	360	676	1,038	647
Cardiac Diagnostics	4,183	9,133	9,728	10,582	12,017	14,627	11,926	11,431	12,993
<b>TOTAL</b>	<b>6,914</b>	<b>15,341</b>	<b>16,770</b>	<b>17,474</b>	<b>19,040</b>	<b>21,157</b>	<b>21,786</b>	<b>20,550</b>	<b>23,490</b>



**Figure 2:** Demonstration of increasing stock requirement in the interventional suite.



**Figure 3:** Demonstration of increasing number of catheters used for interventional procedures



What does the unit need to function optimally:

- Funding for dedicated clinic nurse

- Funding for a 4 bedded daycase unit. To support day stay surgery, medication trials and patients requiring sedation for cardiac imaging. At present patients have to be admitted to the ward for these procedures and if no beds are available, as is often the case, the procedure is delayed or cancelled.
- Funding to initiate and sustain a heart transplant service and mechanical assist device service.
- Funding for EP lab in CHW
- Funding to support the consistent increase in catheter intervention services of between 5%-10% annually since 2010.
- Funding for an ECMO retrieval services (Statewide) requiring mobile ECMO circuits, highly specialised retrieval team including medical, surgical, nursing, anaesthetic and perfusion staff.
- Funding to sustain outreach clinics in rural and regional NSW. It is presently supported by private funding.
- The majority of cardiologists in the department have a 9-12 month waiting list.

**Summary:**

The above data gives a simple illustration of the steadily increasing demand on cardiac services yet the hospital remains chronically under funded.

**A Report from Dr A. Maguire and Dr S. Srinivasan  
Co Heads of Department  
Paediatric Endocrinology  
The Children’s Hospital at Westmead**

Although there are many issues, the following 4 were chosen by the CHW Paediatric Endocrinologists for inclusion in the MSC response:

1. Poor governance and accountability at the Local Health District (LHD) level, with lack of adequate funding by LHDs to provide community based primary and secondary care to children. As a result of this, patients are often not receiving care close to home and are forced to seek care from CHW. This places an added burden of care on CHW as we struggle to provide basic care to patients outside and inside our LHD, in addition to the tertiary and quaternary service we provide to the whole of NSW. This extra activity is not recorded or funded and it diminishes our capacity to deliver a tertiary/ quaternary service. There does not appear to be any mechanism to divert funds from LHD’s that do not provide the basic paediatric services.
2. There is a lack of enhancement/support for technological advances: Over the past decade there have been rapid advances in insulin pump technology and continuous glucose monitoring. NSW Health has not provided the technology infrastructure and workforce enhancements to allow integration of these advances into diabetes care.
3. There seems to be a chronic Junior Medical Officer workforce shortage which at best just manages to staff all positions but leaves a fragile system without reserve when staff are unable to work. The inappropriate use of self-funded research fellows and honorary overseas trainees to prop up NSW Health public Hospital core services is an illustration of a system under pressure.
4. There is a significant lack of Social Work and psychological support for children and adolescents with chronic and complex endocrine disorders and diabetes.

**A Report by Dr Veena Raghupathy  
Network Medical Head  
Psychological Medicine  
Sydney Children’s Hospital’s Network**

**RE: Workforce crisis – Psychological Medicine /Mental Health**

I am writing to bring to your attention a critical matter concerning our network’s State-wide tertiary mental health service. We are currently facing an escalating staffing crisis that has severe implications for the delivery of care to children and adolescents with complex mental health needs. This issue impacts our two acute inpatient paediatric mental health units, consultation-liaison service, neurodevelopmental service, eating disorder program, OCD Bounce and alternatives to emergency department programs. Despite our dedication to excellence, we are confronted with multiple crises that threaten the sustainability and effectiveness of our services.

**Overview:** SCHN Mental Health Service encompasses two acute paediatric mental health inpatient units, a consultation-liaison service, a neurodevelopmental service, and specialised care for eating disorders. Additionally, we offer alternatives to emergency department admissions for cases that do not require immediate hospitalisation. Our paediatric mental health services play a crucial role in addressing the mental health needs of the young population within SCHN. Additionally, we support regional Community Mental Health Services through our telepsychiatry services (CAPTOS).

## Challenges:

### 2. Inadequate Staffing:

- We are currently grappling with poor staffing levels compared to other mental health services in the state. For instance, the other inpatient units are staffed with 2 FTE staff specialist positions, at least 4-6 FTE allied health and nursing staff. In contrast to our inpatient units, which are critically understaffed at 1.2 FTE staff specialists, 3 FTE allied health and nursing staff. We are the only unit in the NSW that provides inpatient mental health care to children who are under 12 years of age.
- Furthermore, 1.0 FTE staff specialists are reduced from the existing Specialist services like Neurodevelopmental Psychiatry Service and Consultation-Liaison Service. Some services like Consultation-Liaison provided at SCH are not funded, adding financial implications to the unfavourable budget. Additionally, special reportable projects like IDMH Hub have a service level agreement with NSW Health/Mental Health for providing short-term care; however, we have a heavy caseload of complex cases due to a lack of services in the community. For instance, autism and developmental disability remain exclusion criteria for many Community Mental Health Services within NSW. Similarly, we have significant gaps in care provided for young people with functional neurological disorders.
- In addition to a shortage of senior medical staffing, we are significantly underfunded for JMO positions, impacting patient care. For instance, there is no JMO cover for the SCH site after-hours. There have been occasions where young people with mental health issues were not reviewed in our emergency rooms due to a lack of staffing.
- Insufficient staffing adversely impacts our service provision, resulting in longer wait times, reduced patient care quality, and increased stress on existing staff, making the network positions less attractive to the workforce.
- The shortage of staff directly influences our ability to meet the growing demand for paediatric mental health services, particularly post-pandemic. Adequate staffing is crucial for maintaining our young patients' safe and therapeutic environment.

### 2. Staff Retention Issues:

- The existing staffing challenges have led to burnout among our dedicated team members, affecting staff morale and overall retention rates. Furthermore, the high turnover rates jeopardise the continuity and quality of care we can provide.

### Request for Funding Enhancement:

We are seeking funding enhancement to address the critical issues outlined above. We request a funding enhancement to support at least five staff specialist positions, 4 JMO positions and 4 FTE allied health professionals to align our staffing with that of LHDs providing similar services. I believe the increase in the workforce would improve the quality of care provided and support a resilient and motivated team committed to providing excellent care. Additionally, it would support research initiatives that contribute to advancements in paediatric mental health care and the integration of innovative therapeutic approaches for better patient outcomes. Specialist services can support LHD's community-based services in building their capacity and expertise in managing complex disorders like neurodevelopmental disorders, functional neurological disorders, eating disorders and young people with chronic medical illnesses.

We sincerely hope our proposal will be considered and support our efforts to enhance paediatric mental health services. Thank you for your time and consideration. We are available for further discussion or any additional information you may require.

Many Thanks



**A Report by Philip Britton  
Head of Department**

**Department of Infectious Diseases and Microbiology  
The Children’s Hospital at Westmead**

Demand on the clinical Infectious Diseases (ID) service at CHW has increased considerably over the last 10 years and shows no signs of abating. This demand is for consultation and liaison associated with COVID-19 and non-COVID-19 issues at CHW and state-wide. COVID-19 burdens have proven to be an ongoing challenge and have fundamentally changed aspects of clinical ID practice. Any impression that these challenges to ID and infection prevention and control (IPC) services will be temporary, has been proven wrong. At a senior medical officer (SMO) level the COVID-19 burden was carried by a separate, unfunded, COVID-19 on-call service at CHW (March 2020-March 2022). Since April 2022, COVID-19 on-call has been rolled back into the clinical ID on-call service. Demand on, and the increased expectation of IPC services at CHW has increased significantly and shows no signs of abating. This is for both COVID-19 and non-COVID-19 issues.

COVID-19 burdens continue to significantly constrain our capacity to maintain the service at a level consistent with the requirements of Standard 3 of the Australian Commission on Safety and Quality in Health Care (ACSQHC), which is a risk to future hospital accreditation. Key surveillance and audit functions (e.g. hospital acquisition of respiratory viruses, hand hygiene audits, hospital-wide IPC meetings) have been severely interrupted during the pandemic and we lack the resources to re-initiate these functions.

In the background to the COVID-19 pandemic, the clinical activity and footprint at CHW had increased significantly over the last decade (and will increase further with the new CHW building) with no ongoing additional resources allocated for clinical ID or IPC services. These are critical support services across all tertiary/quaternary, medical and surgical services including PICU, NICU, Oncology, Solid organ and Bone marrow transplants. CHW is significantly under resourced for IPC when benchmarked with other Tertiary paediatric facilities across the nation. **Table 1, 2 and 3.**

New and emerging risks continue the challenge our ID and IPC services e.g. Carbapenem resistant enterobacteriales (CPE), Monkeypox, Unknown Hepatitis in children. We are constrained in our capacity to evaluate risks, develop and update policies, investigate and respond to cases.

**Table 1: CHW clinical ID on-call duties 2019-2022 relative to recommended ratios - Australian Medical Association (AMA) and Australian Salaried Medical Officers' Federation (ASMOF).**

	<b>ASMOF</b>	<b>AMA</b>	<b>CHW</b>
<b>On-call/FTE</b>	1 in 4 or 13 weeks <i>per annum</i>	No more than 1 in 3* or 17 weeks <i>per annum</i>	18-22 weeks/FTE 2019-2022 <i>per annum</i> #

\*1 in 3 on-call described as a ‘significant risk’ and continuous on-call for >7 days described as a ‘higher risk’ in AMA National Code of Practice.

#Calculated on the basis of 52 weeks on-call cover and total SMO FTE.

**Table 2: CHW Clinical ID JMO staffing and comparable children’s Hospitals.**

	<b>Royal Children’s Hospital (Vic)</b>	<b>Perth Children’s Hospital (WA)</b>	<b>Lady Cilento Hospital (Qld)</b>	<b>Women’s &amp; Children’s Hospital (Adelaide)</b>	<b>Sydney Children’s Hospital</b>	<b>Children’s Hospital at Westmead</b>

<b>Organisation Bed Nos.</b>	350 beds. Opened in '11	298 Bed + day stay beds Opened Jun 18	287 + day stay beds Opened Nov 2014	270 + day stay beds/ services	150 + day stay beds/ services	~ 330 + day stay beds/ services
<b>Clinical ID JMO staffing</b>	2.0FTE (fellow)	2.0FTE (fellow) 1.5FTE immunisation registrars <sup>^</sup>	1.0FTE (fellow) + 1.0FTE (registrar)*	1.0FTE (fellow/registrar)	1.0FTE (fellow) + 1.0FTE (registrar) <sup>#</sup>	1.0FTE (fellow)

\*This position contributes to supporting HiTH services for outpatient antimicrobial therapy. #This position shared with the allergy and immunology service. ^These positions help to cross cover leave of the ID trainees.

**Table 3: Ratio of IP&C staffing to paediatric patients.**

	<b>Royal Children's Hospital (Vic)</b>	<b>Perth Children's Hospital (WA)</b>	<b>Lady Cilento Hospital (Qld)</b>	<b>Women's &amp; Children's Hospital (Adelaide)</b>	<b>Sydney Children's Hospital</b>	<b>Children's Hospital at Westmead</b>
<b>Organisation Bed Nos.</b>	350 beds. Opened in '11	298 Bed + day stay beds Opened Jun 18	287 + day stay beds Opened Nov 2014	270 + day stay beds/ services	150 + day stay beds/ services	~ 330 + day stay beds/ services
<b>Staffing for IPC</b>	3.8FTE	3.5FTE	5FTE	3.4FTE	1.6 FTE	2.0FTE
<b>Ratio IPC : Beds</b>	1:92	1:85	1:57	1:79	1:100	<b>1:165</b>

**A report by Prof Louise Baur  
Child and adolescent obesity in NSW  
Prof Louise A Baur and Dr Shirley Alexander  
Weight Management Services, Sydney Children's Hospitals Network  
September 2023**

Child & adolescent obesity is a major clinical problem in Australia. It is one of the most common chronic diseases affecting this age group yet the provision of effective treatment services is extremely patchy within NSW.

**We request that NSW Health considers a strategy to:**

- c. **Engage and support each Local Health District (LHD) to establish and deliver appropriate high quality multidisciplinary services to treat children and adolescents with established obesity, and**
- d. **Facilitate the coordination of such services across NSW.**

## **1. Obesity in Australian children and adolescents: prevalent, with growing social inequalities**

- About 1:4 school-aged children and adolescents are affected by overweight or obesity. Overall, about 8% have obesity (1, 2).
- About 2% overall have severe obesity (equivalent to age adjusted adult BMI of 35 or more). This should normally require tertiary level care (2).
- Obesity is under-recognised and therefore the majority of children admitted to hospital/ seen in outpatients are not coded correctly which in turn means the cost to the health care services is grossly underestimated.
- There are also growing socio-economic inequalities in Australian prevalence rates, with overweight and obesity continuing to increase among children in families with lower socio-economic status, those from culturally & linguistically diverse backgrounds and those in remote/regional areas (3).
- Obesity is also more prevalent in children and adolescents with developmental and neuro-behavioural disorders and those with a range of other chronic health problems (4).

## **2. Obesity in children and adolescents: associated with complications and increased health care costs**

- These include psychological problems (bullying, stigmatisation, depression, low self-esteem), musculoskeletal problems (flat feet, slipped femoral epiphyses, tibia vara, increased risk of sprains and fractures), insulin resistance, obstructive sleep apnoea, increased asthma severity, fatty liver disease, cardiovascular risk factors, menstrual irregularities and type 2 diabetes.
- In NSW, even community dwelling young children aged 3-5 years with obesity have increased rates of hospitalisations (ENT and respiratory disorders) and 1.6 times the annual health care costs when compared with their healthy weight peers (5).

## **3. Children and adolescents with obesity present frequently to healthcare services**

- Australian and NSW studies show that children and adolescents with overweight and obesity present much more frequently to primary, secondary and tertiary care services than would be expected from the background prevalence of the issue (6-8).
- However, they are not being treated specifically for obesity (6-8). Obesity is an under-recognised and certainly under-treated condition.

## **4. Child and adolescent obesity can be treated**

- Treatment involves provision of multi-disciplinary care, a non-stigmatising approach, whole-of-family engagement in behavioural weight management (covering dietary change, physical activity, screen behaviours and sleep) and long-term maintenance strategies for all patients and families. For those with moderate to severe obesity, treatment options may well also include more intensive dietary interventions, drug therapy (growing evidence of effectiveness, although no anti-obesity medications currently supported by the Pharmaceutical Benefits Scheme in Australia) and bariatric surgery (realistically only available in the private sector for adolescents) (9-14).
- All of these treatment approaches have moderate to strong levels of evidence, as shown in Cochrane reviews (15).

## **5. The provision of such treatment is very patchy in NSW**

- Dr Shirley Alexander and Prof Louise Baur undertook a NSW Health TRGS-funded study (2017-2019) looking at multidisciplinary care services for children and adolescents in NSW (16-20). This showed:
  - the availability of paediatric obesity services is extremely patchy and under-resourced around NSW, with the vast number of LHDs having no formalised services available for those with moderate to severe obesity;
  - in 2019 only 5 (of 17) LHDs/ specialty networks in NSW had some form of multi-disciplinary service for children or adolescents with obesity: SCHN (Westmead), NBMLHD, SSWLHD, NSLHD (Hornsby) and JHCH; all of these services continue to be extremely under-resourced;
  - outcomes of this study indicated the current models of care are effective at improving anthropometry and health behaviours and are rated highly by parents;

- barriers to service delivery included lack of funding and resources in general; lack of services for sub-groups such as Indigenous populations; widespread stigma; and challenges with ease of transport and access to facilities.

## 6. Previous attempt to have state-wide planning for service delivery around obesity in NSW

- In 2009 the old Greater Metropolitan Clinical Taskforce (the forerunner of ACI) issued an Obesity Plan. This was a model of care for delivery of services in each then Area Health Services, across adults, adolescents and children.
- The plan was never implemented because it was not resourced and was not seen as a priority by senior leadership within most Area Health Services/ LHDs.

## 7. Previous NSW Premier's Priority and now a NSW Health Priority – who is now responsible?

- “Tackling Childhood Obesity” was a major NSW Premier's Priority from 2016-2019, the only paediatric health condition mentioned in the priorities. The work on the Priority was led by the Population Health Division within NSW Health.
- In order to address this priority, NSW MoH invested in the provision of Go4Fun, a free, community-based group program for children aged 6 to 13 years and their parents. NSW MoH also supported the development and refinement of series of resources for health professionals – see the Healthy Kids for Professionals website (<https://pro.healthykids.nsw.gov.au/>). There was also a focus on facilitating the measurement of height and weight of children and adolescents presenting to NSW Health facilities.
- Childhood obesity then became a health priority in 2019. See Strategic Priority 1.1: *Implement policy and programs to increase healthy weight in children*. See: <https://www.health.nsw.gov.au/priorities/Documents/strategic-priorities.pdf>

## 8. The current challenge: who is responsible for paediatric obesity clinical service delivery in NSW?

- While the public health/ health promotion aspects of Strategic Priority 1.1 are being very effectively overseen by the Population Health Division of NSW Health, it is not possible nor appropriate for them to oversee the provision of *clinical services* for children and adolescents already affected by obesity.
- Who then should have this role? It appears to be a very low priority in most LHDs, with little engagement of senior paediatric clinicians, program directors or CEs. Nor is it a priority for the Agency of Clinical Innovation.

## 9. Request for consideration

We request that the NSW Paediatric Network consider a strategy to:

- Engage and support each Local Health District to establish and deliver appropriate high quality multidisciplinary services to treat children and adolescents with established obesity, and
- Facilitate the coordination of such services across NSW.

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**A report by Dr Bronwyn Milne  
Senior Staff Specialist  
The Children's Hospital at Westmead**

**SCHN Department of Adolescent Medicine** provides tertiary level health care for adolescents across NSW across with a multidisciplinary model of care for different clinical streams; including Complex and Chronic Illness, Eating Disorders, Adolescent Gynaecology, Adolescent Drug and Alcohol and Fetal Alcohol Spectrum Disorders. Youth and Transition Services for adolescent patients collaborates closely with the Department of Adolescent Medicine.

**Complex Adolescent Clinic (CAC)** provides a multidisciplinary clinic to adolescents with chronic medical conditions who have significant impairment in functioning. Timely holistic and multidisciplinary model of care for adolescents with complex and chronic health conditions improves patient function, health outcomes, reducing inpatient and emergency department utilisation.

Over 50% of referrals are from paediatric subspecialists, 1/3 from regional and rural NSW. Over the past 5 years, there has been an increase in demand for the Complex Adolescent Service. Waiting times have increased 5 fold (from 6 to 30 weeks), despite occasions of service provided increasing by > 400%. There has not been financial or workforce investment into this service despite increased demand, referrals and workload. CAC is a model recognised by all areas of health as providing optimal care, however, it is functioning well above capacity and an institutional/clinician risk.

Impacts from the covid pandemic, including long covid and increases in mental health co-morbidity, particularly on those with poor function and complex chronic illness, have not been met with an increase in funding, workforce enhancement or service delivery.

**Drug and Alcohol Services** provided within SCHN, include care for children impacted by prenatal alcohol and other drugs, parental substance use or moderate to severe substance use during adolescence. Recent funding enhancement from NSW Special Inquiry to the substance use is temporary (3 years). This impacts workforce recruitment and retention as appointments are temporary.

**SCHN Fetal Alcohol Spectrum Disorder Service (FASD)** operates 2 days per week with a multidisciplinary team, providing neurodevelopmental assessment and recommendations for early intervention and NDIS for children and adolescents exposed to prenatal alcohol or other drugs. Non-permanent funding enhancement was secured through a Federal Government Research Grant specific for FASD. Despite this, wait times for multidisciplinary assessment exceed 2 years. This vulnerable populations have an average age of 7 years (0-17years), 30% of whom are in out-of-home care, 31% Aboriginal, 100% exposed to prenatal alcohol and/or other substances. Access to multidisciplinary FASD assessment increases access to NDIS funding, early intervention and subsequent improved health outcomes.

**Tertiary Paediatric Eating Disorder Service** has not received enhanced funding to keep up with the increase in presentations and demand. Patient complexity and co-morbid mental health presentations have increased, placing greater burden on hospital inpatient beds, clinical teams and ultimately patients and families. Innovative models of care (such as day program) is limited to one location at SCH Randwick, creating barriers to access appropriate services for patients from Western, South West and Greater Western NSW. Workforce development for specialist paediatric training in Eating Disorders is limited by lack of Fellowship training positions. Succession planning is impacted when clinicians with expertise retire or resign.

**Paediatric and Adolescent Gynaecology Services** at SCHN has over 6 month wait for outpatient services and similar for elective surgical procedures. Despite being a statewide tertiary paediatric and adolescent service, The Children's Hospital at Westmead do not have funded gynaecology fellowships or training positions. Trainee Gynaecologists apply for an honorary (unfunded, unpaid) position to gain experience in this specialist area. Funding for training positions will increase capacity in the specialist paediatric and adolescent gynaecology workforce increasing access to specialist care for children and adolescents.

SCHN **Center for Adolescent and Young Adult Health** is a purpose-built Adolescent Outpatient Clinical in collaboration with WSLHD (Westmead K-block) and SELHD (Randwick- Bright Alliance). Development of the facility without allocated funding for staffing enhancement has created barriers to co-ordinating and running adolescent outpatient clinics.

**A Report by Dr Gayathri Raman  
Staff Specialist Paediatric Nephrology  
Department of Nephrology  
The Children's Hospital at Westmead**

Mr Richard Beasley SC  
Commissioner of the Inquiry  
Special Commission of Inquiry into healthcare funding NSW Health

Dear Commissioner,

**Re: Current issues for Paediatric Urinary Incontinence Services**

Thank you for the opportunity to address some of the issues facing the care of children with continence problems in NSW and some suggestions on how to improve management of these

children. I am a member of the Medical Staff Council at Children's Hospital Westmead. I will first address the need for more multi-disciplinary continence services, and then specifically address the lack of paediatric pelvic and continence physiotherapy.

### **Issue 1: Statewide lack of public multi-disciplinary urinary incontinence clinics**

I am a Paediatric Nephrologist and General Paediatrician and I manage the multi-disciplinary Bladder Clinic at the Children's Hospital Westmead. I run 2 clinic sessions a week and as part of the clinic, we have a Continence Nurse, a physiotherapist specialising in continence and a psychologist. We accept children with bedwetting from age 7 and above, any child with daytime urinary incontinence and developmentally delayed children who have the capacity to toilet train. I would like to point out that there is no public multi disciplinary clinic service for constipation/ bowel only incontinence at Children's Hospital Westmead and this is also a significant area of need.

Urinary incontinence is associated with recurrent urinary tract infections (2), stigmatization (3), depression (4) and lower quality of life (5), persisting in 0.5 to 2% of untreated adults (6). Despite the strict criteria for referral to my clinic, the waitlist for this clinic is 18 months to 2 years. This is longer than the national wait times averaging 226 to 399 days. (1) As I am aware, this clinic is the only public multi-disciplinary continence service within NSW and I receive referrals from across the state. I even receive referrals from Sydney Children's Hospital as there is no multi-disciplinary service at that site. If any of the clinicians on the team take leave, especially myself or the physiotherapist, it is often difficult to find cover and this contributes to a long waiting list. The paediatric pelvic and continence physiotherapist in my clinic is planning to retire and I am struggling to recruit and train a replacement. This will significantly impact on service provision and waitlist times.

Many of these children are initially seen by primary care physicians and can be treated successfully. However, there is a need for more community-based continence providers so children can receive treatment whilst waiting on our waitlist or can avoid being referred to tertiary continence services. **There is also a need for more public multi-disciplinary clinics across the state.** Efforts should be made to upskill community-based providers and primary care physicians to treat simple continence issues in the community.

A relatively new innovation is the use of e-Health. An avatar based program called e-ADVICE has been trialed in the community to provide support to children waiting on a waitlist for an appointment with a tertiary continence clinic, with involvement of their primary health providers. A randomised controlled trial was performed to assess the effectiveness of this intervention. This study, which is awaiting publication, showed that e-ADVICE doubled the proportion of children who were dry at 6 months and improved their quality of life, whilst they awaited an appointment at a tertiary continence clinic.

Incorporation of this program in the community can reduce the need for review in the tertiary continence services and the number of visits within the clinic. Another benefit is indirect education of primary care physicians so they can feel more able to manage these children in the communities.

Other strategies include increasing educational opportunities for current providers in the community and support to increase the number of public multi-disciplinary continence clinics. **Sydney Children's Hospital in particular MUST have a multi-disciplinary service.**

### **Issue 2: Lack of paediatric pelvic and continence physiotherapists to support both urinary and bowel incontinence.**

The paediatric pelvic and continence physiotherapist is an integral part of continence management. The physiotherapist can assist with evaluating and improving postural and body awareness for optimal voiding and defaecation, normalise pelvic/pelvic floor muscle capabilities, teach relaxed voiding techniques and retrain muscle patterns to improve coordination for bladder/ bowel emptying. The physiotherapist can also educate and train the child and family in using neuromodulation to treat bladder/bowel function including TENS for overactive bladder symptoms and interferential therapy for slow transit constipation.

Assessment and treatment for these conditions is specialised extended scope of practice which requires post-graduate training and mentoring. This includes the use of real time ultrasound, innovative and novel use of therapy and treatment options based on a sound and advanced level of understanding of child development, anatomy and physiology (particularly muscle structure and function), and a robust understanding of the existing evidence base and how to extrapolate that to the complex paediatric population.

Access to physiotherapy at CHW, in all caseloads, is via a specialist referral only.

Currently there is only 1 public paediatric continence physiotherapist in NSW and she also works across palliative care and the acute respiratory service. She is planning to retire soon, and we are struggling to train a replacement, both due to lack of staff and funding for training. There is no regular cover to support these patients when she is on leave, and she often returns to an increased workload.

Current physiotherapy funding and protected time exists for bladder (nephrology) patients: • 9 hours/week to attend 2 x clinics. There is up to a 2 year wait list to get into MDT clinic, with only limited options for triage and advice ahead of clinic review. • Very limited outpatient follow-up for patients once seen in clinic

There is **no specific funding or protected time for children with other pelvic conditions or bowel problems**, however these caseloads require the same level of expertise and confidence in order to treat successfully. These children are complex and have usually failed standard medical interventions and have had hospital admissions for management. These referrals come directly to physiotherapy from predominantly colorectal surgeons, but also from rehabilitation physicians, gastroenterology, gynaecology, urology and general paediatricians. On average, there are 20-30 complex referrals per year for this service.

With no dedicated funding or time available, these patients are managed ad hoc, usually to the detriment of other funded caseloads. The current goal is for these patients to receive their initial physiotherapy review within 3-4 months, however this is suboptimal clinical management and timing, demonstrated through repeat admissions and increased medical interventions for these children. This caseload requires access to timely, expert MDT involvement alongside the relevant referrers.

The physiotherapist working in these caseloads needs to have sufficient time available to upskill and mentor other health professionals to assess, monitor and treat these conditions, and to reserve time to treat the complex cases presenting to the tertiary MDT clinic. At the moment- we only

#### **Recommendations:**

- 1) Additional funding (8 hours/week) for an expert level 4 physiotherapist at CHW to provide above services in a tertiary evidence-based multidisciplinary setting. This service needs to be sustainable and safe, allowing for increasing complexity with novel medical interventions, and increasing population numbers.
- 2) Funding to train other paediatric continence physiotherapists, especially at Sydney Children's Hospital and John Hunter Children's Hospital.

Please contact me if you need more information or want to discuss this further.

Kind regards,

**Dr Gaya Raman Paediatric Nephrologist**



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**A Report by Prof Hiran Selvadurai**  
**Head of Department**  
**Department of Respiratory Medicine**  
**The Children's Hospital at Westmead**

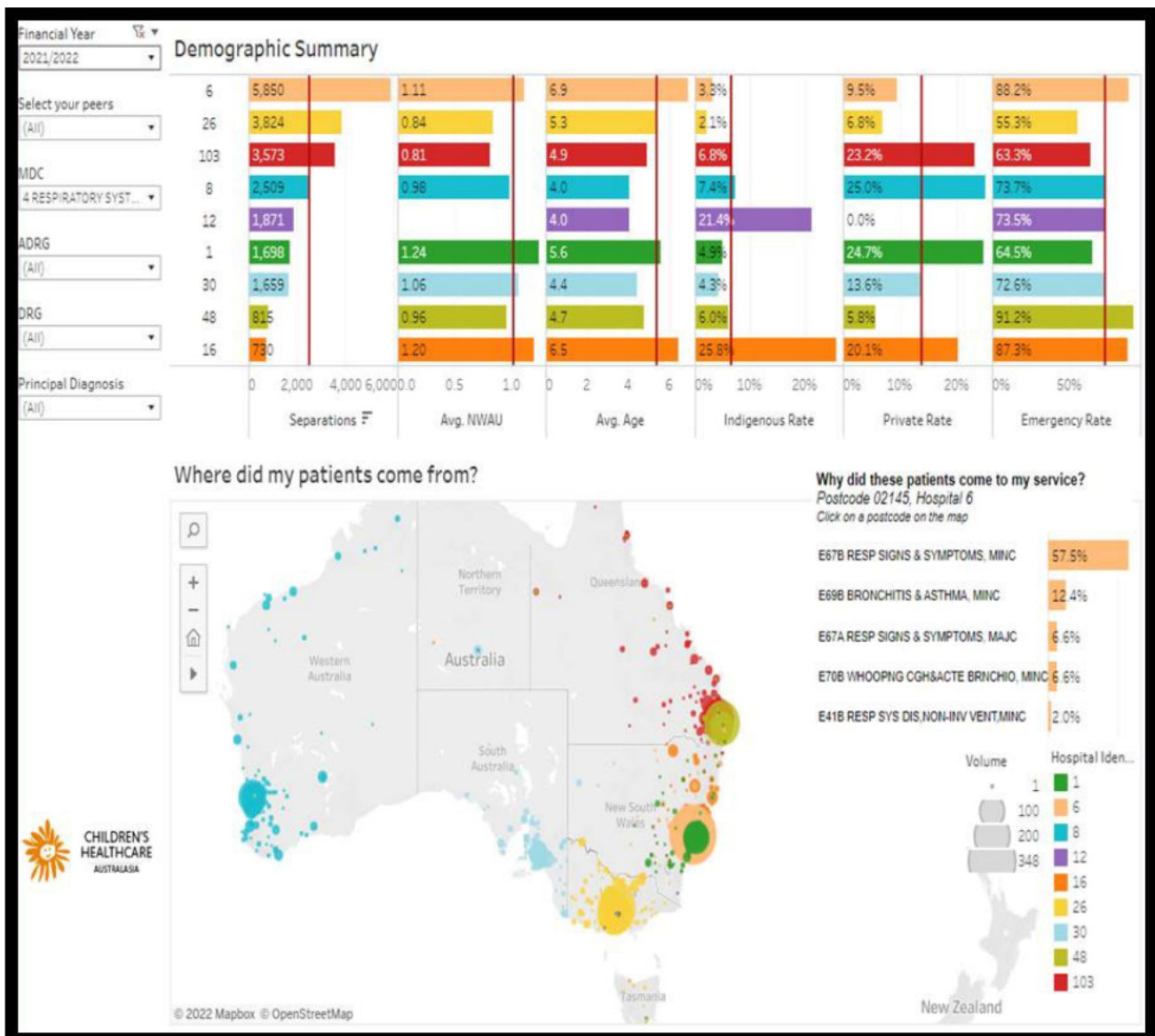
Respiratory medicine has not had an enhancement since 1997. We have 4.0 FTE despite significant increases in NWAU and complexity of patients (respiratory failure, lung transplants etc) in this time frame.

The data from Children's Healthcare Australasia below has been challenged locally. Nevertheless, it demonstrates that not only are our total separations and NWAUs one of the highest in Australia (we are number 6), if we adjust this to FTE, we are by far the busiest in Australia.

The numbers denoting Hospitals of a Similar Size & Capacity

Grouped based on the annual inpatient separations rate. Member hospitals are grouped together if separations p.a > 15,001

- 1 Sydney Children's Hospital
- 4 Mater Children's Hospital (closed in November 2014)
- 6 Children's Hospital at Westmead
- 8 Princess Margaret Hospital, WA
- 10 Women's and Children's Health Network, SA
- 12 Starship Children's Hospital, NZ
- 16 John Hunter Children's Hospital, Newcastle
- 26 Royal Children's Hospital, Melbourne
- 28 Monash Children's Hospital, Melbourne
- 103 Lady Cilento Children's Hospital, Brisbane



**A Report by Dr Natalie Ong**  
**Staff Specialist Developmental Paediatrician**  
**and**  
**A/Prof Natalie Silove**  
**Head of Department**  
**Child Development Unit**  
**Sydney Children’s Hospitals Network**

The Child Development Unit and PECAT (Preschool Early Childhood Assessment Team) at the Children’s Hospital at Westmead is a statewide service for diagnosis and assessment of children, aged between 0 to 16 with complex neuro developmental issues. The unit also provides assessments for the Centre for Effective Reading of children with reading difficulties from rural and regional areas of NSW.

There are critical time pressures for many of these assessments to occur before the return on investment of early intervention becomes economically unviable. In addition, the opportunity cost lost in providing timely, quality intervention to improve developmental trajectories and long term/ adult outcomes for these children is insurmountable in the current climate. The unit sees 1000+ children each year with 12000+ occasions of service activity. From the time of referral of the paediatrician to the attendance at a diagnosis and assessment service can take up to 3 years.

There has been no enhancement in funding to the team in the last decade, despite an exponential increase in developmental, behavioural diagnoses in the community. The population of Western Sydney Local Health District has increased substantially over the past two and a half decades. The current population is 2,621,498 (compared to 2016 where the population was 2,389,122) represents an increase of 1.36% per annum (compared to 0.76% in Greater Sydney). However, the growth rate continues to increase exponentially. In 2031, the overall population is projected to increase to a further 300,000 and with no additional funding to the tertiary diagnostic and assessment services in the area. As a result, the wait time for assessment services will be even longer than the current and missed opportunities for the population of children at risk of poor developmental outcomes will be greater than anticipated.

Research evidence shows that access to early intervention is extremely cost-effective and improves outcomes in terms of function, ability, and independence. In turn, this leads to better long-term outcomes in adulthood from a mental health and well-being, employment, and relational perspective.

However, the Child Development Unit (CDU and PECAT) services have been burdened by long, waiting lists, particularly for school age and adolescents, each child often with added complexities and comorbidities that are not easy to sort out in a single attendance setting. The unit has evolved the service model to meet the needs of increasing patient load and demands with some success. The challenge still lies in the resourcing of more complex and older children and young people, which often require additional time, staffing, and resources to complete, the result of which is an ever-expanding waiting list for school aged children and adolescents to be above 20 - 24 months, which is unacceptable. The current funding is not keeping up with the demand in the need of our population of children with developmental behavioural difficulties. What is of critical importance is that the school aged children who have missed out on assessments when they were under five continue to be disadvantaged and the risk of school failure is high, leading to poor academic success and poor psychosocial trajectories. Funding for these services were not compensated for when the disbandment of Department of Aging, Disability and Home care was disbanded in exchange for the National Disability Insurance Scheme (NDIS). The NDIS does not fund private assessments for school aged which further adds to the burden of publically funded diagnostic assessment services. Furthermore, the lack of resources in service navigation has been made more difficult since the commencement of the National Disability Insurance Scheme and the lack of resources and gaps in services including case management support for these complex families. Of critical importance is that school aged children who are missing out on the Brighter Beginnings funding are being doubly disadvantaged by long wait times in CDU and that there is no other diagnostic assessment service in the state that services doing school aged children.

The lack of resources for timely assessment has direct impacts on childhood and adult outcomes leading to greater economic and social cost to the health, education, economic and disability care sectors.

The other significant gap is in the transition age group. There is no provision for children and young people to receive assessments at critical transition periods of their development and support for families of children with intellectual and developmental disability transitioning into post school options and adult health care services is greatly lacking causing significant stress to the families seeking continuity of care for their child or young person. To date we have been unable to run transition clinics due to funding limitations.

During the COVID pandemic, the team had to pivot to online and new technologies for the conducting of these assessments. We now have ways to assess children who are unable to attend in person for learning, cognitive, language and autism assessments but a lack in staffing precludes us from expanding clinical services and reach to many of these children who are unable to access these services due to travel/ economic and psycho-social factors.

In terms of training positions in Developmental Behavioural Paediatrics, there have been no funding enhancements for the development of a fellow position within the network. This is in spite of numerous requests for paediatric trainees and paediatricians to train in Developmental Behavioural Paediatrics in CDU many of whom we had to turn away. In a recent study, it was found that 75% of general paediatric clinics comprise of children with significant developmental behavioural issues with families who are at breaking point in terms of balancing work, family life and caring for a child with intellectual/ developmental disability. Opportunities to be able to train more paediatricians to undertake diagnostic assessments is very limited in the unit without additional resources. Revenue from drug trials have been used to fund a fellow position for 2023 but this is only temporary and not sustainable in the long run.

In addition, the unit also supports the training, education and pathway development and improving systems of various departments in the network to better meet the needs of children with intellectual and developmental disability in hospital. These initiatives have led to significant improvements to staff confidence and skills in caring for these children and positive parent feedback on the indispensability and value of these service transforming activities. These services are offered on an adhoc/ pro bono basis. Funding is required for its maintenance, and sustainability which is critically important as it has impacts on the safety and quality of how healthcare is delivered to children and young people with intellectual and developmental disability and the wider health care system.

We would also like to highlight the urgent need for funding to support the software engineering and data entry process to transition from paper to electronic assessment and record keeping for all assessments in a confidential and clinically meaningful manner. The NSW and SCHN electronic data collection provides generic information but not discipline specific tools that are required for the diagnostic and assessment process. To date we have relied on the generosity and goodwill of our university colleagues, but it is not sustainable. At least \$150,000 is urgently required to complete this process to be able to get it to a point of being sustainable and clinically functional so that it can be implemented across all health districts.

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**A Report by A/ProfKaustav Battacharya  
Senior Staff Specialist  
Genetic and Metabolic Service  
The Children's Hospital at Westmead**

**Complex medical care**

The tertiary children's hospitals in NSW have developed expertise in reviving and sustaining life in complex physiological situations such as in extreme prematurity, complex congenital heart defects and in critical neurological disorders such as spinal muscular atrophy (SMA). The severest form of SMA was universally fatal but now children survive with early data suggesting that outcomes are good if treated very early in life. Those that survive with non-classical forms or late treated can survive requiring support with breathing, nutrition, ambulation and social activities. For these situations and for several other disorders – the treatment paradigms have shifted towards intense early treatment on the basis of early diagnosis with subsequent lifelong support of the treating medical, surgical and primary care teams. Other novel treatments in chemotherapy, biological agents and enzyme replacement therapies have led to survival of chil-

dren that hitherto would have died. Models of care have developed rapidly across these domains in keeping with contemporary research, but is out-of-step with slowly responsive funding models. Contemporary models of care require multi-disciplinary research translational teams that could embed newer therapies into the lives of families in NSW to sustain treatment both in hospital and when the child returns to their local community.

### **Genomics and genetic therapies**

Genomic testing has become mainstream in clinic practice offering the opportunity for a definitive diagnosis earlier in the clinical history of many conditions. This allows timely intervention with appropriate therapeutics and appropriate surveillance of rare conditions. Despite the opportunities, genomic investigations need careful interpretation in order to be integrated into healthcare systems, Personalized treatment could be delivered, sometimes with relatively cheap interventions such as vitamins, or alternatively with high cost precision medicines. In order to deliver life-saving treatments, the healthcare system needs a more flexible approach to novel therapeutics and service delivery. Tandem mass spectrometry and genetic technologies have been used to enhance the specificity of newborn bloodspot screening leading to better outcomes with higher cost drugs, but the clinical services have not been funded to manage long-term survivors of previously fatal disorders. The federal government is increasing the numbers of disorders that can be screened which will lead to patients requiring increased radiological surveillance, hematopoietic stem cell transplants and enzyme replacement therapies. There is no increase in the provision of clinical services to meet this demand.

## **A Report by Dr Kasia Kozlowska, Dr Michelle Lorentzos, Dr Veena Raghupathy and Dr Sachi Gupta**

### **A Joint Report from the Functional Neurological Disorders Team**

#### **SERVICE GAP: Lack of NSW Services for children with functional neurological disorder (FND)**

August 2019: Spotlight Report on Functional Neurological Disorder (FND) published by the National Mental Health Commission found that in Australia people with FND face significant challenges in accessing the treatment they need. The report underlined the need for an interdisciplinary (or multidisciplinary) approach to FND diagnosis and treatment with collaboration between neurology, psychiatry, psychology and physical rehabilitation services.

August-September 2019: A Neurology/Psychiatry audit at CHW identified that 32 children with FND were seen via the Neurology and Psychiatry Department in the 3-month period (see flow chart). A presentation rate of 10.6 patients per month. Almost half received inpatient treatment via the Mind-body program (see flow chart). The rest had to find treatment via services from services in the local community.

Whilst this data was collected in 2019 it remains valid since there has been no development of services for paediatric FND since that time and the Mind-Body Program has a wait list (akin to 2019).

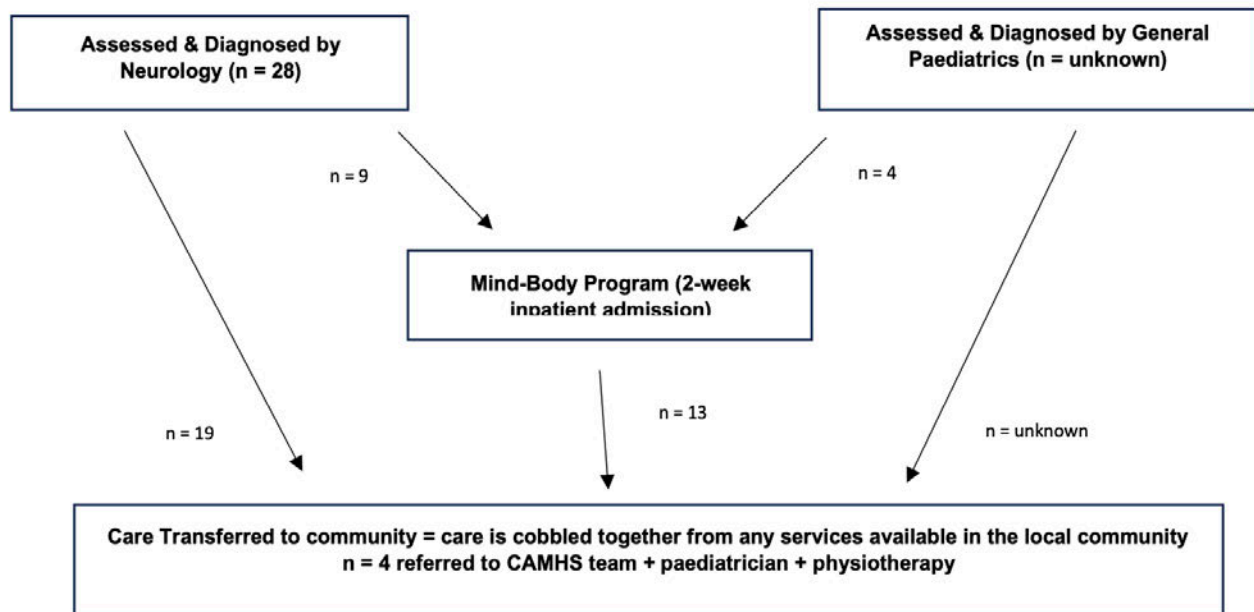
**Flow Chart:** FND presentations to CHW over a 3-month period (audit Aug-Sep 2019, following 2029 Mental Health Commission Report)

#### **In summary:**

In NSW there is a gap in services: there is no treatment pathway in the public health system for children and adolescents with FND.

CHW provides an inpatient service (two-week admission) to the most disabled children presenting to CHW (age <16 years of age).

There are no established FND services that clinicians at CHW can refer children with FND (aged <16 years of age) following neurology assessment or treatment at CHW. A multidisciplinary



nary team has to be cobbled up from services in the patients' local health area (often from private providers).

In NSW there are no identified inpatient or outpatient options for adolescents 16-18 years of age.

In NSW there are no transition pathways for adolescents with chronic FND symptoms. In NSW there are no dedicated adult services with embedded interdisciplinary intervention. In 2023, The Prince of Wales Hospital has run a tertiary FND clinic for adults with a 6-session interdisciplinary FND program funded by a translational research grant from the Mindgardens Neuroscience Network (Initial 12-month grant). No other comparable services are available in NSW.

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## A Report by Shoma Dutt Head of Department Paediatric Gastroenterology The Children's Hospital at Westmead

I write to support the MSC submission to the Special Commission of enquiry into funding of child and adolescent care services offered through the Children's Hospital at Westmead.

Paediatric Gastroenterology is a good example of a service that requires recurring funding to provide a world class service to children with inflammatory bowel disease (IBD). These children require tertiary and quaternary level specialist care and we have not been able to provide an adequate service to these children.

Currently, following numerous business case submissions to the hospital, we received donor funded support, through the Sydney Children's Hospital's Foundation (SCHF), for 12 months. This year of funding was provided with a view to further SCHF funding, depending on the initial reported outcomes. Although this is a start, this soft money with no guarantee of future funding,

highlights the problem we have in creating a sustainable service for our patients with this incurable bowel disease.

We're now in the process of pitching for further funding for the following year. Our business cases already demonstrate the need for a sustainable service for a disease where the incidence is growing exponentially. A growing burden that is in keeping with published worldwide trends.

Many of our children we care for need longterm biological medications, all of which are available to adults on the Pharmaceutical Benefits Scheme (PBS). However, only a select few of these drugs are available to paediatric patients. CHW funds these drugs, costing the hospital millions of dollars every year and highlighting the inequity of existing funding models and access to medications, faced by children.

Crohn's and Colitis Australia (CCA) published standards for the care of children and young people with IBD which states a minimum ratio of staffing for 240 patients. It specifies 2 FTE gastroenterologists, surgeons, 1 FTE dietitian, 1.5 FTE IBD Nurse specialists, transition coordinator, and psychological care. The CHW Unit cares for 469 patients and should have double the staffing mentioned above. Unfortunately, we are falling despairingly short of these ratios even when including the temporary enhancement afforded by soft funding.

Soft funding for short term positions creates problems for recruitment and retention of staff. This makes planning for and creating a high quality, multidisciplinary, academic team extremely difficult. A fully funded, substantive position is always going to be more attractive than the uncertainty associated with temporary positions.

Without an adequately funded IBD service at CHW, we limit the multidisciplinary vision of providing a world-leading service and ultimately limit the quality of care we can provide.

It is imperative that NSW health provide the budget to support core specialised services providing children's healthcare. Without this funding we are forced to abandon best practice recommendations and will be treating this vulnerable group of children with substandard care.

**A Report by Dr Michelle Lorentzos  
Head of Department  
Neurology Service  
The Children's Hospital at Westmead**

The Neurology service at The Children's Hospital at Westmead is inadequately funded, having had no increased funding for a decade, despite a dramatic increase in the population we care for, and the need for more complex diagnostic services and treatments. This has resulted in an inability to continue to provide world leading clinical care, access to novel diagnosis techniques, novel disease curing treatments and clinical trials for kids with severe neurological disease. Funding the services below will be a cost saving measure in both the short and long term, decreasing ED presentations and admissions, and improving outcomes and disability in children with neurological illness.

**Neurology Nursing:**

The Neurology Nurses provide a unique model of care supporting children and families with severe epilepsy and providing a quick response triage service that keeps children out of hospital. They receive a large volume of calls everyday from families of children having an increase in seizures while at home. They will institute a management plan that stops the child from needing

to present to ED and being admitted to hospital. The volume of work has now become unmanageable, with the outcome that not all calls can be answered in the required time frame, causing staff burnout. If the service remains unsupported then the department will likely need to move to a model of requesting ill children to present to the CHW ED for initial assessment if parents are concerned.

### **Neurology Staff Specialists:**

There has been no increase in recurrent funding for Neurology staff specialist FTE for a decade, despite the knowledge that the complexity of childhood neurological syndromes, the required investigations (eg: inpatient MRI's under anaesthetic and overnight EEG's) and treatments (complex immunomodulatory and anticonvulsant treatments) are unable to be offered by neurologists in private practice or paediatricians in LHD's. Representative examples include:

1. the lack of funding to enable Neurogenetics and Neuromuscular Service to bring cutting edge genetic diagnosis and genetic therapies to their patients.
2. the inability of the complex epilepsy service to provide stereo-EEG diagnostic technique that may lead to curative surgery for patients with severe epilepsy.

### **Neurology Administrative staff:**

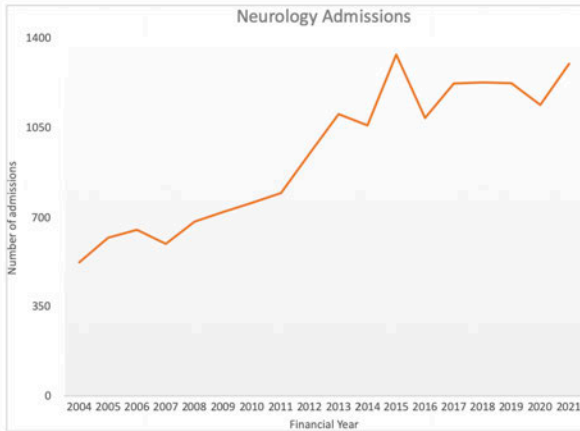
The focus on maintaining front line capacity has led to a reduction in administrative staff which in turn has meant that each staff member is assisting multiple doctors. This has resulted in an increase in the administrative workload of neurologists and neurology nurses, taking them away from treating patients, delayed responses to patient emails and phone calls, and poor billing of Medicare funded services.

### **Feto-maternal neurology:**

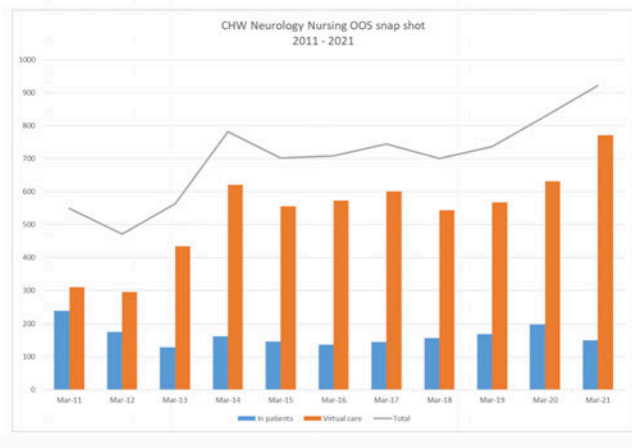
The neurologists are increasingly being consulted for prenatal neurology in the last few years. Currently, SCHN provides prenatal care for approximately 10,000 newborns per year, a steep rise in the population when compared to a decade ago. To date, there is no formalised referral pathway for foetal neurology, and tertiary consults are requested ad-hoc from foetal medical units. The rapid evolution of a spectrum of screening and diagnostic modalities in the prenatal period, including foetal MRI and prenatal exomes, has led to increasing detection of neurological anomalies within the antenatal period. Referrals range from reviews of common anomalies such as mild ventriculomegaly, poster fossa syndromes, to rare cases of spina bifida, microcephaly, corpus callosum partial agenesis, antenatal stroke and neurological sequelae because of cardiac anomalies.

The graphs below illustrate the steady increase in the demand for neurological care. A growth that is outstripping allocated funding despite many representations for enhancement.

**Figure 1: Neurology Admissions by financial year (2004-2021)**



**Figure 2: Neurology Nursing Occasions of Service 2011-2021**



**A Report from Prof Luciano Dalla-Pozza  
 Head of Department and Director of the Cancer Centre for Children  
 Paediatric Oncology  
 The Children’s Hospital at Westmead**

To state the obvious, health care services do not exist in a vacuum. Deficiencies in one “specialty” impact on others to varying but substantial degrees. It is highly unlikely that downstream ramifications that stem from unmet “resourcing” in one specific service are confined to that one discipline.

Oncology is, and has been particularly vulnerable to deficiencies in other services. We, in Oncology enjoy a privileged status and are usually (with few exceptions) provided with "deserved" favouritism in the admission queues during times of bed shortages that so frequently result in deferred admissions for other services. While understandable, it points to some basic inadequacies in care for the general paediatric population.

The "advances" in Oncology have not been quarantined to specific drugs or treatment paradigms but include nursing, allied health, clinical trials, and supportive care. The gap that exists between the time a therapy or intervention has been proven to be of value and subsequent implementation of a sustainable public funding model for that service is so great that it has always threatened our capacity to deliver optimal or standard of care. Oncology 's response over decades to this gap has been to find alternative funding sources to deliver the demanded level of care.

Examples include:

- Funding for an anaesthetist 0.5 FTE for decades to allow us to deliver general anaesthetics for painful procedures,
- Blood collectors to draw blood in clinic prior to therapies
- Psychological interventions to address mental health issues
- Educational support to keep our patients on track in school
- Medical officers in clinic, Fellows, clinical nurse consultants, social workers, dietitians
- Clinical trials which have a massive impact on health care excellence.

Specific Examples:

- A service that we have had to implement is genetic predisposition assessment....a service requiring an oncologist, geneticist, genetic counsellor, clinical nurse specialist, and administrative officer. ....\$1 million for 3 years...courtesy of philanthropy (and it takes blood sweat and tears).
- The vascular anomalies service for the most complex patients for which Oncology has now assumed responsibility (with input from others). It is funded with soft funds. It is an area of great need...requiring oncologist, clinical nurse specialist. The vascular anomalies service has struggled, at present staffing, to meet the complex needs of patients and families.
- Survivorship and long-term follow-up is an area that has relied on philanthropy for decades. Children often survive with legacies and need services to guide them into adulthood, maximise their educational potential etc etc. How do we support them?...on the vapours of philanthropy.
- Neuro-oncology- about 25% of our patient load has totally inadequate medical and ambulatory support and are relying on grants and philanthropy to piece together basic services.
- Access to diagnostic and medical imaging for investigation, staging surveillance and for clinical trials participation...the load on other service departments is enormous.
- Management of benign bone lesions (Giant Cell Tumours, Aneurysmal Bone Cysts) is a combined service initiative between Endocrinology and Oncology. A new area in addressing the care of patients with complex needs.
- Developing Thyroid cancer service- an initiative with Endocrinology.
- Outreach Metropolitan and Rural Oncology Service

In addition to this reliance on soft funds to support our own department, Oncology was asked to fund the purchase of the RETCAM for management of children with retinoblastoma. Cost \$250,000. Oncology has agreed.

Over the past 5 years, Oncology has contributed \$3 million to the electronic medical record, contributed \$500,000 to the redevelopment of the Emergency Room, installed protective isolation suites and redeveloped facilities in our Ambulatory Care area.

**Oncology:**

- In terms of RFA dependent funding for Operational positions (clinical and admin) we are looking at a figure of approx.. \$ 2.6million in 2023-24. This supports 19.6 FTE's. This

figure excludes the CRAs (data managers, Precision Medicine staff, nurse, Genetic predisposition etc.

- Has the workload increased: Yes by virtue of absolute numbers AND the addition of adding new services (Vascular anomalies, benign bone tumours, genetic predisposition). I am unable to quantify currently.
- Newer technologies have been responsible for advances both in diagnostics and therapeutics. Specific examples include:
  - Minimal residual disease testing (\$250,000 annually) currently outsourced. This is paid through Oncology general funds- a cost recently imposed after grant funding was exhausted.
  - Cellular therapies to reconstitute specific immunity to viral infections.
- Over decades there has been a perfectly understandable and appropriate expansion of available, but costly salvage therapies. Access is through clinical trials, drug committee or compassionate use. The overwhelming majority of children and families vigorously seek salvage therapies. If I look at say the last 100 children who died in our care, 97 will have died from progressive disease- ie failure of current treatments to cure. The remainder die of toxicity

Philanthropy should not be propping up essential clinical services in the absence of adequate funding from NSW Health. Having said this, the Oncology service highlights the incredible work that can be done when patients, families, communities, health workers and leadership all work together in the best interests of our patients.

## **In Summary**

All of us who work at the Children's Hospital at Westmead have an ambition to provide a world class service to the Children of NSW.

In order to achieve this goal we need leadership within NSW Health to genuinely share that ambition.

We need to develop a vision that adequately describes world class Health care and resonates with every facet of Paediatric Health in NSW.

This vision, within reason, needs to inform the budget and should not be undermined by an inadequate one.

Good healthcare begins in community, in rural and regional areas, but also needs to have centres where the our sickest and most complex patients can get tertiary and quaternary services.

Politics must be put aside in favour of the best practice.

Research and training must be valued.

Good leadership must nurtured.

Remuneration need not be equal but must be equitable. Hard work should be rewarded.

We all need to find ways to save money and generate revenue for our hospital.

We look forward to the outcome of this enquiry and hopefully some meaningful change to present funding models



