Special Commission of Inquiry into Healthcare Funding

Submission Number: 181

Name: Senior Medical Staff Council, Sydney Children's Hospital

Date Received: 27/11/2023

Richard Bearsley SC

Commissioner

The Special Commission of Inquiry into Healthcare Funding

27 November 2023

Dear Mr Bearsley,

Re: Sydney Children's Hospital Senior Medical Staff Council Submission to Special Commission of Inquiry into health care funding.

We welcome the establishment of the Special Commission of Inquiry into Healthcare Funding.

Please find below issues we wish the Commission to consider. We apologise for the late submission but trust it is still accepted. As full-time clinicians, we have limited resources and time to make extensive submissions but have put together what we can. We are happy to provide representatives to present to the Commission as required and provide further detail upon request.

Our submission focuses on the medical aspects of the enquiry as they pertain to Sydney Children's Hospital. However, we acknowledge the work of all of our colleagues across NSW – nursing, medical and allied health, as well as the entire NSW Health workforce.

SUSTAINABE WORKFORCE

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.

Our response to this section largely focuses on the medical workforce and administrative support for front line positions and services. However, we are aware the issues extent to nursing, allied health and the paramedic workforce, as well as other NSW Health workers.

a) Front-line medical workforce

There are key essential purposes of the NSW Public Hospital System

1. To provide high quality, comprehensive, free, accessible, excellent inpatient and outpatient elective and emergency clinical health care in all surgery and medicine specialties, paediatrics, obstetrics, and in rehabilitation.
2. To teach, train and nurture the next generation of health care professionals, at medical student and junior medical staff levels, ensuring our health care system and the quality of care it delivers is sustainable into the future.
3. To facilitate, undertake and be part of wide-ranging health care research that maintains and builds on the quality of health care provided.

While NSW public hospitals, by and large, are meeting the first aim, this is becoming increasingly difficult. Staff are leaving and the remaining workforce is stressed and, in some areas, very demoralised. *We are now at the crisis point where the NSW Health front-line health care workforce is not sustainable.*

The increasing use of locums, agency staff and other temporary arrangements (frontline and support staff) is indicative of this looming failure.

Submissions from the Professional Colleges are likely to cover point (2) – the teaching and training of the future health care medical and surgical workforce.

We will focus on the effects of working conditions and salary on this crisis, as this is related to how well the work force is nurtured.

NSW Health has fallen behind all other states in the salaries of front-line health care workers – nurses, allied health, paramedics and staff doctors. Salaries are across the board 25% lower. For Staff Specialist doctors, other conditions/employments standards are also inferior (on call, recall, allowances, administrative support).

Example: *A first year Staff Specialist surgeon job has just been advertised in Perth WA –*

Salary: $336,466.00 - $427,886.00

Queensland Heath

We understand that Staff specialists receive a base salary similar to that in NSW but are paid for on-call, recall, overtime, public holiday payrates, and phone-call/digital recall. There are attraction/retentional allowances and motor vehicle allowances.

NSW First year Staff Specialist:

Salary: $186,241.00 + 17.4% SA + 20% PPA = 255,885.14 *(24-40 % lower)*

No on-call/recall or digital recall allowances, no overtime payments, no attraction/retention, no standard motor vehicle allowances.

Junior Doctors (JMOs)

For junior doctors, disparity in wages and conditions compared with other states is resulting in them choosing to do locums or train/work in other states. This is a brain drain for NSW Health. In paediatrics, for the first time, in SCHN, there are vacant training posts in NSW for 2024, as junior doctors elect to do paediatric training in other states.

Most non-training junior doctors in the early years are on 1-2 year contracts. Once they have their jobs lined up for the following year, junior doctors often resign from their current contract, leaving critical vacancies in front line positions from September/October every year. They have a break or go to do locums where they can make more money, choose their hours and have less stress. Examples can be provided.

Senior Medical Staff, including Staff Specialists, Clinical Academics and Visiting Medical Officers working in paediatrics.

There is increasing pressure on senior medical staff who work in children's hospitals. Community expectation in paediatric care is understandably high. There is an expectation, and a clinical requirement, that Senior Medical Staff will be hands on in care provision for children – more so than in adult medicine and surgery. This is required to provide good care and to ensure good teaching and training of junior doctors. It is also essential when junior doctor posts are unfilled or filled with less qualified, less experienced staff – both increasingly common as outlined above, transferring workload to the senior medical staff. In addition to this, it is widely ackowledged that time required per patient is higher for the care of children. The specialist medical workforce in paediatrics, especially in sub-specialty areas,

is small. In some sub-specialty areas, there are not enough suitably qualified specialists to fill positions eg paediatric radiology, interventional radiology, cardiac surgery, transplant surgery, other areas of subspecialty training. In other specialty areas, positions are needed but not funded.

Poor remuneration of Staff Specialists in NSW Health leads to them

- leaving to work in other states where pay and conditions are vastly superior,
- taking fractional appointments in order to earn money privately – reducing the quality and quantity of service in the public hospital and increasing dissatisfaction.

Regarding fractional appointments: Small fractional appointments are also often offered by the organisation – some as low as 0.1 or 0.2FTE. It is our view that in many circumstances these arrangements benefit no-one in the long term. With fractional appointments:

- The benefits to the organisation of committed on-site staff are lost as staff specialists need to find other employment to supplement their income.
- The benefits to the individual of being on site and contributing to the work, development, vision and culture of the organisation are lost. It is often quite unfulfilling. Job satisfaction is affected. It is also very difficult to work out what pro-rata non-clinical time is reasonable – so this is often lost. And what pro-rata on call is reasonable – this is often too much. It is stressful being fractional but having inpatients under one's care – still taking responsibility for their daily management. For example, this is particularly so for surgeons, haematologists and oncologists. For example, the haematology and oncology on-call is one week at a time– so someone on a fractional appointment of, say 0.5 FTE, still needs to be available all of that week to take call and manage acutely ill patients. This has implications for other work commitments necessary to make an income, and/or for family commitments such as childcare.

b) Administrative workers

Good administrative support and service coordination enables front line health care workers and multidisciplinary teams to deliver complex multidisciplinary health care services. It is essential to the safe delivery of high quality, timely, equitable and accessible patient-centred care to the people of NSW, now and into the future.

Many administrative positions are unfilled because the pay grades are too low and noncompetitive with other industries. This results in doctors, nurse specialists, nurse consultants and other health professionals performing administrative and service coordination work inefficiently, incompletely and at great expense. For example, at SCH there are whole surgical departments with no administrative staff. Doctors type and send

letters, and arrange appointments and follow ups. It also means there is no one to receive patient enquiries, coordinate appointments and ensure referring doctors and other involved practitioners receive timely communication. Other examples can be provided upon request. This collectively leads to inefficient, poorly coordinated services, a high risk of missed calls, and inability to respond in a timely manner, leading to the further risk of adverse events to patients, long waiting lists, staff burnout, and poor patient and family satisfaction through their hospital journey.

c) Distribution of Health workers in NSW

We can only comment on the effect of the distribution of health care workers to Sydney Children's Hospital (SCH) at Randwick, in relation to the Sydney Children's Hospital Network. We are, however, mindful of the dire situation in non-metropolitan hospitals and non-tertiary hospitals in Sydney.

Sydney Children's Hospital and Children's Hospital at Westmead (CHW) are quaternary treatment centres. This means that, regardless of their geographic location, they each have a primary role for the care of complex paediatric conditions across the whole of NSW. As such, SCH Randwick, while being situated in Eastern Sydney, cares for sick children requiring tertiary care from all over NSW. The SCH Randwick receives approximately 75% of all children requiring urgent transfer to an Intensive Care Unit in NSW. Thus, it is essential that it is staffed and has the resources to meet this need.

The Liver Transplant Unit and the State-Wide Burns Service at are situated at CHW and are independently funded. Aside from these services, both Metropolitan Children's Hospitals need to be staffed and resourced to provide tertiary and quaternary care.

The distribution of the health workforce does not always reflect workload. This includes doctors, nurse specialists and consults, nurse practitioners, administration, and business support staff.

In some instances, less staff are employed for the same workload.

> e.g., The Paediatric Intensive Care Unit (PICU) at SCH Randwick has the lowest Consultant Staff to admission ratio of any PICU in Australia despite being the fourth largest. Consequently, SCH PICU staff specialists have higher on-call frequency (about double) of those at CHW.

In other instances, work that had previously been referred and distributed across both SCHN hospitals is now concentrated at one site, mostly due to administrative decisions. This leaves one site too busy and burning out while the other has unused capability and capacity.

e.g., the recent ministerial decision that no cardiac bypass surgery is to be done at SCH Randwick, despite cardiac surgical and PICU outcomes at SCH Randwick indisputably meeting or exceeding best practice benchmarks. Yet this has led to:

1) critically sick children that are unlikely to require bypass, nevertheless being transferred to CHW. Examples can be supplied upon request.

2) major non-cardiac surgery programs at SCH requiring or possibly requiring cardiac by-pass, being shut down. E.g., airway reconstruction surgery. Other examples can be supplied upon request.

3) long waiting lists at CHW for cardiac surgical patients, cancelations, and operating afterhours. This leads to staff burnout and dissatisfaction and is not patient centred.

4) SCH PICU physical capacity and medical and nursing expertise in the area of cardiac surgery is underutilised leading to staff dissatisfaction and difficulty retaining medical and nursing staff in PICU

This is covered in more detail later in this submission.

<u>Nurse Practitioners</u>: Nurse practitioners are unevenly distributed and underutilised in SCHN. There is a huge opportunity for NSW health to grow the number of nurse practitioners. With the growth of multidisciplinary care, there is a vital role for nurse practitioners in patient centred care. But cost is a barrier to individuals becoming a nurse practitioner.

d) The relationship between NSW Health agencies and medical practitioners (doctors)

Doctors are slowly being removed from leadership and decision-making positions. Being disempowered in a system where doctors are still ultimately responsible for the lion's share of patient outcomes is difficult. At SCHN there is no surgeon on the executive.

e) Workforce planning

Workforce planning in NSW is disjointed. For medical practitioners, it is unclear whether NSW Health or the Colleges are responsible for ensuring training numbers meets future workforce needs.

There appears to be a disconnect between the service needs of hospitals and the training needs of junior staff. This is demonstrated by the not infrequent news articles about specialty units in both rural and metropolitan hospitals losing the relevant specialist College accreditation to train junior doctors. These crises create many negative flow on effects for all involved: the provision of care to patients is likely adversely affected; the junior doctor has their training interrupted and presumably extended; reputational damage to the hospital and their ability to recruit, to name but a few.

Solutions

- Urgently address pay and conditions for NSW front line health care workers, providing parity with other states, including doctors, nurses and allied health
- Urgent award reform for NSW Staff Specialists including parity with others states and remuneration for on-call / recall
- Urgently address pay and conditions for NSW administrative staff and recruit to vacant positions as well as ensure all services are appropriately administratively staffed.
- Address junior doctor contracts, pay, conditions, career paths and incentives to see out their contracts.
- Address training needs of NSW Health JMOs
- Fund time for Senior staff input to JMO training (e.g., paying supervisors of training)
- Fund training of and positions for Nurse Practitioners
- Keep medical practitioners in leadership roles along-side other skilled health professional leaders.
- Undertake formal workforce planning for the Public Hospital System to ensure the future health needs in NSW can be met.

f) Training the next generation of health care professionals

As summarised at the start of this section, NSW Public Hospitals have a key responsibility to participate in teaching, training and nurturing of the next generation of health care professional, ensuring our health care system and the quality of care it delivers is sustainable into the future. If we don't prioritise this, then we don't have a sustainable health care system in NSW.

Focusing on the priority of training the next generation of health care workers, time, expertise and material resources and infrastructure need to be dedicated to education, training, and trainers.

Example: This week there is trauma simulation training, but our JMO team is short staffed by 60% on that day so the juniors cannot go – and in fact, won't go as they insist on prioritising patient care. As a result, trauma team training doesn't happen this time.

The pressure to put more cases on our theatre lists because of waiting list mandates means the opportunity to train and teach surgical registrars is lost. So, our centres become less desirable places for trainees to want to come, and we have lost the opportunity to train our future workforce.

<u>Solution:</u>

Acknowledge and prioritise the vital role NSW health plays in training and retaining the future health workforce, by allocating time, personnel, and resources, and building training into all levels of the hospital's functioning.

THE IMPACT OF PRIVATISATION AND OUTSOURCING ON THE DELIVERY OF HEALTH SERVICES AND HEALTH OUTCOMES TO THE PEOPLE OF NSW.

It is very difficult and costly to outsource delivery of health care services for children in NSW hospitals:

a) <u>Training</u> – outsourcing paediatric operative work from NSW hospitals means training opportunities for paediatric surgical trainees are lost. (see above)

b) <u>Surgery</u> - Outsourcing of paediatric operations ('collaborative care') due to waiting list demands is costly, short sighted and messy. Care is disjointed. It is very difficult to administer. It is not a long-term solution to waiting lists in Public Hospitals. It does not provide patient centred equitable access to care. Examples of suboptimal outcomes and cost can be provided

Current waiting list criteria are a blunt instrument and do not take into account health related social needs.

Solutions:

- adequate resourcing of theatre and other procedural services at NSW Children's Hospitals, including appropriate operating time for staff surgeons
- review waiting list processes with consumer input. so they are holistically patient focused

c) Radiology

There is a major conflict of interest between public and private radiology services in NSW. Public hospital radiology for children is grossly inadequate in amount and scope. Resources required for radiology in children are proportionally more per patient than for adults.

There is a dire shortage of paediatric radiologists in general, and paediatric interventional radiologists (IR) in particular, for children in public hospitals. A big part of this is poor workforce planning, poor pay, poor conditions and poor paediatric interventional radiology infrastructure.

Sydney Children's Hospital has a particular shortage of paediatric radiologists and interventional radiologists. Sydney Children's Hospital radiology after hours service is staffed approximately 50% by locum radiologists. This is costly and disjointed for clinical care.

The on-call availability of interventional radiologists across SCHN is haphazard. Where IR is not available, children need to undergo procedures and management strategies that may not be first choice – e.g., surgeons are required to undertake procedures that in most centres internationally are now done by IR.

Examples (not exhaustive) of procedures that are increasingly expected to be done by paediatric IR but are still largely done by paediatric surgeons due to lack of IR resource:

- Central line insertion for children with cancer and other chronic conditions requiring long term IV access; (one -two days per week of IR time required in each SCHN hospital)
- Drainage of empyema for children with severe pneumonia (2-3 per week in winter)
- Tumour biopsy

This shortage means that best practice in the care of children requiring procedures that are meant to be performed with interventional radiology cannot be delivered. It is either done in a less ideal way or the child waits until a radiologist is available – sometimes days. We

must stress that patient safety is always front and centre for surgical staff. Nevertheless, this is stressful for families and for the clinicians caring for them. It is costly in terms of bed days and potentially patient outcomes.

Children regularly have to bypass John Hunter Childrens' Hospital in Newcastle, to Sydney, because there is no paediatric radiologist available there to perform procedures. This is at great cost and distress to families and cost to the health care system. It is not patient-centred care.

Two enquiries/reviews into radiology services at Sydney Children's Hospital (one current) have been undertaken, resulted in no change or material benefit. Clinical staff are privy to neither. It is likely that having the service entwined with the administration of POW radiology is resulting in a suboptimal service for children. While SCH and POW radiologist themselves are always endeavouring to provide the best care possible, there are big gaps in what *is* possible and the needs of SCH patients re not always considered in administrative decisions.

MRI services for children are grossly inadequate. Young children needing MRI either require a general anaesthetic (GA) or child life therapy. Older children with neurological problems also require GA. Thus, paediatric MRI services need to be provided and accessible in public hospitals that can provide both. **The waiting list for a non-urgent MRI is up to one year.** This is far too long to wait for an investigation to direct care.

Example: Children with brain tumours have had routine scans, critical to detect tumour progression, delayed, in some cases for 12 months.

SCH recently purchased an MRI for the Randwick campus but it is in the POW new services building. There are no paediatric GA lists on it. No child can have an MRI of their arm on the Randwick campus because children do not have access to the MRI machine that can do this.

<u>Solution:</u>

- Fund paediatric radiology training positions in NSW hospitals, including IR fellowship training
    - The potential paediatric IR experience obtainable in an IR Fellowship available at SCHN is easily equivalent to that available at international centres.
- Fill all vacant paediatric radiology positions, and staff to required levels.
- Fund and staff appropriately Paediatric IR (elective and emergency) at each major children's hospital
- Separate paediatric and adult radiology at Randwick Campus
- Provide up to date MRI machines and associate infrastructure to allow paediatric MRI to be done in appropriate time frame in NSW paediatric public hospitals.

HOW GOVERNANCE STRUCTURES CAN SUPPORT A SUSTAINABLE WORKFORCE AND DELIVERY OF HIGH QUALITY, TIMELY, EQUITABLE AND ACCESSIBLE PATIENT-CENTERED CARE TO IMPROVE THE HEALTH OF THE NSW POPULATION

Measuring outcomes that matter

The care delivery in NSW hospitals is increasingly complex. The health care workforce needs to be supported by an appropriate governance structure in the delivery of this complex clinical care. When resources are lacking, clinicians are still expected to deliver excellent care and are judged on this standard of care. The worse the resource issues, the bigger the stress on frontline workers as they continue to strive to deliver.

To provide and develop and evolve patient and family centred care in paediatrics, we need to engage with meaningful development and measurement of paediatric PREMS (Patient Reported Experience Measures) and PROMS (Patient Reported Outcome Measures). This requires resourcing.

Solution:

Fund the development, collection, evaluation and response to PREMS and PROMS in paediatric health care at a service level.

Ability of hospital staff to express concerns about patient care and safety: (a '*non-financial issue impacting retention and attraction of staff'*)

There are circumstances across NSW Health where hospital staff (medical, nursing, or allied health) are concerned about patient care or safety. These reasons could be multiple: for example, lack of or inadequate resources for patient care, inadequate staffing, staff performance, or removal of existing services at the hospital. These concerns are, in the first instance, highlighted in the hospital incident reporting system (IMS). This process is overarched by hospital executives and clinical governance. If there are still ongoing concerns, there are limited further avenues for staff to escalate or express ongoing patient care and safety concerns. There are limited avenues for hospital medical, nursing or allied health staff to highlight concerns beyond hospital executives. This makes hospital medical, nursing, or allied health staff vulnerable if they do. It means genuine concerns that often only front-line staff can appreciate, cannot be further articulated, without the risk of disciplinary action and dismissal. There are high profile cases reported in Australian and international media where staff have been initially silenced, only to be ultimately vindicated when the truth of their concerns is borne out. Sadly, it is the patients and their families who suffer.

The NSW code of conduct for NSW Health staff deals largely with behaviour that most reasonable citizens would consider inappropriate. However, there is also reference to avoiding 'conduct that could bring NSW Health…. into disrepute'. This clause can be used to dissuade front line staff from raising concerns beyond their LHD and accusations of such 'misconduct' can be used across NSW Health as a tool of intimidation and isolation. There is also a significant risk of a conflict of interest in the application of the code of conduct in these circumstances.

Solution:

- Staff should not be disciplined for raising genuine concerns about issues affecting or potentially affecting patient safety.
- An independent code of conduct process is required.
- There needs to be an objective, unbiased, arm's length process to deal with staff concerns about issues that affect patient safety. For example, a Health Ombudsman.

WASTE

Health is a huge energy consumer and generator of waste. Every day I walk past a skip at the hospital that is full of recyclable rubbish, destined for landfill. The coordination between waste contractors and site staff to achieve good waste management is suboptimal. Contractors do not always deliver on promises. A recent recycling initiative in our theatres lead by the waste contractor was not what it appeared, and all went to landfill. There is no meaningful recycling in the hospital. There is no mandate on clinical, administrative, or domestic staff to reduce, reuse and recycle.

It appears that devolution of environmental sustainability and waste management to LHD's or individual facilities and outside contractors has not been uniformly successful.

This poses an enormous cost to future generations.

Solution

- NSW health to take responsibility for environmental sustainability in public hospitals with uniform enforceable criteria and standards.
- Make environmental sustainability a KPI

NEW MODELS OF CARE AND TECHNICAL AND CLINICAL INNOVATIONS TO IMPROVE HEALTH OUTCOMES FOR THE PEOPLE OF NSW, INCLUDING BUT NOT LIMITED TO TECHNICAL AND CLINICAL INNOVATION, CHANGES TO SCOPE OF PRACTICE, WORKFORCE INNOVATION, AND FUNDING INNOVATION

While not funding experts, we understand that current funding models do not fit well with covering the true cost of the delivery of paediatric health care, nor do they value the long-term individual, community and societal benefits of providing timely appropriate health care to children. This is covered in the submission from SCHN p 21-24.

At a hospital level, the true cost of delivering paediatric health care is not captured. The EMR, which is often used to assess service delivery, under-represents the cost in time and resources. Many episodes of care are not captured in the EMR due to administrative resource constraints and clinical workload. Examples include:

- Lack of ability to be funded for multidisciplinary and care planning meetings.
- Multiple phone calls and conversations with family members - these are not scheduled and therefore not funded as episodes of care.

Many children live with chronic complex conditions. They are coping with this while growing and developing, learning to engage socially, going to school, and finding their place in society. It's tough on them, It's tough on their families. It even tougher if you are socioeconomically disadvantaged and live away from major centres.

Increasingly the best care is delivered to children via multidisciplinary services. This fosters patient centred clinical care, optimises the interdisciplinary training and experience of health care professionals, and is an ideal environment for future focused health care research in all its facets.

In NSW, the resource constrained environment means it is almost impossible to be funded to establish or move to a multidisciplinary model of care that would help children wherever they are live their best lives despite their complex health issues.

We understand the Commission will receive a number of submissions from individual teams/departments in SCHN and other LHDs outlining how these constraints effects their individual service delivery. **Rather than these being isolated instances, such submissions are emblematic of the wider problem of funding for developing and implementing innovative models of health care in NSW hospitals, particularly those related to the care of children.**

Following are further examples supplied to us (not exhaustive)

SCH Vascular Tumours and Anomalies Centre (V-TAC)

30 years ago, we established a multidisciplinary service for children diagnosed with vascular tumours and anomalies. These diagnoses encompass a number of conditions, some of which are individually rare but collectively they represent a large number of patients. At present we have upwards of 700 patients in our service. Vascular tumours and anomalies are complex chronic problems, with a life-long impact on quality of life of the child and family. We have built the V-TAC into a centre of excellence, with multidisciplinary patient care at the forefront. We have established a research and education programme and developed a national profile.

To advance our model of care, we have recently moved our service to sit in the Kids Cancer Centre, to leverage and build on the synergies between managing these conditions and the management of childhood cancer. We believe this is the first Vascular Tumours and Anomalies multidisciplinary service in Australia to do so. Further, we are creating partnerships with adult practitioners across many LHDs, to build expertise and to ensure seamless transition of care into adult services.

Despite a review concluding that funding was required, and in-principal support from the Executive, there was no money to support this innovative service until this year, when short term money for nursing/ allied health and administrative resourcing was provided through the generosity of donors to SCHN Foundation. This is absolutely fantastic, and is allowing us to provide and build patient centred individualised multidisciplinary care. But the funding is donated money (which is deeply appreciated) and only for 3 years and it has taken almost 12 months for some but not all of those positions to be filled due to the administrative process involved. What we do to continue to care for these children after the 3-year funding ends is uncertain. In addition, the service is heavily reliant on interventional radiology which is a major issue in paediatrics (see earlier). There are successful effective models of care internationally and here in NSW Australia. They just need to be funded.

Solution:

- Adequately fund multi-disciplinary care of children with complex vascular anomalies and tumours, incorporating nurse-led individualised, patient centred management and access to allied health skills, coordinated with medical expertise and novel interventions, as well as carrying out research into novel diagnostics and management options.
- Resource the transition of care to adult services of these children/young adults with life-long chronic complex conditions.

SCH and CHW Surgical Bowel Clinic

Another example is a multidisciplinary service for children who are born with complex structural bowel problems. Many require operations in the neonatal period and first years of life. Skilled surgical teams at each of the three children's hospitals in NSW provide this care. This is approximately 60-80 children per year in NSW, all of whom require long term management, and thus remain in our care throughout childhood (this equals at least 1000 children in the care of paediatric centres up to the age of 18). We have a clinic to care for these children at SCH and one at CHW. The paediatric surgeons across SCHN collaborate and support each other with discussion about complex cases. We meet. We assess and operate on complex cases together. But, despite the best possible operation, these children and families need long term support. No-one likes talking about poo but many of our children get to the age of 5 still having difficulties and go to school smelling of poo, because they are incontinent. We could support these families and achieve better outcomes for the children if each hospital could offer integrated multidisciplinary care including individualised pelvic floor and toileting physiotherapy, a nurse practitioner-led individualised bowel management program and psychology support. But we have none of that to offer. Its so sad. And the problems that develop and impact their lives through childhood and into adulthood, are avoidable for so many of the children. The cost to them socially, and psychologically is huge. Avoidable costs are borne in education, hospital admissions, extra procedures, mental health care, and ultimately potentially inability to join the workforce. Funding proper models of care would be cost effective in the avoidance of the significant cost of doing nothing.

Not surprisingly, even if the only option was donated money, this condition is very hard to champion and attract donors for. The successful models of care exist internationally and here in Australia. Examples can be provided. They just need to be sustainably funded in NSW.

Solution:

At each children's Hospital in NSW, adequately fund multi-disciplinary care of children with chronic complex colorectal conditions, incorporating nurse-led individualised, patient centred bowel management and access to allied health skills, coordinated with medical expertise and interventions.

Cardiac Surgery including Cardiac bypass surgery at Sydney Children's Hospital

This section further expands on that about PICU and cardiac bypass availability earlier. It is covered here, as a successful cardiac model of care that incudes low and medium complexity surgery at SCH will improve health outcomes for all children in NSW cares for at SCH Randwick, and we believe its absence at SCH Randwick materially risks adversely affecting health outcomes for children of NSW.

Cardiac services including cardiac surgery are an integral part of safe delivery of services provided at the Sydney Children's Hospital Randwick. This is true of any tertiary/quaternary paediatric centre. Removal of cardiac surgical services at SCH has, and will continue to, adversely affect children from around NSW cared for across all departments of SCH including Trauma, Oncology, Intensive Care, Neonatology, the Emergency department, Paediatric Surgery, ENT, Gastroenterology, General Surgery and Thoracic Surgery.

The SCH PICU team's ability to maintain an ECMO service (cardiopulmonary support akin to cardiac bypass for seriously ill babies and children) is intricately linked with the skills of the team required to offer elective cardiac surgery.

Nowhere else in Australia does a children's hospital maintain an ECMO Service without a cardiac surgery program including cardiac bypass. Nowhere else in Australia does any hospital place a child on ECMO without the presence of a cardiac surgeon.

Because of the decision to cease all cardiac bypass surgery at SCH, the ECMO service will dissolve over time, as we lose the skilled staff and teamwork required.

It is often not apparent prior to the transfer of a sick child whether or not lifesaving treatment such as ECMO, will be required. Removing cardiac surgery including cardiac bypass from SCH Randwick is going to put children's lives at risk. Critically sick children are transferred to SCH from all around NSW. This means that many of these children will now need a dangerous and costly second transfer from SCH Randwick to Children's Hospital at Westmead (CHW). There is an expectation that when transferring a critically ill child to a tertiary referral hospital such as SCH Randwick, that the hospital has all the services required to safely care for these children. To not have those services is costly and exposes vulnerable children to significant risk. Existing examples of how the current set up is at risk of failing can be provided upon request.

The Cardiac Surgery program at SCH Randwick had been providing service for more than 3 decades to children of NSW and with outstanding results, meeting or exceeding international benchmarks. This has never been in dispute. It is safe, cost effective and uses resources efficiently.

Solution:

- Restart low to medium complexity cardiac surgery including cardiac bypass surgery at SCH Randwick.
- Provide necessary personnel and resources needed for the reinstatement of cardiac surgery program at SCH.

SCH Haematology Service

The SCH Randwick Haematology department provides an inpatient service, conducts outpatient clinics at SCH, outreach clinics around the state of NSW and the ACT and provides an expert consultative service to fellow SCH colleagues, paediatricians and general practitioners in NSW and the ACT. It is a very active service: 24 hours per day, 7 days a week.

We have a Haemophilia Treatment Centre, a thrombosis service and a haemoglobinopathy and chronic red cell transfusion and red cell exchange programme. We manage children with bone marrow failure syndromes, hereditary platelet disorders and acquired red cell, white blood cell and platelet disorders. We advise on and manage paediatric anticoagulation. We are intimately involved in the new model of care for children with Vascular Tumours and Anomalies. This includes management of coexisting coagulation disturbance and treatment of their anomalies with novel agents including targeted drug therapies, in the multidisciplinary team setting described above.

We have 3 senior haematology consultants who are all fractional appoiuntments 0- the pitfalls aof which have bene described earlier: "on paper" they are designated as working a total of 1.4 FTE to manage all of the above. The 3 consultants participate in a 1 in 3 on call roster, working one whole week at a time. It is only possible to cover the around the clock work load due to the dedication and goodwill of the practitioners involved.

In total we conduct 15 outpatient clinic sessions at SCH per week. We conduct the equivalent of 8 full day outreach clinics at the Canberra Hospital, 8 full day clinics in Wagga Wagga Base Hospital and 4 full day clinics at Campbelltown Hospital, per year. We have been asked to consider expanding the number of outreach clinics to include other regional areas in NSW. This would ensure access to expert and timely haematological care and firm up professional networks of communication and consultation, as well as providing education to general paediatricians and other practitioners in rural and regional areas. But this is not possible with the current FTE.

In addition to the clinical work-load, the doctors have many other competing demands on our time: we participate in research trials, educate medical students and junior medical and nursing staff, attend conferences and on occasion organise them. We develop policies and

procedures, engage in quality assurance and accreditation systems, and sit on a number of hospital, network, state and federal committees relevant to our practice.

To support all of this, we have a 0.5 FTE nurse CNC that we share with the apheresis service. There is no social worker or physiotherapist dedicated to the service. We have one full time advanced trainee junior medical staff member.

We are in urgent need of funding for sufficient medical, nursing and allied health staff to run this vital state-wide service properly - the current mechanisms for resourcing such essential services have failed us. We are in effect proposing a new model of care for the provision of specialist paediatric haematology services, to the children of NSW. <u>However</u>, the provision of a state-wide service requires an innovative approach to funding, beyond those constrained by LHD borders.

<u>Solution:</u> develop a funding model for the maintenance and enhancement of this state-wide paediatric haematology service, where the cost for consultation and access to expert advice, and the delivery of outreach clinics from SCH, is shared across Jurisdictions who engage with and benefit from the service.

<u>Transitioning the care of children with chronic complex health conditions to adult services</u>

As children with chronic complex health conditions grow up, their care needs to be transitioned from paediatric to adult services. This is a time of major stress and transition for families. Subjectively, some adult services express feeling ill-equipped and are unfunded to take on their complex needs. Families can feel left in the wilderness. Examples include children with vascular anomalies, bowel conditions, oncology patients and neurologically impaired children. While the children's hospitals fund transition care services, this doesn't necessarily translate to practitioners in the adult setting feeling resourced and staffed adequately to take such children and their families on.

<u>Solution:</u>

- Fund proven models of multidisciplinary care for children with chronic complex life-long conditions
- Review funding models and their suitability for determining funding required for paediatric acute and chronic multidisciplinary care.
- Develop and adequately fund models of care across NSW health, including front line resources, that enable the transition of the care of people with chronic complex health conditions from paediatric to adult services that meet their health and social needs.

Clinical Trials Capacity in Oncology

It is accepted internationally that the standard of care for children with cancer is to enrol them into clinical trials. This practice has directly let to the improvement in survival rates that has been documented over the past five decades. Clinical trials are not just 'research' but afford children with cancer, access to state-of-the-art treatments that may otherwise be unavailable. Unlike in adult oncology, most trials in paediatric cancer are collaborative trials – that is they are not funded by the pharmaceutical industry. They therefore require investment and support from the local health service. In NSW, clinical trial infrastructure for children with cancer is grossly underfunded compared to almost every other state in Australia. The oncology clinical trials team at SCH is almost completely funded by soft funding, through philanthropy or other external sources with minimal core hospital funding – at odds with the national practice, and at odds with the international standard of clinical trials as the standard of care. The clinical trials staff are poorly remunerated and on yearly contracts, affecting recruitment and retention of high-quality staff.

Solution:

- Provide core funding for the oncology clinical trials teams.
- Increase the remuneration for clinical trial co-ordinators.
- Make trial enrolment a Key Performance Indicator for hospital executive.

Thank you for the opportunity to make this submission.

We can provide examples and personnel to comment further if required,

Yours sincerely, SCH SMSC executive:

Dr Puneet Singh, SMSC Chair

A/Prof Susan Adams, SMSC Secretary

Prof David Zeigler, SMSC Treasurer