Special Commission of Inquiry into Healthcare Funding

Statement of Dr Nigel Lyons

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1. This statement made by me accurately sets out the evidence that I would be prepared, if necessary, to give to the Special Commission of Inquiry into Healthcare Funding as a witness. The statement is true to the best of my knowledge and belief.

My role

2. I am the Specialist Advisor for the Ministry of Health (**MOH**). I have held that role since September 2022.

3. Between October 2016 and August 2022, I was the Deputy Secretary, Health System Strategy and Planning, NSW Ministry of Health with responsibility for strategic health policy development, inter-jurisdictional negotiations, funding strategies and budget allocation, system-wide planning of health services, capital planning and investment, integrated care, palliative care and management of the non-government organisation grants program. I was also responsible for the direction of child and family health policy.

How and where paediatric services are delivered in NSW

4. Paediatric services are provided across NSW, informed by paediatric service capability guidelines which assist Local Health Districts (**LHDs**) and Specialty Health Networks (**SHNs**) to plan and deliver safe, high quality paediatric medicine and surgery to meet population needs. An updated *Paediatric Service Capability (Paediatric Medicine and Surgery for Children)* guideline was published in 2023 (MOH.0002.0144.0001). The Guideline outlines the service capability standard for each level of Paediatric Medicine or Surgery for Children service. Service capability describes the activity and complexity of clinical care that a service can safely provide in collaboration through formal agreements with its supporting services (allied health, pathology, child protection services, etc). The Guideline specifies the standards for each level of service capability

including Paediatric Medicine service capability levels (2, 3, 4, 5 and 6) and Surgery for Children service capability levels (2, 3, 4 and 6) (no level 5).

5. Services providing paediatric health care include NSW Health services (inpatient and outpatient), NSW Health transport and retrieval services, and service partners in other jurisdictions. NSW Health also provides a range of mental health services and supports to children and young people as well as perinatal services. Services are linked through local networking arrangements. The 'highest' or most complex level of care is provided by Level 6 services. A Level 4 Paediatric Medicine Service has the capacity to provide paediatric inpatient and non-admitted care for patients with a broad range of medical conditions, delivered by a dedicated multidisciplinary team and led by a paediatrician, with inpatient care delivered in a paediatric ward.

6. The majority of medical care to children and young people is delivered in primary and secondary care settings. Medical care of children and young people is a core service of Local Health Districts (**LHDs**) and all LHDs, including rural and regional LHDs, have capability to provide up to level 4 inpatient care to children and young people (with the exception of Hunter New England LHD, which provides some Level 6 services at John Hunter Children's Hospital). This includes general paediatrics and a small number of paediatric surgery specialties, commonly including ENT and orthopaedics, in both inpatient and outpatient settings.

7. Specialist paediatric medical care in regional NSW is provided by NSW Health facilities through emergency departments, inpatient child and adolescent wards, hospital in the home and acute review services as well as newborn services in postnatal wards and special care nurseries. Ambulatory community child health and paediatric outpatient clinics occur in some Level 3 paediatric services and most Level 4 services. Outpatient clinics accept referrals for general paediatrics as well as referrals for specific illnesses that require management in subspecialty clinics – the most common is diabetes, but other subspecialties are also represented. Subspeciality clinics exist in differing forms, including in-reach from the three tertiary children's hospitals, local expertise, or a hybrid model which can include virtual health.

8. There are three paediatric tertiary facilities which provide specialised paediatric services, John Hunter Children's Hospital (**JHCH**), The Children's Hospital at Westmead (**CHW**), and Sydney Children's Hospital (**SCH**). CHW and SCH form part of the Sydney

Children's Hospital Network (**SCHN**) meanwhile JHCH is embedded within Hunter New England LHD. The three paediatric tertiary facilities have a statewide role and undertake more complex surgeries as well as subspecialised care, such as oncology, neurology, cardiology and endocrinology. These facilities also provide secondary care to patients.

9. SCH and CHW do not operate in a defined geographical area like LHDs and there is no particular community they are responsible for, save for the limited secondary paediatric services provided to parts of Western Sydney LHD and South Eastern Sydney LHD.

10. Clinical care and inter-hospital transfers for infants, children and adolescents are delivered through a statewide system of networked care. In line with the *NSW Paediatric Clinical Care and Inter-hospital Transfer Arrangements* (MOH.0002.0146.0001) when an inter-hospital transfer is being considered, clinical decision-making must primarily match the paediatric patient's condition to the most appropriate service and consider:

    a. service capability and capacity of referring and receiving services capability and capacity of transport and retrieval services;

    b. providing care as close to home as possible;

    c. child and adolescent and family needs and preferences, and

    d. logistics such as weather and modes of transport.

11. Statewide quaternary services such as burns, open heart surgery and transplants are provided by SCHN at CHW and SCH. The SCHN also provides a limited number of national services including cardiac and liver transplants and Islet cell transplantation.

12. Non-admitted patient, admitted patient and emergency department data for paediatric (those up to 16 years) services in the 2023 calendar year indicated that the majority of paediatric care is provided outside of SCHN (82% of non-admitted activity, 68% of admitted and 84% of emergency). However, SCHN has the highest volume of activity for paediatric services, followed by HNELHD and SWSLHD. The majority of SCHN occasions of service are delivered to patients from metro areas.

Changes in how paediatric services are delivered

13. The majority of medical care to children has historically been provided by the LHDs and at non tertiary paediatric facilities. However, there have been some significant shifts in the care needs of the paediatric cohort which has impacted where and how paediatric services are provided and the need to network services across the state.

14. There has been a trend internationally towards increasing consolidation of activity which has been primarily driven by:

    a. Increasing subspecialisation of the medical workforce which has reduced the number of general paediatricians. For example, providing cardiology or rheumatology services was previously within the scope of practice of a general paediatrician however now falls within specialised paediatric care. As a result, more paediatric care falls within specialties or subspecialities, more of which is provided at tertiary and quaternary facilities, rather than the work of general paediatricians.

    b. Changing demographics of patients. Behavioural and psychosocial issues as well as developmental assessments for the National Disability Insurance Scheme (**NDIS**) take up more time of the general paediatrician workforce than it has before.

    c. Consolidation of activity within LHDs. Historically, children have been admitted to hospital without a specialist paediatrician having oversight of their care. However due to the need for specialist support, where a child or young person requires inpatient admission for treatment that will extend beyond an overnight stay, the patient should now be transferred to a level 4 tertiary service to have their care overseen by a specialist paediatrician. This in turn has consolidated paediatric inpatient services into specialised services.

    d. Specialised paediatric patients are generally now lower volume presentations. Where you have highly specialised care, there is a need to consolidate activity into a smaller number of sites to maintain skills and access to supporting technologies.

    e. Technological advancements. Advancements in minimally invasive procedures, cellular therapies and gene therapy require high level of expertise in delivery. The volume for these services is not going up and the highly specialised workforce that

can provide these services is constrained nationally. Consolidation of services occurs by necessity to ensure there the workforce is available to provide treatments safely and in a way that is accessible to all.

15. The revised guideline for *Paediatric Service Capability (Paediatric Medicine and Surgery for Children)* introduces new notification and reporting requirements for service capability assessment. This statewide data on service capability, expected to be available in early 2025, will assist the Ministry, LHDs and SHNs to plan and deliver safe, high quality Paediatric Medicine and Surgery for Children services to meet population needs.

Governance of health services for children, young people and families within the NSW Health system

16. Following advocacy from clinicians across the state for the need for an assessment and prioritisation of investment in children's health services, Emeritus Professor Richard Henry AM was appointed to undertake an independent review of health services for children, young people and families within the NSW Health system (**the Henry Review**).

17. The Henry Review was released in January 2020 and focused on the current status of governance and the delivery of health services to children, young people and families within the NSW Health system. The Henry Review provided an outline of current issues and challenges associated with the provision of care for this group of patients.

18. The Henry Review made 77 recommendations on the delivery of health services to children, young people and families within the NSW Health system and the sufficiency of current governance arrangements to ensure safe, effective and high-quality care across NSW. The recommendations highlight opportunities for improvement and align with the strategic priorities of the Secretary, NSW Health, across the areas of governance and accountability, value-based health care, patient safety and experience, digital health and analytics, and systems integration.

19. All recommendations from the Henry Review were accepted. The Henry Review Implementation Plan released in July 2022 guides work that responds to the Review's recommendations.

20. In September 2020, the Children, Young People and Families Executive Steering Committee (**CYPFESC**) was established. CYPFESC is the state-wide committee which

provides leadership to strengthen the provision of NSW Health services for children, young people and families and provide greater focus and direction for the system.

21. In December 2023, the CYPFESC 2023 Annual Report was released (MOH.0002.0147.0001). The Report summarises progress in implementing the recommendations from the Henry Review and noted 22 recommendations have been completed with the remaining 55 recommendations in progress.

22. The Agency for Clinical Innovation (**ACI**) has a key role in bringing patients, clinicians and managers together to support the design and implementation of innovation in healthcare. The ACI supports a number of clinical networks, including the Paediatric Network which aims to improve the healthcare experiences and outcomes for children and young people across NSW.

23. The ACI Paediatric Network's priorities are:

    a. providing guidance to the NSW Health system on how to standardise paediatric care;

    b. establishing new models of care;

    c. partnering with clinicians and consumers, and

    d. fostering an environment of collaboration.

JHCH and SCHN

24. The SCHN was formed in 2010 following the 2008 Garling Inquiry into Acute Care Services in NSW Public Hospitals (**the Garling Inquiry**).

25. Prior to the establishment of the network, there were two children's hospitals based at Westmead and Randwick which operated independently of each other. The network structure was seen as advantageous over independent children's hospitals due to the growing trends of specialisation requiring consolidation of activity, as well as the benefits for a single management and governance structure for clinical services and patient care.

26. The Garling Inquiry also recommended investigation of the need and desirability of a new NSW Kids hospital providing quaternary and tertiary facilities. While a new hospital has not been developed, other investments have been made including the Stage 2 Redevelopment of Campbelltown Hospital which has increased children's surgical services and children's outpatient and ambulatory care services for the SWSLHD.

27. JHCH had been established as the third tertiary hospital due to geography and the centralisation of the tertiary paediatric facilities within Sydney. JHCH has not formed part of the network largely due to the way paediatric services are delivered in the District, with paediatric services intertwined with adult services provided at John Hunter Hospital (**JHH**). For example, anaesthetics, intensive care and other subspeciality adult services feed into the paediatric service. There is also an integrated service delivery model used at Hunter New England LHD, with both inpatient and community care provided to adults and children as one service stream. This makes it more difficult to separate JHCH and JHH to run them separately, which would be required for JHCH to form part of the network.

28. Health equity for rural and regional patients with the SCHN being Sydney based is currently an area of focus for NSW Health. Work is being done in the following areas:

    a. Establishment of the Children Young People and Families Health Network (**CYPFHN**), bringing together a statewide team to support implementation of identified statewide priorities, jointly governed by Sydney Children's Hospitals Networks (SCHN) and Hunter New England Local Health District (HNELHD). CYPFHN will work system-wide and build relationships with LHDs, Speciality Health Networks (SHN), NSW Health agencies, clinical networks, peer groups and communities of practice.

    b. Building capability in other facilities. For example, there has been significant investment in Campbelltown Hospital, with the opening of South West Kids which has approximately 100 inpatient beds. There may eventually be benefits to having Campbelltown Hospital networked with other facilities to the south.

29. As part of the consideration of how paediatric services should be provided across the two children's hospitals, NSW Health convened an Expert Review Panel to review the current governance of the Sydney Children's Hospitals Network (**the Alexander**

Review). The Final Report (MOH.0002.0143.0001) was produced in June 2019. Neither the Alexander Review nor the Henry Review recommended the cessation of the network structure.

Funding models

30. LHDs and SCHN receive Activity Based Funding (**ABF**). It is accepted that the level of care is usually higher for children and young people in comparison to adult patients. As a result, an adjustment is applied to account for the relative cost of treating paediatric patients.

31. There are however challenges with ABF even with the paediatric adjustor for tertiary and quaternary services. Where services are highly specialised and lower volume, the cost of the services may not be adequately reflected by the average cost of providing care across the State, which the adjustor is based on. New and emerging treatments arising from technological advancements, such as gene therapies, are also very expensive and not yet adequately captured by ABF.

32. The pressure on the health system means that there is an emphasis on an ageing population and chronic health conditions which can be challenging for paediatrics when resource allocation decisions are made. However, strategies such as the First 2000 days provide sound evidence for investment in early intervention services for paediatrics to effect medium and long-term change. The evidence for the benefits of investment in the first 2000 days of a child's life is such that if the targets are appropriate, there should be tangible benefits seen in the next 30 years with a reduction in physical and mental health conditions requiring ongoing care. These medium and long-term benefits also support a shift in resource allocation.

33. In addition to the statewide leadership provided by the CYPFESC, the Ministry is establishing a new Lead Committee for Paediatrics and Child Health in the Middle years (**PCHM**). This committee will be the statewide strategic forum for health services, policy and programs relating to acute and community paediatrics (children and adolescents 16 years and younger), and the health and wellbeing of children in the middle years (6-12 years of age). The first meeting of this committee will be held in June 2024.

New models of care

34. There has been a focus on upskilling the existing workforce so that staff are working at the higher end of their scope. For example, there was previously a reliance on Registrars to run the Neonatal Intensive Care Unit (**NICU**) however that became challenging with fewer Registrars and an increasing number of NICUs. Nurse Practitioners have been upskilled to provide this service which has improved the ability to care for babies and the number of cots available.

35. **VirtualKIDS** is another example of effective use of new models of care. VirtualKIDS uses video conferencing technology to connect families with a clinical nurse to determine the best care pathway based on each child's needs. Patients may be referred to virtualKIDS from several sources and will be enrolled into an appropriate model of virtual care according to their level of need. This service is available to all children and families across NSW and helps children and families avoid unnecessary trips to hospital and potentially long waits to be seen, especially if after hours.

36. **Management of children with behavioural issues and/or ADHD in regional NSW**: In 2021, $7.7 million was committed to trial a new model of care for management of children with behavioural issues and/or ADHD in regional NSW, over four years. The enhanced model of care is designed to improve treatment pathways for children and their families by establishing a dedicated multidisciplinary team and building partnerships with local GPs to enhance their capacity in shared care ADHD management. The two district-run pilots will assist accessibility and affordability of ADHD services in Western NSW and Hunter New England Local Health Districts. An independent evaluation of the pilots is underway.

37. **Specialised Intellectual Disability Health Service (IDHS)** and **Statewide Intellectual Disability Mental Health Hub – Paediatric (MH Hub):** The IDHS is made up of a network of six teams and nine clinical positions across NSW which are focused on supporting and building the capability of the health system to meet the health care needs of people (including paediatric patients) with intellectual disability in NSW. Funded by NSW Health, the MH Hub supports those people with intellectual or developmental disability access appropriate mental health care through access to a combination of face-to-face support and virtual care. The MH Hub also provides education, training and support for mental health clinicians and disability workers providing care to people with intellectual disability.

38. **Paediatric Rehabilitation: Minimum standards toolkit:** the Agency for Clinical Innovation's Rehabilitation Network developed Minimum Standards for coordinated delivery of paediatric rehabilitation in NSW Health accompanied by a digital toolkit. These were developed through a process of co-design and extensive consultation with clinicians and consumers via a series of workshops and interviews in partnership with local health districts, speciality health networks and health consumers. Paediatric rehabilitation is a family-centred, multidisciplinary program of goal-directed care. It is for children and young people who, as the result of injury, a health condition or surgical or medical intervention, would benefit from this care. The Minimum Standards are designed to set the benchmark for the coordination of services providing paediatric rehabilitation in NSW Health.

Dr Nigel Lyons	Witness: Analiza Capati
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