

Witness Statement

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Occupation: Head of Paediatric Rheumatology, the Sydney Children's Hospital Network

1. This statement sets out the evidence that I would be prepared to give as a witness to the Special Commission of Inquiry into Healthcare Funding.
2. The contents of this statement are true and correct.

A. My Role

3. I am the head of Paediatric Rheumatology within the Sydney Children's Hospital Network ('SCHN'). I have worked within what is now the SCHN for over 25 years, principally between the two main sites, The Children's Hospital at Westmead ('CHW') and Sydney Children's Hospital, Randwick ('SCH').

B. Paediatric Rheumatology Services across SCHN

4. The Paediatric Rheumatology Services ('the Service') is a statewide service primarily operating out of the CHW, the SCH and the John Hunter Hospital. The Service sees inpatients at these Hospitals and provides outpatient clinics. The Service also provides outreach clinics at Orange, Wagga and Canberra.
5. Juvenile arthritis affects 1- 2 per 1000 children under the age of 16 years and at least 50% will continue to have arthritis into adulthood. Many children with childhood arthritis suffer daily pain and disability affecting their school attendance, sports participation and social interactions. Other complex and often life and organ threatening inflammatory diseases such as juvenile systemic lupus erythematosus, juvenile dermatomyositis, juvenile scleroderma and others also require specialist paediatric rheumatology care. Optimum care for children and young people with rheumatic disease is provided by an expert multi-disciplinary team.
6. The Service receives funding from the SCHN for the equivalent of about one full-time equivalent ('FTE') position split between two 0.8FTE staff specialist and less than 2 sessions

per week of VMO contracted hours. The service also receives 0.15 FTE funding from John Hunter Hospital and separate funding from the ACT Government for the Canberra clinic. The Wagga and Orange outreach clinics are funded via the Rural Doctors Network. The total FTE allocated to the Service by NSW Health's Paediatric Hospital Organisations is about 1.15 FTE.

7. Within the SCHN, Paediatric Rheumatology is the only truly networked service where clinicians provide clinical care, education, research and advocacy at both sites equally. No other service has even attempted to achieve this.
8. Currently myself and my VMO colleague who are the only permanent Medical Specialists are required to service an on call roster which is effectively a 1:1 ratio for the entire state of NSW.
9. The Service also has one FTE specialist nurse (Nurse Practitioner). However, it has no dedicated allied health support and is required to access wider hospital allied health services which are not always available due to shortfalls in those services.
10. In the 20 weeks since the start of 2024, approximately 950 patients were booked into outpatient clinics within the SCHN alone. There are currently approximately 50 new patients waiting to be seen by the Service but not yet booked into clinics due to a lack of availability. The Service receives an average of 8-10 new referrals per week.

C. Challenges facing the Service

11. There is an unmet need for patients who have not been able to access the Service due to the level of demand and lack of staff coverage.
12. The Service's lack of resources is the greatest barrier to appropriate provision of care. The Staff Specialists in the Service attend to approximately four times the number of patients per FTE (across both in- and out-patient services) compared to specialists working in other comparable paediatric subspecialty services in the SCHN, this is a situation which is not safely sustainable into the future.

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13. An initial report on the Service's sustainability, in terms of the workload of staff and the sufficiency of the FTE allocations, undertaken by the Agency for Clinical Innovation ('ACI') was published in May 2013. That report made recommendations that included an immediate significant increase in staffing numbers in the Service. These recommended staffing levels included 2.5 FTE Rheumatologists, 2.5 FTE Clinical Nurse Consultants, and dedicated Allied Health and support staff. This recommendation was not implemented despite endorsement from NSW Health and the SCHN. A copy of the report is annexed to this statement and marked "DSG-1".
14. I have recently assisted the ACI with the re-evaluation of the Service. The report is currently in before the SCHN and the Ministry of Health ('MoH') for comment. A copy of the draft report is annexed to this statement and marked "DSG-2". The draft report identifies that the staffing of the Service is less than 50% of what would be considered to be minimum safe staffing levels.
15. In the draft report, the ACI proposes a number of measures including:
 - a. Enhanced staffing to meet current needs, which would include 4 FTE rheumatologists, 3 FTE advanced practice nurses (nurse practitioner or clinical nurse consultants), dedicated allied health including 2.5 FTE physiotherapists, 1.5 FTE occupational therapists and 0.5 FTE ophthalmologists.
 - b. New models of care facilitated by Nurse Practitioner-led and allied health-led clinics with specialist skillsets. The draft report notes that in order to establish these models of care the Service would need additional funding for additional staff and to support staff in upskilling them.
 - c. The SCHN regaining paediatric rheumatology advanced trainee accreditation, with dedicated training positions.

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- d. NSW Health should consolidate services into a state-wide network with a centralised state-wide triage system and rural and regional outreach to improve equity of access.

16. A further challenge faced by the service is that a significant portion of its work undertaken involves the delivery outpatient clinics, which do not generate much activity based funding ('ABF') for hospitals.

D. Governance and Service Delivery Plan Strategies

17. There has been a lack of planning for the Service over many decades, which reflects an attitude within the SCHN and NSW Health where resource allocation has not always been transparent or clearly needs based and reactionary decision making seem to predominate. Data about workload, or clinical need is not well or uniformly collected and not openly available. Our service has overperformed over decades with very few resources hoping that this behaviour would be recognised and rewarded but in hindsight creating a series of crises which require reactionary funding decisions may have been more successful as it fits more readily with NSW Health and the SCHN pattern of behaviour.

18. Currently the Service has no key performance indicators ('KPIs'). I consider that the Service would benefit from KPIs as it would allow for the demonstration of increasing demand for the Service, and could assist in the formulation of a responsive plan to meet increased demand.

19. KPIs may further assist by illustrating how other Services similar to Paediatric Rheumatology, which do not generate a large amount of ABF, are meeting service expectations, are valuable for patients' needs, and are economically viable in their service delivery.

E. Training Opportunities for Medical Staff

20. Presently, the Service is not accredited by the Royal Australasian College of Physicians to provide a formal training program. I agree with the College that with the current staffing

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levels and workload, we would not be able to properly provide a formal training program even if we were accredited.

21. The lack of a training program impacts the ongoing viability of the Service, and means the Service cannot provide the necessary training opportunities for medical staff who wish to pursue this speciality.
22. This, compounded by the NSW Staff Specialist Award being among the lowest remuneration across Australia, has made it challenging for the Service to recruit and retain senior staff.
23. The Service also needs the SCHN's input in order to commence succession planning to recruit and train suitable replacement staff into the Service as many of the current staff are moving towards the latter stages of their careers. I am in my mid-50s, and the other staff specialist and the nurse practitioner are approaching acceptable retirement ages. As we are unable to bring in new clinicians and nurses presently due to staffing constraints and lack of training accreditation, I am concerned that this will soon lead to burnout among staff and a breakdown of the Service completely. This will affect the whole of NSW as the Service is the only one of its kind in the State.
24. Considering this situation as a whole, in my view there is a clear need for future planning at a Network and NSW state level. The Ministry of Health's own ACI has already provided an accepted and well informed plan for this process.

F. Network arrangement for paediatric services

25. There are some clear potential benefits to delivering paediatric services under a network structure; however, in my view, it has not been well implemented, and there have been lost opportunities.
26. The potential benefits of a network structure include that clinical services can be coordinated, collaboration can be encouraged and duplication of services can be avoided. In my opinion, SCHN, as it currently operates, has not managed to achieve these outcomes,

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with many services being duplicated across the two sites (CHW and SCH) and there being little in the way of coordinated service delivery across the Network. Unfortunately the

27. I also believe that all paediatric services should be planned state-wide. A statutory body, such as the Chief Paediatrician's office, should be responsible for mapping the clinical needs state-wide, and then should be responsible for making decisions about how and where primary, secondary, tertiary and quaternary services should be delivered, whether they be in the Tertiary Children's Hospitals, from other LHD's or as outreach services. This body needs to be given authority and back up from Government to make these decisions independently and rationally. Government should be excluded from interfering for its own political purposes.

Signature:



Name:

Davinder Singh - Crewal

Date:

9/6/2024