



28 November 2022

Mr Gerard Hayes General Secretary Health Services Union NSW/ACT/QLD Locked Bag 3 AUSTRALIA SQUARE NSW 1215

Re: Statewide Paediatric Pathology Service Feasibility Project

Dear Mr Hayes

Further to the correspondence we sent you in September 2022, our consultation meeting on 27 October 2022 and further letter of 31 October 2022 regarding the project we want to update you on outcomes from the project consultation sessions held throughout September and October 2022. We received input and feedback on how we can enhance and improve paediatric pathology services for patients, families and clinicians.

The response has been fantastic with over 400 stakeholders contributing, including staff from the Sydney Children's Hospitals Network and NSW Health Pathology (NSWHP), referring clinicians from across the state and families that access our services. High level themes include the importance of:

- Providing a dynamic **child-centred paediatric pathology service**, where patient outcomes drive the priorities, to ensure timely diagnosis and appropriate management for all children of NSW
- Paediatric pathology expertise recognition of the highly specialised services we provide and how this can be best supported into the future
- Providing integrated child and family centre care care closer to home where we can, and better access for collections, considering access for rural and regional children that require access to paediatric pathology
- Building a **sustainable paediatric pathology workforce** for the future, with a focus on succession planning, support for training and development
- Improving opportunities for research, research collaboration and data analytics
- Technology to standardise and enhance service delivery

What came through very clearly was the value of close clinical collaborations with the pathology expertise in delivering the best outcomes for patients and clinicians. We acknowledge the importance of this and are committed to continue providing comprehensive on-site pathology services at our specialist children's hospitals.

Based on the feedback provided we are also reviewing our referral pathways and how we can better connect with regional and rural clinicians. As outlined during the consultation sessions, there will be no reduction in services and we have not made any decisions about what paediatric pathology services might look like in the future.

A consultation summary has been developed (please see attached) and we have shared this with staff to further consider and prioritise what we heard during the consultation sessions. If you would like to provide feedback on the consultation summary, please send it by Friday 9 December 2022 to:

- <u>SCHN-CHW-DiagnosticServices@health.nsw.gov.au</u> or
- NSWPATH-SPPSProject@health.nsw.gov.au.





With regards to your recent request for additional representation on the Steering Committee we have comprehensive representation including staff with clinical and laboratory expertise. In addition, as part of our extensive consultation we have sought input from CHW Pathology and NSWHP staff. We appreciate your interest in the project and would be happy to meet with you to further discuss project progress.

We are committed to an open and transparent process to consider how we can enhance and improve paediatric pathology services that is informed by what is important to staff, referring clinicians, children, young people and families that access our services.

Yours sincerely

Cathryn Cox PSM Chief Executive

Sydney Children's Hospitals Network

Tracey McCosker
Chief Executive
NSW Health Pathology

Usuny Meloster





Statewide Paediatric Pathology Service – Feasibility Project Consultation Feedback

During September and October 2022, the Sydney Children's Hospital Network (SCHN) and NSW Health Pathology (NSWHP) held consultation sessions for staff and other key stakeholders to provide feedback on how we can enhance and improve paediatric pathology services. Over 400 people participated in these sessions including staff, families, referring clinicians and other stakeholders from across NSW with over 1,700 individual comments which we have coded and themed.

This document outlines what we heard in response to the consultation questions. What came through very clearly was the value of close clinical collaborations with the pathology expertise in delivering the best outcomes for patients and clinicians. We acknowledge the importance of this and are committed to continue providing comprehensive on-site pathology services at our specialist children's hospitals.

As stated during the consultation sessions, there will be no reduction in services and we have not made any decisions about what paediatric pathology services might look like in the future. We will use the information you have shared to further consider what is working well, where there are opportunities, and how we can best provide paediatric pathology services into the future.

High Level Themes

During the consultation sessions, high level themes included the importance of:

- Providing a dynamic child-centred paediatric pathology service, where patient outcomes drive the
 priorities, to ensure timely diagnosis and appropriate management for all children of NSW
- Paediatric pathology expertise recognition of the highly specialised services we provide and how this can be best supported into the future
- Providing integrated child and family centre care care closer to home where appropriate, better
 access for collections, and improved access for rural and regional children who require access to
 paediatric pathology
- Building a **sustainable paediatric pathology workforce** for the future, with a focus on succession planning, support for training and development
- Improving opportunities for research, research collaboration and data analytics
- Technology to standardise and enhance service delivery



Image - word cloud of themes from the consultation sessions





Consultation Response Summary – SCHN and NSWHP Staff

What is working well?

- The paediatric pathology expertise, leadership, and specialised knowledge is highly regarded
- Strong clinical collaboration and interaction between pathology and clinical services and support for clinical liaison and the provision of advice e.g. via multi-disciplinary teams (MDTs) is highly valued and acknowledged as critical to exemplary patient care
- For NSWHP, paediatric diagnostic skills in non-specialist paediatric services
- Services at some sites are child and family centred, responsive to the needs of paediatric patients, and paediatric referrals are prioritised
- Effective working relationships and support within the laboratories, between the services and with referring clinicians, this extends to opportunities for shared clinical education and research collaboration
- Effective and efficient services and structures were identified as strengths with the ability to develop/onboard new tests, and synergies between laboratories and clinical services
- For CHW Pathology (CHWP), the proximity to services and having laboratories adjacent to clinical services
- Where established referral networks and access to expertise exist in regional areas this works well
- For NSWHP co-location of adult and paediatric pathology services facilitates the sharing of knowledge, experience and resources as well as the effective transition of patients
- · Statewide collaboration for paediatric pathology

What could we improve?

- Equity of access to paediatric pathology in regional areas
- There is a high demand for paediatric pathology advice and support although no formal network or funding for its provision. It relies on existing relationships and good will.
- Improve access to coordinated expertise and leveraging specialist services
- Invest in paediatric pathology capability including:
 - Additional staffing (pathologists, scientists and technical staff) to support enhancement of services
 - Increased education, training and development
 - Funding and resources to improve and expand current services including genetics and emerging areas of demand e.g. Campbelltown, ensure child friendly collection services and provide after-hours services e.g. Anatomical Pathology (AP)
 - Increase the number of paediatric haematologists
 - Ability to develop and implement new tests
- Improve communication/engagement of paediatric pathology services available and how to access them
- Ensure integration of services and result delivery
- For NSWHP, ensuring a continuum of care, particularly as children transition to adulthood
- Collections could be more child and family centred consider collection times and flexibility e.g. outside
 school hours and weekends, collections closer to home where possible and child friendly amenities,
 sedation pathways (as currently being developed at CHW)
- For NSWHP greater communication, engagement and collaboration between services, and with paediatric units, and between NSW and ACT
- For CHWP, a dedicated Centralised Specimen Reception to improve efficiencies
- Address the separate research governance requirements and processes that currently impede timely research collaboration
- Provide an integrated state-wide LIMS system (noting this is a key priority for the Fusion Program) that:
 - Improves access to patient results regardless of location and/or tests across NSW
 - Identifies paediatric specimens
 - Streamlines and standardises patient reports and ordering
 - Simplifies data extracts e.g. single data lake





- Facilitates enhanced referral pathways
- Supports digital reporting
- Enhanced support from IT application specialists with expertise in paediatric pathology
- Improve turnaround times (TATs)
- Provide education to referrers as to the best testing pathways for their patients
- Improve systems and processes including:
 - Better referral and escalation processes
 - Increase automation
 - Streamline current manual and time-consuming processes for specimen transfer
 - Reduce wastage by combined currently separate blood ordering processes
 - For CHWP improved billing processes
- Harmonise paediatric reference ranges across the state and LIS capability for reporting based on age
- Support digital pathology e.g. AP and haematology
- Inclusion of CHWP specimens in NSWHP's tracking system
- Greater alignment between pathology and LHD referral pathways
- Include specialised paediatric pathology training of registrars (including perinatal training for AP), provide cross training opportunities for clinicians, support increased paediatric collections training
- Explore a specific paediatric scope of practice to recognise existing staff expertise and skills

Where are service gaps?

- Provision of integrated and coordinated service delivery across the state including with national programs and other jurisdictions e.g. ACT
- Ensuring greater consistency and equity of access to paediatric pathology services for regional patients
 and their families, and support regional collections, while at the same time, ensuring expertise/capacity to
 support highly specialised testing
- Enhance services to improve the patient experience:
 - Virtual MDT approach for complex cases
 - Local genetic testing
 - Statewide morphology services e.g. Cellavision, AP
 - Paediatric pathology collections including access to and amenity
- Inclusion of CHW testing catalogue in the NSWHP statewide test catalogue
- Specialised paediatric pathology education and training opportunities including paediatric collections
- Future proof service with workforce enhancements and growth to support a sustainable specialised future
 workforce with a focus on training to address shortages of specialist paediatric pathology staff and
 succession planning
- Research:
 - Embedding research within the service
 - Current research pathways processes could be streamlined to enhance research engagement and collaboration
- Embedding data analytics in every day practice and using data to drive improvements in service and research
- Statewide processes for assessing new technology
- Greater investment in genetic pathology as well as functional genomic testing to supplement nonconfirmatory genomic results
- Enhanced bioinformatic services for genomic testing
- Enhanced capacity for translational diagnostics bringing tests from the research lab into the diagnostic arena. System for research and development embedded in services
- Capacity to provide services for tailored personalised medicine, including implementation of broader range of testing to keep up with clinical changes in recommended testing and monitoring of patients. As well as improved integration and availability of services where there are potential new therapies e.g. gene therapy or precision medicines.





- Accommodating specialised or niche tests that will be developed in the future
- Some discipline specific gaps were raised including:
 - Out of hours Microbiology testing (e.g. 24 hour blood culture and sub identification)
 - Need to support enhanced paediatric micro testing for patients external to CHW
 - Rapid molecular pathology identification of infectious agents
 - Sequencing of infectious agents for better identification, and source control
 - Enhanced Endocrine LSMS testing
 - Cancer genetics Personalised testing, Pharmacogenomics, cancer genetic testing, RNA diagnostic services, NGS sequencing, Disease monitoring methods
 - Ultra-rapid Acute Care whole genome sequencing for ICU patients
 - Broader range of haematology testing including Inhibitors, and platelet function investigations
 - Broader implementation of digital haematology morphology for provide faster TAT for external films.
 - Increased options for minimally invasive perinatal post-mortem examinations
 - Implementation of digital AP in the future
 - Enhanced metabolomics and proteomics

For future services what are key outcomes we want?

- Improved patient outcomes, and child, family and staff experiences
- Child and family focused care:
 - equitable access to paediatric pathology expertise regardless of location
 - timely and accurate results with easy visibility across all NSW public hospitals
 - convenient collections and child friendly collection spaces with highly trained paediatric collectors
 - service delivery informed by referring clinician, patient and stakeholder priorities
 - flexible and adaptable service that meets patient needs
- A highly skilled and sufficiently resourced paediatric pathology workforce
- Better pathways for referral and access to expertise and support for result interpretation e.g. online tools
 and opportunities for collaboration across all sites, development of a virtual network for expertise and
 access for rural and regional sites
- Improved systems and processes:
 - fast, accurate and timely results with improved TATs
 - electronic referrals and results
 - improved patient timeliness to diagnosis and reduction of patient diagnostic journey through provision of expert paediatric pathology advice on testing pathways
 - enhanced access to MDTs with pathologists, scientists and clinicians to deliver excellence in diagnostic services to the patients
- A coordinated approach to research (translational), new technology and service improvements
- Technology enabled service delivery including enhanced use of POCT, digital pathology, a single IT system for streamlined access to patient results/reports regardless of their location, improved referrals and management of specimens and sendaways.

What future models would help us deliver the best paediatric pathology services across the state?

- An integrated statewide paediatric pathology service that retains a focus on the value and expertise of paediatric pathology capability and capacity, and recognition and support for sub-specialisation
- Accessible services to support service provision closer to home for children and their families across NSW
- Clear pathways to specialist expertise e.g. virtual network of care and/or access to advice for significant pathology results
- Investment in paediatric pathology services e.g. infrastructure, capacity to respond to new and emerging tests and therapies and provide after-hours care
- Ensuring that we leverage current paediatric pathology skills and expertise





- Leverage and enhance existing relationships between the services and clinical liaison between disciplines e.g. Clinical Streams, Genetic Services
- Single IT system to support reporting, referrals and sendaways, statewide digital morphology
- Some models suggested by participants in the consultation sessions included:
 - CHWP retaining its specialist status and maintain their own laboratory with a more formalised relationship and collaboration for CHWP and NSWHP
 - Co-located adult and paediatric pathology services
 - Hub(s) and spoke(s) model with specialist centres and the integration of core services with routine diagnostics, with support for supervision
 - Centralised service delivery and/or centres of excellence
 - Provision of outreach clinics and support for upskilling in paediatric pathology
 - Single paediatric pathology service model with CHWP integrated into NSWHP while maintaining local clinical relationships
 - Integrated services harmonised/rationalised around clinical needs and expertise in various locations
 - Paediatric specialties and the provision of specialist interpretation and advice
 - Utilisation of technologies (e.g. digital morphology) to provide patients in district, regional and remote hospitals more equitable access to paediatric pathology services
- Focus on research and development, embedding translational research capability within service areas
- Improve governance structures, provide multiple sites for testing to improve patient access e.g. hub(s) and spoke(s) model, and improved integration
- Increased specialist education and training for paediatric staff, including collection staff
- Succession planning and workforce enhancements to address current shortages of specialist paediatric pathology staff and to support a sustainable specialised future workforce
- Dedicated spaces for paediatric laboratories and collections

Other considerations?

- Improving engagement/awareness of paediatric pathology services for users
- Ensuring paediatric pathology expertise and investment is not lost in any future model(s)
- Exploring governance and funding requirements for future service model/s
- Greater collaboration and interaction between CHWP and NSWHP
- Ensuring dedicated spaces for paediatrics
- Investing in regional paediatric capabilities
- Ensuring any future model(s) is informed by consumer and stakeholder priorities
- Greater use of POCT and digital pathology
- Ensuring the services attract, upskill and retain specialist paediatric pathology capabilities
- Exploring concerns raised about the impact to TATs and/or Rights of Private Practice through changes to service delivery
- Maintaining existing relationships irrespective of where services are delivered





Consultation Response Summary – Local Health Districts and Referring Clinician Survey

What is working well?

- Recognised expertise of laboratory and clinical staff with a diverse range of tests and expertise e.g. paediatric blood collections, genetics services and responsiveness to clinician requests
- Efficient service delivery and provision of advice
- Pathology staff were acknowledged as approachable, friendly and helpful, there are strong clinical relationships and good engagement e.g. MDT meetings, on-site access and in the case of (former) SEALS laboratory, the provision of tertiary expertise that covers all major subspecialties
- Where available, skilled paediatric blood collection works very well Turnaround times through the week, prioritisation of paediatric samples and some access to results depending on location of the test e.g. works well if collected in hospital
- The use of POCT blood gas machines in ED and neonatal units
- The fact that patients do not have to pay for paediatric pathology services
- Statewide test catalogue

What could we improve?

- Access to paediatric expertise across NSW including interpretation of paediatric blood samples
- Better integration and access to results and clinician notification e.g. push notifications and ability for interstate clinicians to access cross border patient results
- Genetics ordering and consent using online processes
- Electronic ordering of tests, result notification to clinician emails and communication with clinicians about results, particularly those without access to the eMR
- Improve TATs particularly on the weekend and/or include estimated processing and delivery times
- Enhanced specimen tracking for genetic samples
- Improve information about what is offered in the test catalogues and what will be accepted by
 laboratories. Current disparity between volume of blood required for neonates and the size of the patient
 not being recognised by laboratory staff leading to requests for repeat collections
- Improve collector education and training about paediatric blood collection for different age groups, extend
 collection centre operating hours and increase the availability of specialised collectors/service to collect
 bloods including neonates (heel and finger pricks) and challenging populations e.g. children with severe
 delays or autism who would be combative and difficult to access
- Specialised paediatric testing for some metabolic and genetic tests currently sent outside the organisation
- Broader access to testing as appropriate for level of clinical care provided on site
- Harmonise paediatric reference ranges
- Address understaffing and inexperience, particularly in AP
- Increase the availability of POCT
- Streamline processes for complex testing particularly where there is inter lab transfers and standardise lab and test details including Medicare billing details to avoid confusion (Noting NSWHP's statewide test catalogue is currently available for use)
- Shared understanding of priority of specimen for testing
- Improve and streamline research processes to enhance collaboration

What are key outcomes we want?

 High quality integrated paediatric pathology services across NSW with access to paediatric expertise when needed





- Greater collaboration between clinicians and pathology e.g. advice about volumes in tubes, transport requirements
- Timely and transparent access to patient results
- Highly skilled paediatric collectors and enhanced paediatric collections methods e.g. finger or heel pricks and clear instructions on blood clots in tubes to minimise recollects
- Availability of specialist tests closer to home
- Continued access to Medicare funded pathology services to minimise costs to patients and their families
- Dedicated paediatric pathology investment and services to support paediatric hospitals
- Clearer advice and information pathways to specialist paediatric expertise

What future models would help us deliver the best paediatric pathology services across the state?

- Broader community access to collection centres, with capacity to cater to vulnerable, disadvantaged and non-English speaking populations
- Enhanced testing capability and processes including:
 - Coordination of testing around processing of specific tests and provision of after-hours support to EDs
 - Support for state of the art testing e.g. paediatric oncology
 - In house urine and blood cultures and ammonia or fast TATs for these tests if sendaways
 - Personalised testing for all children across the state
 - Electronic requests/ordering for outpatients
- Enhanced integration and communication between clinicians and pathology to improve local service delivery matched to LHD priorities
- Enhanced IT service and electronic access to patient results
- Pool of highly trained paediatric collectors, child friendly collection centres and more information about sample volumes, days tests are run and consistent paediatric reference ranges
- Improved governance structures varying perspectives including: Statewide but centralised specialised paediatric pathology service to maintain specialist expertise versus an integrated on-site service versus state wide expertise and services on each tertiary site in line with clinical care and paediatric network

Other considerations?

- Rural paediatric pathology service and expertise to ensure service delivery closer to home for patients
 and their families e.g. mapping services available by: LHD and level of paediatric unit and making that
 available to staff across all LHDs
- Processing of time critical samples in rural areas and enhancing access to and processing of culture results for children
- Investment in emerging technologies and tests e.g. molecular tests and metagenomics, MRD, serum
 neurofilament light chain assay and JC viral serology to increase access (outside of research laboratories)
 and equipment that can manage paediatric and neonatal samples and volumes
- Culturally safe and welcoming collection centres
- Maintaining individual site strengths and capacity around paediatric pathology service delivery rather than centralising services
- Improved engagement and liaison with NSWHP and Red Cross to minimise duplicate testing





Consultation Response Summary - Families and Consumers

How could we improve paediatric pathology?

- Patients with highly complex needs and when difficult to collect blood consider:
 - Size of vials used able to take smaller vials and do a FBC on 0.5ml blood
 - Need to collect to meet needs of the child
- Access to results and diagnosis of rare diseases:
 - Family access to pathology results would be useful when seeing multiple clinicians
 - Pathology wait times can be a time of anxiety for families especially collections
 - Improvements for collections and limit retesting requirements
 - Align collections with clinic days/public holidays
- Physical design of labs and waiting areas e.g. child in a wheelchair and accessibility:
 - Training for children that are non-verbal and increase awareness
 - Access to collections in wards currently available at CHWP although only once a day in the morning
- The CHWP collections team are very good, and working with families on strategies to help children overcome a fear of needles would be helpful

If regular monitoring is required would families prefer to travel or have pathology services provided closer to home?

- Mixture of both e.g. surveillance closer to home
- Increased training for regional areas hub and spoke