The Paediatric Society of New Zealand
Te Kāhui Mātai Arotamariki o Aotearoa

Annual report

2024

Ōtākou Whakaihu Waka
UNIVERSITY OF OTAGO

Te Hunga Aroturuki Mate Tamariki
New Zealand Paediatric Surveillance Unit

New Zealand Paediatric Surveillance Unit

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PREFACE: NEW ZEALAND PAEDIATRIC SURVEILLANCE UNIT

The New Zealand Paediatric Surveillance Unit, Te Hunga Aroturuki Mate Tamariki, (NZPSU) is pleased to present this annual report.

The NZPSU undertakes surveillance of acute flaccid paralysis (AFP) for Manatū Hauora (Ministry of Health) as part of a national programme to certify elimination of poliomyelitis. The data collected are reviewed by the National Certification Committee for the Eradication of Poliomyelitis (NCCEP), and contribute to the Global Polio Eradication Initiative in association with the World Health Organization and other partners. This report covers acute flaccid paralysis surveillance from 1 July 2023 to 30 June 2024.

In addition to AFP surveillance, the NZPSU undertakes surveillance of a number of other rare childhood conditions that have high impact for individuals or health service delivery through reporting paediatricians via the monthly survey. These conditions may be included at the request of Manatū Hauora or approved by the Scientific Review Panel (SRP) following a request from paediatricians with a clinical research interest. For these conditions, hen a case is reported to the NZPSU, the principal investigator is notified and is responsible for requesting additional from the reporting paediatrician through a questionnaire approved by the SRP. Unless otherwise stated, this report is for the 2023 calendar year.

The ongoing success of the NZPSU is relies on the voluntary participation of busy paediatricians who have taken the time to notify relevant cases and provide the additional information requested. We acknowledge and appreciate ongoing funding from Manatū Hauora.

Professor Peter McIntyre, Co-director

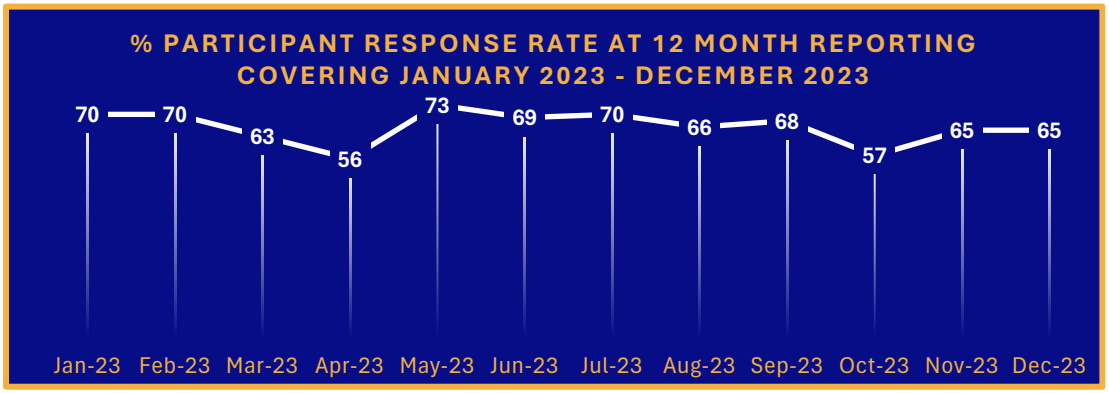
Professor Benjamin Wheeler, Co-director

Mrs Mel O'Brien, Administrator

NZPSU SURVEILLANCE ACTIVITIES IN 2023

In 2023, there were between 262–303 clinicians participating in the surveillance programme with an average monthly response rate of 66% (Fig 1). The NZPSU has ensured that there is at least one participating paediatrician in each district of Te Whatu Ora and encourages participation through regular communication with paediatricians and presentations at relevant conferences and scientific meetings.

Fig 1: Monthly survey response rate from active Paediatricians on NZPSU mailing list



From 1 January 2023–31 December 2023 the NZPSU monitored eight rare childhood conditions (Table 1). Some of the protocols and questionnaires used were adapted from those used by the Australian Paediatric Surveillance Unit or other INOPSU members

Table 1: Conditions under surveillance in 2023

Condition	Surveillance started	Surveillance ending	Principal Investigator(s)
Acute flaccid paralysis	October 1997	Ongoing	Dr Mavis Duncanson Professor Peter McIntyre Professor Ben Wheeler
Congenital rubella syndrome	January 1998	Ongoing	Dr Mavis Duncanson Professor Peter McIntyre Professor Ben Wheeler
Perinatal HIV exposure	January 1998	Ongoing	Dr Sue McAllister Ashleigh de Gouw
Serious paediatric adverse drug reactions	May 2008	Ongoing	Prof Michael Tatley Ass Prof David Reith Prof Keith Grimwood
Potential prenatal exposure to syphilis	April 2018	Ongoing	Prof Tony Walls Dr Leeyan Gilmour
Multi-inflammatory syndrome - SARS-CoV-2 infection (hospitalised)	May 2020	Ended September 2023	Prof Stuart Dalziel Dr Mavis Duncanson
Acute self-harm seen by Paediatrician	June 2020	December 2024	Dr Sarah Fortune Dr Gabrielle McDonald
Severe acute hepatitis	April 2022	Ongoing	Dr Helen Evans Prof Andrew Day

Acute Flaccid Paralysis

Dr Mavis Duncanson
(until March 2024)

Professor Peter McIntyre
(from March 2024)

Professor Ben Wheeler
(from December 2016)

Ongoing study started October 1997

Introduction

Acute flaccid paralysis (AFP) is a clinical description of sudden onset of muscle weakness without any spasticity or rigidity. These symptoms are consistent with those observed clinically in polio. The most common medical conditions resulting in AFP in Aotearoa are Guillain-Barré syndrome and Transverse Myelitis.

As part of the global initiative to eradicate polio, countries in the Western Pacific region of the World Health Organization (WHO) confirm the absence of poliomyelitis through active surveillance that captures an annual incidence of acute flaccid paralysis (AFP), not due to poliomyelitis, of at least one case per 100,000 children aged under 15 years. It is also a WHO expectation that at least 80% of cases of AFP have two stool samples taken at least 24 hours apart, within 14 days of onset, which test negative for wild polio virus in a WHO-accredited laboratory.

Immediate notification to the NZPSU by email or phone of all cases of AFP is required to ensure that the necessary stool containers are dispatched in time to the notifying paediatrician.

Key Results July 2023- June 2024

There were six cases notified to the NZPSU with onset of AFP from 1 July 2023 until 30 June 2024. Information has been obtained on all AFP cases, including follow-up information two months after diagnosis:

- 5 were from the North Island
- 2 females, 4 males
- Age range 1 to 13 years
- 4 children were fully vaccinated for age against polio, one was unvaccinated and one had unknown vaccination status
- Adequate stool samples (two samples at least 24 hours apart within 14 days of illness onset) were obtained for all cases (100%)
- All cases were discarded as non-polio by the National Certification Committee for the Eradication of Polio (NCCEP)
- The AFP incidence rate was 0.6 cases per 100,000 children aged under 15 years
- The NZPSU has notified the Western Pacific Regional Office of the World Health Organization of these findings

The AFP rate expected by WHO in a country without endemic polio is one case of acute flaccid paralysis per 100,000 age-specific person-years. This rate was not met in the 12 months to 30 June 2023, with 0.6 cases per 100,000 children aged 0–14 years. This followed a very high detection rate of 2.2 cases per 100,000 children aged 0–14 years from 1 July 2022 to 30 June 2023. The stool sample collection is very pleasing and the NZPSU will continue efforts to maintain a high level of testing.

Congenital Rubella Syndrome (CRS)

Dr Mavis Duncanson
(until March 2024)

Professor Peter McIntyre
(from March 2024)

Professor Ben Wheeler
(from March 2024)

Ongoing study started January 1998

There have been no cases of congenital rubella reported in newborn infants throughout the surveillance period. There was one notification of a child aged 5–9 years, in 1998. This remains the only case that has been reported to the NZPSU.

Perinatal HIV Exposure

Dr Sue McAllister

Ashleigh de Gouw

Ongoing Study started January 1998

Study Objectives

To determine the extent and outcome of recognised perinatal exposure to HIV infection in Aotearoa.

Key Results for 2023

In 2023 there were 6 infants reported to have been born in Aotearoa to women infected with HIV who were diagnosed prior to or during their pregnancy, and one infant born to a woman who was diagnosed after their pregnancy. Information has been received on all of these infants.

Of these 7:

- Four were born in Northland, 1 in Auckland, 1 in Wellington, and 1 in Christchurch.

- One was born to a mother whose HIV had been diagnosed before their pregnancy, 5 were diagnosed during their pregnancy and one diagnosed after their pregnancy.
- Three of the mothers were of Asian ethnicity, 2 Māori, 1 African, and 1 European.
- Six of the mothers were given antiretroviral treatment during pregnancy; 5 gave birth by caesarean section and 2 gave birth vaginally; two of the babies were breastfed.

One of the children is believed to be infected with HIV (although most are still awaiting confirmation).

Serious Paediatric Adverse Drug Reactions (ADR)

Professor David Reith

Professor Michael Tatley

Professor Keith Grimwood

Ongoing study started August 2007.

Study Objectives:

1. To gain a greater understanding of serious paediatric adverse drug reactions (ADRs) in children below the age of 16 years.
2. To determine the level to which the NZPSU active surveillance method captures information about serious paediatric ADR's not currently captured by an existing passive spontaneous reporting system (Centre for Reactions Monitoring, CARM) operated by the New Zealand Pharmacovigilance Centre (NZPhvC).

Key Results for period January 2023 – July 2024

NZPSU:

Over the one-year period January 2023 to December 2023 there were six reports of serious ADR to the NZPSU.

There were three reports in the time period January to June 2024. One of the reports involved sodium valproate, but there were no other details.

CARM Database:

The data cover the period 1 January 2023 to end July 2024. Report is for ages 17 or less (note this will be an undercount if the age was not provided in the report). The data exclude vaccine reports.

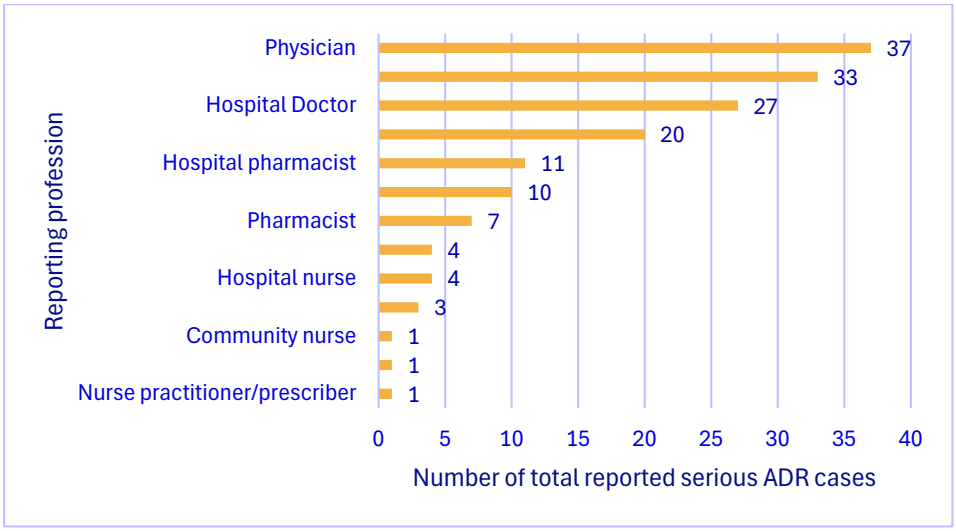
There were 198 reports total, of which 159 were serious.

Of the serious reports, the majority were reported by health professionals (Figure 2), with ;

- 37 (23.3%) reported by a physician
- 27 (17.0%) by a hospital doctor
- 14 (8.8%) by a nurse, 11 (6.9%) by a hospital pharmacist
- 7 (4.4%) by a community pharmacist

- 4 (2.5%) by a GP
    - There were 33 (20.8%) reports by a consumer or non-healthcare practitioner.

Figure 2: Characteristics of the reporter:



The ethnicity data was incomplete with a high proportion of unreported or “don’t know” for ethnicity (Figure 3).

For 41 (25.8%) reports the medicine was an antibiotic (Figure 4). There were three reports for nusinersen, which could reflect its recent introduction. The remaining reports were for medicines with known risks of serious adverse reactions.

Figure 3: Ethnicity:

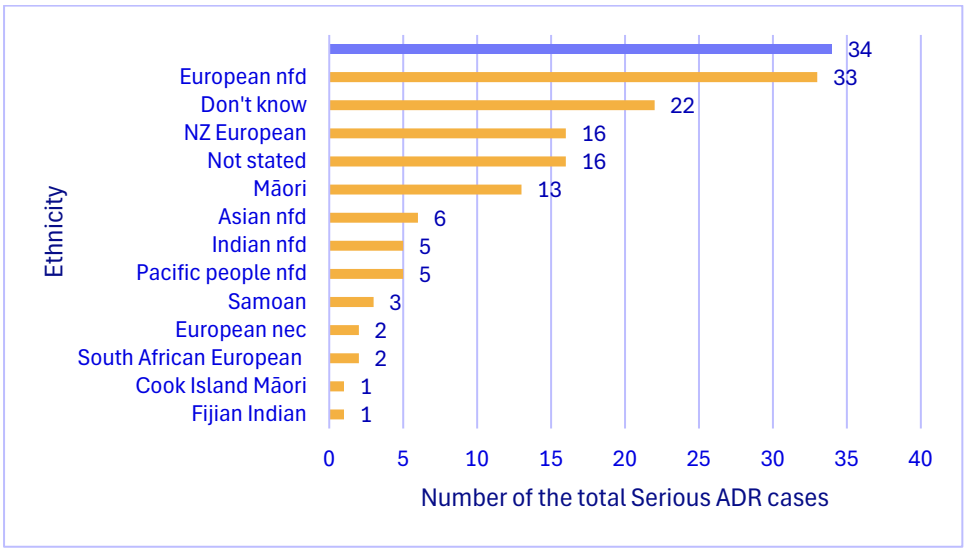
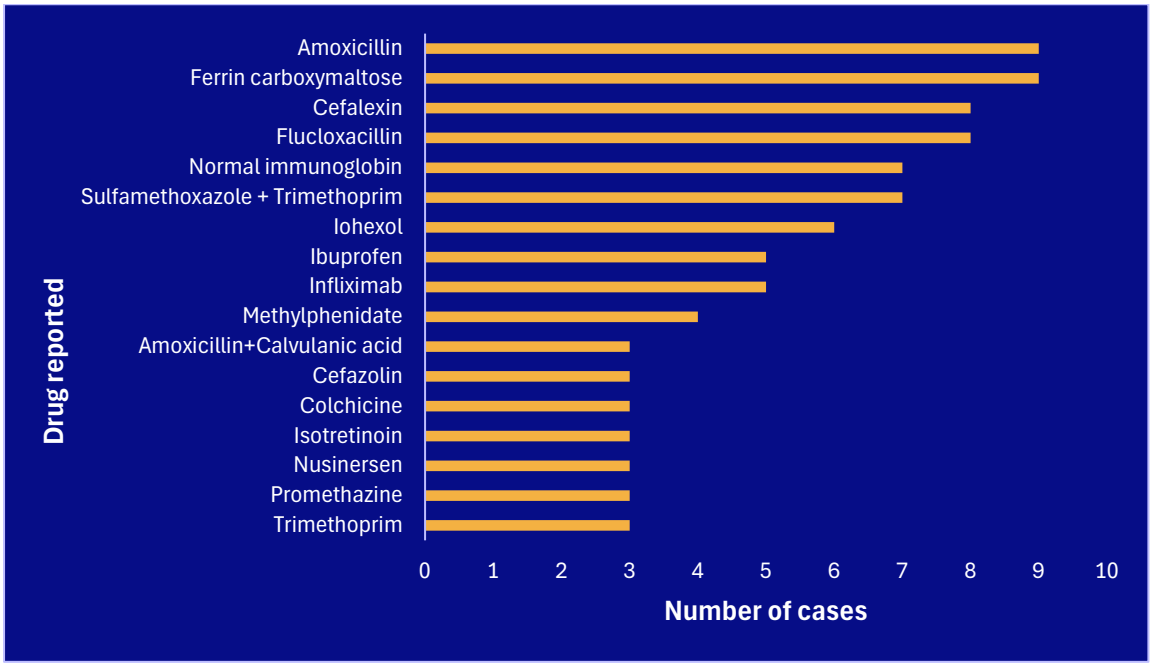
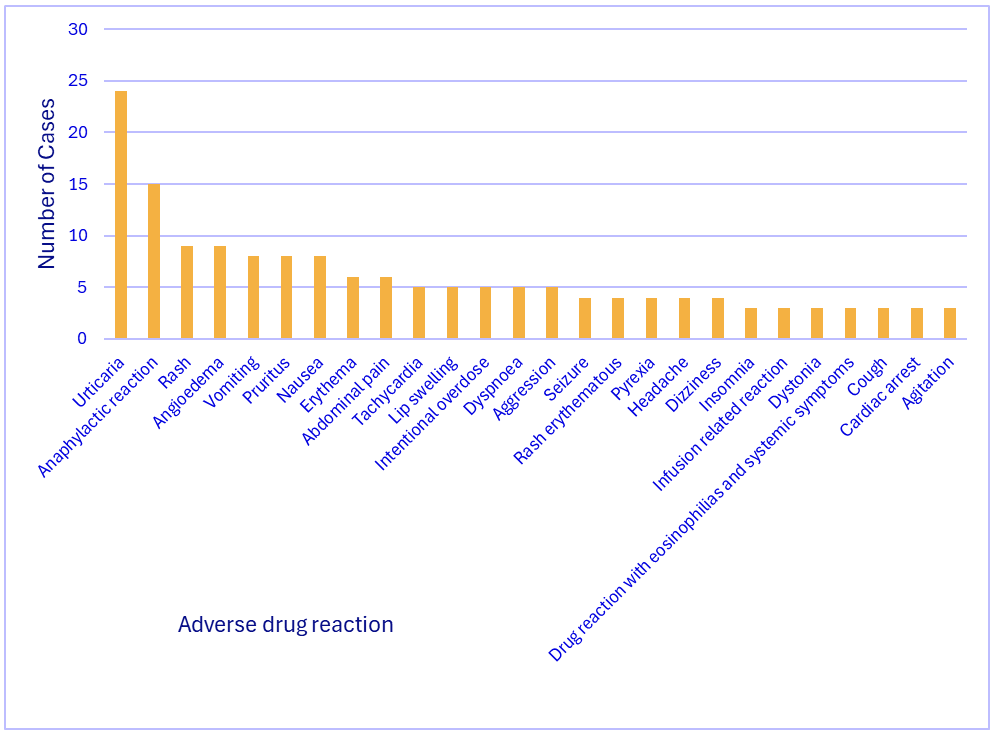


Figure 4: Most common medicines reported:



The most common events were allergic reactions: urticaria in 24 (15.1%), anaphylactic reaction in 15 (9.4%) and angioedema in 9 (5.7%) (Figure 5). Nausea was reported in 8 (5.0%), abdominal pain in 8 (5.0%) and vomiting in 8 (5.0%). Over the same time period, CARM had 2 reports from the NZPSU, including one that was notified but doesn't appear to have been reported to CARM.

Figure 5: Most common reactions reported:



Conclusions:

Of the reports of serious ADR to the NZPSU, follow-up reporting to CARM was incomplete. However, a much greater number of serious ADRs were reported directly to CARM.

Potential Prenatal Exposure to Syphilis

Professor Tony Walls

Dr Leeyan Gilmour

Ongoing study commenced April 2018

Study Objectives:

To collect incidence data and identify cases of possible mother to child transmission of syphilis. In addition to identifying confirmed or probable cases of congenital syphilis (as defined by the 2018 Ministry of Health Congenital Syphilis case definition), we also captured data relating to cases of "potential" transmission of syphilis; that is, cases where maternal syphilis serology tested positive, but infection of the infant may not have occurred.

Key results for 2023:

- 21 infants born in 2023 were reported
    - The previous years of the study period found one infant born in 2017, 13 in 2018, 11 in 2019, 22 in 2020, 15 in 2021 and 24 in 2022
- Of the 21 cases born in 2023 with available data, 5 infants had findings consistent with congenital syphilis, with 1 confirmed cases and 4 probable cases. The remaining 16 cases had antenatal exposure to syphilis but were not diagnosed with congenital syphilis.
    - Regarding confirmed and probable cases, the previous years of the study period found one infant born in 2017, 4 in 2018, 5 in 2019, 7 in 2020, 3 in 2021 and 7 in 2022.
- All but 1 of the 21 cases from 2023 arose from the North Island of Aotearoa, with 7 cases notified from the Waikato region, 4 cases from the Auckland region, 3 cases from the Counties Manukau region, and one each from the Northland, Waitemata, Bay of Plenty, Tairawhiti, MidCentral, Hutt Valley and Nelson Marlborough regions.
- Of the 21 cases from 2023, 11 of the women were of Māori descent, 5 of Pacific Peoples, 1 NZ European, 2 of Asian ethnicity, and 1 each of Latin/Hispanic ethnicity, and unknown ethnicity.
- Of the 5 infants with confirmed or probable congenital syphilis born in 2022:
    - One infant died at day 4 of life from severe hydrops fetalis
    - Gestational age of the 5 infected infants were 31+3, 33, 33, 36 and 37 week
    - 3 infants had clinical signs, which included hepatosplenomegaly, anaemia, jaundice/hepatitis, CNS/eye signs, and thrombocytopaenia

- 4 had bone changes visible on X-ray (the other did not receive X-rays), 2 had CSF findings (elevated protein, and/or reactive VDRL), 1 had normal CSF findings, and CSF tests were not done in 2 infants
- 1 had direct identification of treponeme by PCR from ascitic fluid (baby with hydrops)
- None of the women had effective syphilis treatment during pregnancy:
  - 3 did not receive syphilis testing during pregnancy
  - 2 did not receive syphilis treatment in a timely manner
- All of the probable and confirmed cases were treated appropriately with penicillin.

Multi-inflammatory syndrome in children - SARS-CoV-2 infection

Professor Stuart Dalziel

Dr Amanda Taylor

Study started May 2020 and ended September 2023.

This study was supported by an expert group including:

Professor Tony Walls

Assoc. Professor Emma Best

Dr Mavis Duncanson

Study Objectives

To describe the impact of the COVID-19 pandemic on children and young people in Aotearoa through identifying paediatric cases with severe symptoms requiring hospitalisation and describing the clinical course for these children.

In 2022 the case definition of previous surveillance for confirmed or probable SARS-CoV-2 infection (COVID-19) in children was amended to identify cases requiring ICU level care and children with a multi-inflammatory syndrome. Cases to June 2022 have been previously reported.

Surveillance was discontinued in September 2023, taking into account the low incidence of MIS-C in Aotearoa and internationally.

Key Results

Results to June 2022 have been previously reported;

- From July 2022 to September 2023 the NZPSU received reports of 22 children hospitalised with SARS-CoV-2 infection who required intensive care or who were diagnosed with a multi-inflammatory syndrome

- Most (16) were hospitalised because of clinical concerns due to SARS-CoV-2 (COVID-19) positivity or due to SARS-CoV-2 (COVID-19) like symptoms and six were hospitalised because of clinical concerns for another reason and found to be SARS-CoV-2 (COVID-19) positive
- 7 children were reported to have a pre-existing comorbidity or chronic condition
- 19 children required ICU level care and 6 were diagnosed with MIS-C (of whom 3 required ICU level care)
- There were 8 children in the Northern region, 2 in Manawa Taki, 6 in Central region and 6 in Te Waipounamu
- The age range was from birth to 15 years
    - 7 aged under one year
    - 5 aged 1–4 years
    - 3 aged 5–9 years
    - 7 aged 10–15 years
- There were 16 males and 6 females
- Over one-third were tamariki Māori and almost one-fifth were Pacific children (prioritised ethnicity)
    - 8 tamariki Māori
    - 4 Pacific children
    - <4 Asian children
    - <4 Middle Eastern, Latin American or African children
    - 6 European/Other children
- At the time of reporting
    - 13 children had been discharged home
    - 5 children were still in hospital
    - 4 children had diedThe aim of this project was to describe the NZ incidence of MIS-C in children less than 15 years of age, following the first sustained wave of SARS-CoV-2 transmission in Aotearoa with the Omicron variant.

Acute Self-Harm seen by Paediatrician

Dr Sarah Fortune

Dr Gabrielle McDonald

Linda Hobbs

Ongoing Study started June 2020

Study Objectives:

Surveillance by NZPSU is part of a broader research study.

The primary objectives of this study are:

1) To establish multi-centre sentinel surveillance of SH patients at four large public hospitals, as per the recommended WHO practice guidelines on sentinel surveillance for self-harm
2) To establish and test robust data collection methods as per the recommended WHO practice guidelines on sentinel surveillance for self-harm
3) Identify the epidemiology of current presentations for SH or suicidal ideation in terms of age, gender, ethnicity, methods of SH, alcohol misuse, prior history of SH, intention to die, exposure to suicide, mental health assessments and discharge outcome
4) Identify patterns of repetition of non-fatal SH
5) Undertake surveillance of self-harm among children and adolescents under 15 years of age via the NZ Paediatric Surveillance Unit (NZPSU)

Key Results for 2023

This ongoing four-year study is collecting sensitive data that will be reported on completion of the study in 2024. In 2023 there were 52 reports to the NZPSU of self-harm seen by a paediatrician in under-15-year-olds.

Severe Acute Hepatitis

Dr Helen Evans

Professor Andrew Day

Ongoing Study started April 2022

Study Objectives:

This is a rapid surveillance study in response to an emerging condition. The UK reported more cases than expected of severe acute hepatitis of unknown origin in April 2022, and hundreds of cases have since been reported in multiple countries. A small cluster of up to 15 cases of acute hepatitis was detected in New Zealand children between May and September 2021. The study seeks to answer the research question: In New Zealand, what features are associated with acute hepatitis with aspartate transaminase (AST) or alanine transaminase (ALT) over 300 UL in children aged under 17 years, presenting after 1 January 2021.

Case definition:

An acute hepatitis, in a child aged 0–16 years (inclusive), with discrete or acute onset of symptoms (e.g. fever, jaundice, abdominal pain, fatigue, loss of appetite, dark urine, pale coloured stools, itchy skin, muscle or joint pain, nausea or vomiting); AND elevated serum transaminase (ALT) levels (>300U/L).

Key Results for 2023

There were 23 cases of severe acute hepatitis reported to the NZPSU in 2023. Study report not received in time for the Annual report.

REPORTING PERIOD NZPSU SURVEILLANCE PUBLICATIONS[1]

Sandy JL, Nunez C, Wheeler BJ, et al. Prevalence and characteristics of paediatric X-linked hypophosphataemia in Australia and New Zealand: Results from the Australian and the New Zealand Paediatric Surveillance Units survey. *Bone* 2023;173:116791. https://doi.org/10.1016/j.bone.2023.116791

Taylor A, Duncanson M, Mitchelson B, Nuthall G, Voss L, Walls T, et al. Multisystem Inflammatory Syndrome in New Zealand Children. The Pediatric Infectious Disease Journal 42(7): e232–e234.2023. **http://dx.doi.org/10.1097/INF.0000000000003933**

Duncanson M, Wheeler B, McIntyre P, et al. Paediatricians in Aotearoa contribute to rare disease surveillance. Presentation at Paediatric Society of New Zealand Te Kāhui Mātai Arotamariki o Aotearoa 74th Annual Meeting; November 2023, Rotorua.

Elliott EJ, Teutsch S, Nunez C, et al. Improving knowledge of rare disorders since 1993: the Australian Paediatric Surveillance Unit. Archives of Disease in Childhood Published Online First: 13 May 2024. https://doi.org/10.1136/archdischild-2023-326116

APPENDIX

Introduction to NZPSU

The NZPSU was established in 1997 to facilitate and improve knowledge of rare childhood conditions in Aotearoa. These are conditions of sufficiently low incidence or prevalence that case ascertainment on a national scale is needed to generate adequate numbers for meaningful study. The method was developed in the United Kingdom by the British Paediatric Surveillance Unit (BPSU) and has been used there since 1986. Subsequently, it has been introduced into several other countries, including Australia and Canada.

Paediatricians in Aotearoa gave their support to the surveillance programme after the concept was discussed at several annual meetings of the Paediatric Society of Aotearoa. All paediatricians practising in Aotearoa are eligible to participate in the surveillance programme.

The core activities of the NZPSU are funded through a contract with Manatū Hauora to provide active surveillance of acute flaccid paralysis (AFP). The World Health Organization (WHO), as part of the global certification and surveillance process to document continued elimination of polio from New Zealand the Western Pacific and ultimately global eradication. Another seven conditions were under surveillance in 2023.

The NZPSU is a member of the International Organisation of Paediatric Surveillance Units (INoPSU).

Study Objectives

The aim of the NZPSU is:

> 'To conduct clinical surveillance for monitoring acute flaccid paralysis in children less than 15 years of age To facilitate national surveillance to improve knowledge of other important rare childhood conditions.'

The NZPSU maintains a database of paediatricians in Aotearoa, and audits it against publicly- available data regarding specialist registration in paediatrics with Te Kaunihera Rata o Aotearoa (the Medical Council of New Zealand). There are participating paediatricians in every district of Te Whatu Ora and clinicians in each hospital are encouraged to invite colleagues to join.

Every month participants are sent an email with linked REDCap survey to report whether in the previous month they have seen any children with the conditions under surveillance. This survey is sent out every 8 days to those who have not completed the questionnaire. Cases of AFP are required to be reported immediately by phone or email to the NZPSU.

When a case is reported to NZPSU, the principal investigator for the specific study is advised and seeks further clinical information from the reporting clinician, often in a questionnaire to complete on the case. The identity of the cases remains anonymous. The child's NHI is used only to identify duplicate notifications but not linked to other health data.

Study protocols, which include definitions of the conditions under surveillance, specific reporting instructions, and a contact telephone number are available on the NZPSU website www.otago.ac.nz/nzpsu. The process

used by the NZPSU, and the conditions under surveillance, have been approved by the Health and Disability Ethics Committee OTA/95/10/113.

Study selection

A Scientific Review Panel (SRP) considers applications for new conditions to be added into the programme. There were no applications for new studies in 2023.

A study is eligible for consideration in the scheme if the condition in the scheme if the condition of interest is:

- A rare childhood disease or condition with high impact at personal or population level (or an uncommon complication of a more common disease)
- Of such a low incidence or prevalence that ascertainment of cases is needed on a national scale to generate adequate numbers for the study

The SRP may also consider inclusion of more common conditions on a short term or geographically limited basis. The SRP considers the scientific interest and public health importance of the proposed study, methodology, and suitability of the condition for ascertainment through NZPSU.

The SRP members are listed in Table 2.

Table 2. Members of the Aotearoa Scientific Review Panel in the reporting period

Name	Institution
Dr Mavis Duncanson	University of Otago (ex officio)
Professor Ben Wheeler	University of Otago (ex officio)
Professor Peter McIntyre	University of Otago
Professor Tony Walls	University of Otago
Dr Anne Morris	University of Sydney
Dr Asad Abdullahi	Ministry of Health
Professor Elizabeth Elliott	University of Sydney
Dr Emma Best	University of Auckland

After review by the SRP, additions to the surveillance programme are subject to approval by the Southern Health and Disability Ethics Committee and must be agreed to by Manatū Hauora.

Manatū Hauora may request surveillance of emerging diseases or health conditions deemed to be of national or international significance.

ALL NZPSU SURVEILLANCE STUDIES and PUBLICATIONS[2]

Condition	Report Period	Findings Reported
Acute Flaccid Paralysis	1997 ongoing	Dow N., Dickson N. & Taylor BJ. The New Zealand Paediatric Surveillance Unit: Establishment and first year of operation. New Zealand Public Health Report. 1999;6(6):41-44. Chambers ST & Dickson NP. Global polio eradication: progress, but determination and vigilance still needed. New Zealand Medical Journal. 2012;124(1337):100-104. Desai S, Smith T, Thorley BR, Grenier D, Dickson N, Altpeter E et al. Performance of acute flaccid paralysis surveillance compared with World Health Organization standards. Journal of Paediatrics and Child Health. 2015;51(2):209-214. Duncanson M & Wheeler B. Don't forget about polio. Update on local surveillance and international trends. Presentation at Paediatric Society of New Zealand 71st Annual Scientific Meeting – In our backyard, Albany, Auckland, November 2019.
Haemolytic Uraemic Syndrome	1998 ongoing	Prestidge C & Wong W. Ten years of pneumococcal-associated haemolytic uraemic syndrome in New Zealand children. Journal of Paediatrics and Child Health. 2009;45(12):731-735. Wong W, Morris MC, Kara T, Ronaldson JE. Haemolytic uraemic syndrome in New Zealand children. A nationwide surveillance study from 1998-2009. Poster presented at 15th Congress of International Pediatric Nephrology Association, New York, August–September 2010. Wong W, Prestidge CP, Ronaldson J. Shorter prodrome of symptoms is associated with an increased severity of diarrhoea associated HUS (D+HUS). Poster presented at 18th Congress of International Pediatric Nephrology Association, Venice, October 2019

[2] 2023–2024 references in **bold type**

		Wong W, Prestidge CP, Ronaldson J, Dickens A. Atypical HUS in New Zealand children; outcomes without Eculizumab. Poster presented at 18th Congress of International Pediatric Nephrology Association, Venice, October 2019. Wong, W. Shiga Toxin Producing Escherichia coli Infections and Associated Haemolytic Uraemic Syndrome in New Zealand Children: Twenty Three Years of Epidemiology and Clinical Observations. International Journal of Pediatric Research. **https://doi.org/10.23937/2469-5769/1510085** Wong, W., Prestidge, C., Dickens, A. and Ronaldson, J. Diarrhoea-associated haemolytic uraemic syndrome and Shiga toxin-producing Escherichia coli infections in New Zealand children: Clinical features and short-term complications from a 23-year cohort study. Journal of Paediatrics and Child Health. **https://doi.org/10.1111/jpc.16332**
Congenital Rubella Syndrome	1998 ongoing	
Perinatal HIV Exposure	1998 ongoing	Dickson N, Paul C, Wilkinson L, Voss L & Rowley S. Estimates of HIV prevalence among pregnant women in New Zealand. New Zealand Public Health Report. 2002;9:17-19.
Neonatal herpes simplex virus (HSV)	1998–2000	
Proven neonatal bacterial or fungal infection in the first week of life	1998–2008	Darlow BA, Voss L, Lennon DR & Grimwood K. Early-onset neonatal group B streptococcus sepsis following national risk-based prevention guidelines. Australian and New Zealand Journal of Obstetrics and Gynaecology. 2017;56(1): 69-74.
Vitamin K deficiency bleeding (VKDB)	1998–2008	Darlow BA. Vitamin K deficiency bleeding (VKDB) in New Zealand infants: results of surveillance over five years (1998 to 2002). Pediatric Research. 2004;56 (3):474 Darlow BA, Phillips AA & Dickson NP. New Zealand surveillance of neonatal vitamin K deficiency bleeding (VKDB): 1998-2008. Journal of Paediatrics and Child Health. 2011;47(7):460-4.

Fetal Alcohol Syndrome	1999–2001	Leversha AM & Marks RE. The prevalence of fetal alcohol syndrome in New Zealand. New Zealand Medical Journal. 1995;108(1013):502–505.
Subdural Haemorrhage	1999–2002	Kelly P & Farrant B. Shaken Baby Syndrome in New Zealand, 2000–2002. Journal of Paediatrics and Child Health. 2008;44: 99–107.
Retinopathy of Prematurity (stage III)	1999–2000	
Diabetes Mellitus	1999–2000	Campbell-Stokes P L & Taylor BJ. Prospective incidence study of diabetes mellitus in New Zealand children aged 0 to 14 years. Diabetologia. 2005;48(4):643-648.
Kawasaki Disease	2001–2002	Heaton P, Wilson N, Nicholson R, Doran J, Parsons, A & Aiken, F. Kawasaki Disease in New Zealand. Journal of Paediatrics and Child Health. 2006;42:184–190
Bronchiectasis	2001–2002	Twiss J, Metcalfe R, Edwards E & Byrnes C. New Zealand National Incidence of bronchiectasis "too high" for a developed country. Archives of Disease in Childhood. 2005;90:737–740. Twiss J. Childhood bronchiectasis: national incidence, disease progression and an evaluation of inhaled antibiotic therapy [PhD Thesis]. University of Auckland; 2008. http://hdl.handle.net/2292/5747
Idiopathic Nephrotic Syndrome	2001–2003	Wong W. Idiopathic nephrotic syndrome in New Zealand children, demographic, clinical features, initial management and outcome after twelve-month follow-up: Results of a three-year national surveillance study. Paediatrics and Child Health. 2007;43:337–341.
Inflammatory Bowel Disease	2002–2003	Yap J, Wesley A, Mouat S & Chin S. Paediatric inflammatory bowel disease in New Zealand. New Zealand Medical Journal. 2008;121(1283):19-34.
Prolonged Infantile Cholestasis	2004–2005	
Pertussis	2004–2005	Somerville R, Grant C, Grimwood K, Murdoch D, Graham D, Jackson P, Meates-DM, Nicholson R & Purvis D. Infants hospitalised with pertussis: Estimating the true disease

		burden. Journal of Paediatrics and Child Health. 2008;43:617-622.
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Renal stones	2008	Dickson N, Kara T & Tuohy P. Rapid national survey of renal stones in New Zealand infants. Journal of Paediatrics and Child Health. 2009;45(11): 633-635.
Adverse Drug Reactions (ADR)	2008 ongoing	Kunac D, Tatley M, Grimwood K & Reith D. Active surveillance of serious drug adverse reactions in New Zealand children. Archives of Disease in Childhood. 2012;97(8):761-762.
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Moderate and Severe Neonatal Encephalopathy	2011–2013	Battin M, Sadler L, Masson V & Farquhar C. Neonatal encephalopathy in New Zealand: Demographics and clinical outcome. Journal of Paediatrics and Child Health. 2017; 52(6):632-636
Vitamin D Deficiency Rickets	2011–2013	Wheeler BJ, Dickson NP, Houghton LA, Ward LM & Taylor BJ. Incidence and characteristics of vitamin D deficiency rickets in New Zealand children: a New Zealand Paediatric Surveillance Unit study. Australian and New Zealand Journal of Public Health. 2015;39(4):380-383.
Varicella and post-varicella complications	2011–2013	Wen SCH, Best E, Walls T, Dickson N, McCay H & Wilson E. Prospective surveillance of hospitalisations associated with varicella in New Zealand children. Journal of Paediatrics and Child Health. 2015;51(11): 078-1083.
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Tongue-Tie	2016–2018	Hale M, Mills N, Edmonds L, Dawes P, Dickson N, Barker D & Wheeler BJ. Complications following frenotomy for ankyloglossia: A 24-month prospective New Zealand

		Paediatric Surveillance Unit study. Journal of Paediatrics and Child Health. 2020;56,557-562.
Potential Prenatal Exposure to Syphilis	2018–2020 then ongoing	Gilmour LS, Best EJ, Duncanson MJ, Wheeler BJ, Sherwood J, Thirkell CE, Walls T. High Incidence of congenital syphilis in New Zealand. The Pediatric Infectious Disease Journal, 2022;41(1):66–71
Self-harm seen by paediatrician	2021–2024	Fortune S, Hetrick S, Sharma V, McDonald G, Scott K, Mulder RT, Hobbs L. Multisite sentinel surveillance of self-harm in New Zealand: protocol for an observational study. BMJ Open 2022;12(5):e054604.
Delay in paediatric care during COVID-19 response	2020	Duncanson M, Wheeler BJ, Jelleyman T, Dalziel SR, McIntyre P. Delayed access to care and late presentations in children during the COVID-19 pandemic New Zealand-wide lockdown: A New Zealand Paediatric Surveillance Unit study. Journal of Paediatrics and Child Health. 2021;57(10):1600-4. Duncanson M with acknowledgment of Ben Wheeler, Tim Jelleyman, Stuart R Dalziel, Peter McIntyre, Johann de Water Naude and Chris McKinlay. Perceived impact of COVID-19 pandemic response on paediatric hospitalisations in New Zealand. Presentation at Paediatric Society of New Zealand 72nd Virtual Conference (replacing 72nd Annual Scientific Meeting) November 2021.
Multisystem inflammatory syndrome associated with COVID-19	2021 - 2023	**Taylor A, Duncanson M, Mitchelson B, Nuthall G, Voss L, Walls T, et al. Multisystem Inflammatory Syndrome in New Zealand Children. The Pediatric Infectious Disease Journal 42(7): e232–e234.2023.** **http://dx.doi.org/10.1097/INF.0000000000003933**
X-linked hypophosphataemic rickets	2020	**Sandy JL, Nunez C, Wheeler BJ, et al. Prevalence and characteristics of paediatric X-linked hypophosphataemia in Australia and New Zealand: Results from the Australian and the New Zealand Paediatric Surveillance Units survey. *Bone* 2023;173:116791.** **https://doi.org/10.1016/j.bone.2023.116791**

GENERAL SURVEILLANCE PUBLICATIONS

Elliott EJ, Nicoll A, Lynn R et al. Rare disease surveillance: An international perspective. Paediatrics and Child Health. 2001 (5):251-60.

Grenier D, Elliott EJ, Zurynski Y et al. Beyond counting cases: Public health impacts of national Paediatric Surveillance Units. Archives of Disease in Childhood, 2007; 92(6), 527-533.

Grenier D, Ugnat AM, McCourt C et al. Can active surveillance provide a rapid response to an emerging child health issue? The melamine example. Journal of Paediatrics and Child Health, 2009;14(5), 285-286.

Dickson N., Duncanson M & Best, E. Twenty years of the New Zealand Paediatric Surveillance Unit and the future. Presentation at Paediatric Society of New Zealand 69th Annual Scientific Meeting – Strengthening our foundations, 16 November 2017, Christchurch

Maeusezahl M, Lynn R, Zurynski Y et al. (on behalf of the International Network of Paediatric Surveillance Units INoPSU). The power of surveillance data to change Public Health policy and practice in rare paediatric conditions. Poster presentation at European Society of Paediatric Infectious Disease conference 28 May 2018, Malmö, Sweden

Duncanson M, Wheeler B, McIntyre P, et al. Paediatricians in Aotearoa contribute to rare disease surveillance. Presentation at Paediatric Society of New Zealand Te Kāhui Mātai Arotamariki o Aotearoa 74th Annual Meeting; November 2023, Rotorua.

Elliott EJ, Teutsch S, Nunez C, et al. Improving knowledge of rare disorders since 1993: the Australian Paediatric Surveillance Unit. Archives of Disease in Childhood Published Online First: 13 May 2024. https://doi.org/10.1136/archdischild-2023-326116

INTERNATIONAL NETWORK OF PAEDIATRIC SURVEILLANCE UNITS (INoPSU)

Establishment of INoPSU

The International Network of Paediatric Surveillance Units (INoPSU) is a collaborative organisation. Established in 1998, it currently joins eleven diverse countries which span the globe from Canada to New Zealand. More than 10,000 clinicians contribute and over 300 conditions have been studied so far.

INOPSU was accepted for membership in the International Paediatric Association (IPA) at their September 2011 meeting in Beijing.

INoPSU has held regular scientific meetings since 2000. The most recent meeting was held virtually in 2021. Members communicate regularly with each other and in recent years there has been increasing collaboration in developing surveillance studies.

Mission

The mission of INoPSU is the advancement of knowledge of uncommon childhood infections and disorders and the participation of paediatricians in surveillance on a national and international basis so as to achieve a series of benefits.

Aims

- To collaborate with and provide information to other groups interested in rare childhood diseases, such as parent support groups and policy-makers
- To respond promptly to international emergencies relating to rare childhood conditions where national and international studies can make a contribution to science or public health
- Facilitating communication and cooperation between existing national paediatric surveillance units
- To assist in the development of new units
- To facilitate sharing information and collaboration between researchers from different nations and scientific disciplines
- To share information on current, past and anticipated studies and their protocols, and on conditions that have been nominated for surveillance but are not selected
- To encourage the use of identical protocols to potentially enable simultaneous or sequential collection of data on rare paediatric disorders in two or more countries
- To share and distribute information of educational benefit to constituent units, notably on study and surveillance methodologies
- To share school techniques and models of evaluation for units
- To peer review and evaluate existing and proposed units
- To identify rare disorders of mutual interest and public health importance for cooperative surveys through each national unit
- To collaborate with and provide information to other groups interested in rare childhood diseases such as parent support groups
- To respond promptly to international emergencies relating to rare childhood conditions where national and international studies can make a contribution to science or public health.

There are currently 10 surveillance units that form the INoPSU network (Table 5). Services of the Netherlands Paediatric Surveillance Unit have been suspended since 1 January 2020.

Table 4: Members of the International Network of Paediatric Surveillance Units

Country	Acronym	Email	Website
Aotearoa	NZPSU	nzpsu@otago.ac.nz	www.otago.ac.nz/nzpsu
Australia	APSU	SCHN-APSU@health.nsw.gov.au	www.apsu.org.au
Belgium	PediSurv	pedisurv@sciensano.be	https://www.sciensano.be/en/projects/network-pedi infectious-disease-surveillance
Canada	CPSP	cpsp@cps.ca	https://cpsp.cps.ca/

Germany	ESPED	esped@uni-mainz.de.	https://www.unimedizin-mainz.de/esped/home/
Ireland	IPSU	robert.cunney@hse.ie	https://www.inopsu.com/
Netherlands	NVK	nvk@nvk.nl	www.nvk.nl/onderzoek/nsck
Switzerland	SPSU	spsu@bag.admin.ch	https://www.spsu.ch/en/home
UK	BPSU	bpsu@rcpch.ac.uk	https://www.rcpch.ac.uk/work-we-do/british-paediat surveillance-unit
Wales	WPSU	enquiries@welshpaediatrics.org.uk	https://www.welshpaediatrics.org.uk/

Special thanks to all the paediatricians who regularly contribute every month to Aotearoa's Paediatric Surveillance Unit.

Your contribution is valued and appreciated.

Ngā mihi nui ki a koutou!