New Zealand Paediatric Surveillance Unit Annual report 2023

New Zealand Paediatric Surveillance Unit
Te Hunga Aroturuki Mate Tamariki
Department of Women's & Children's Health
Te Tari Hauora Wāhine me te Tamariki
Otago Medical School
Te Kura Hauora o Ōtākou

p: (+64) 021 279 1728
e: nzpsu@otago.ac.nz
w: www.otago.ac.nz/nzpsu

Table of Contents

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 2022 to 30 June 2023.

Regular surveillance of paediatricians provides an opportunity to investigate other rare childhood conditions and diseases that have high impact for individuals or health service delivery. These additional studies are undertaken by paediatricians with a clinical research interest, or by NZPSU staff at the request of Manatū Hauora, and the conditions are included alongside AFP in the monthly survey. When a child with a condition under surveillance is reported to the NZPSU, the principal investigator is notified and will request additional information relevant to the study. Unless otherwise stated, reports for these additional studies cover the 2022 calendar year.

The ongoing success of the NZPSU is largely due to the high level of support from New Zealand paediatricians who have taken the time to provide information on the conditions under surveillance. We acknowledge and appreciate ongoing funding from Manatū Hauora.

Dr Mavis Duncanson, Co-director
Professor Benjamin Wheeler, Co-director
Ms Rachel Bates, Administrator

INTRODUCTION

The NZPSU was established in 1997 to facilitate and improve knowledge of rare childhood conditions in New Zealand. 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 New Zealand gave their support to the surveillance programme after the concept was discussed at several annual meetings of the Paediatric Society of New Zealand. 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 eradication process, requires such surveillance to confirm New Zealand is free of poliomyelitis. There were seven additional conditions under surveillance in the 2022 calendar year.

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

Aims

The aims of the NZPSU are:

- To operate a system for monitoring acute flaccid paralysis, as part of the global certification of eradication of poliomyelitis, required by the World Health Organization.
- To facilitate national surveillance and improve the knowledge of rare childhood conditions in New Zealand.

Surveillance method

The NZPSU maintains a database of paediatricians in Aotearoa, and audits it against publicly-available data regarding specialist registration in paediatrics with 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. 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 2022.

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. In making a decision 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 1:

Table 1. Members of the New Zealand Scientific Review Panel

Name:	***Institution:***
Dr Mavis Duncanson	University of Otago
Professor Ben Wheeler	University of Otago
Professor Peter McIntyre	University of Otago
Professor Tony Walls	University of Otago
Dr Anne Morris	University of Sydney
Dr Geoffrey Roche	Manatū Hauora
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.

SURVEILLANCE ACTIVITIES IN 2022

In 2022, there were between 260–280 clinicians participating in the surveillance programme with an average monthly response rate of 67%. 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.

In the 2022 calendar year the NZPSU monitored eight rare childhood conditions (Table 2). Some of the protocols and questionnaires used were adapted from those used by the Australian Paediatric Surveillance Unit or other INOPSU members.

Table 2: Conditions under surveillance in 2022

Condition	Surveillance Started	Surveillance Ending	Principal Investigators
Acute flaccid paralysis	October 1997	Ongoing	Dr Mavis Duncanson
Congenital rubella syndrome	January 1998	Ongoing	Dr Mavis Duncanson
Perinatal HIV exposure	January 1998	Ongoing	Dr Sue McAllister Dr Lesley Voss
Serious paediatric adverse drug reactions	May 2008	Ongoing	Dr Michael Tatley
Potential prenatal exposure to syphilis (positive maternal serology)	April 2018	Ongoing	Professor Tony Walls Dr Leeyan Gilmour
Confirmed or probable SARS-CoV-2 infection (COVID-19)*	May 2020	Ongoing	Dr Amanda Taylor Prof Stuart Dalziel
Self-harm seen by Paediatrician	June 2020	June 2024	Dr Sarah Fortune Dr Gabrielle McDonald
Severe acute hepatitis	April 2022	Ongoing	Dr Helen Evans Professor Andrew Day

*Case definition restricted to children requiring ICU level care or with a multi-inflammatory syndrome in March 2022

REPORTS ON ONGOING STUDIES

Acute Flaccid Paralysis

Dr Mavis Duncanson
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 2022- June 2023

There were 17 cases notified to the NZPSU with onset of AFP from July 2022 until June 2023, and a further 5 cases were identified through audit of hospital discharge data. One case was determined by the National Certification Committee for the Eradication of Polio Information to be non-AFP. Information has been obtained on the remaining 21 AFP cases, including follow-up information two months after diagnosis:

- 18 were from the North Island
- 8 females, 13 males
- Age range 7 months to 14 years
- The AFP incidence was 2.2 cases per 100,000 children aged under 15 years
- All 21 cases were discarded as non-polio by the National Certification Committee for the Eradication of Polio (NCCEP)
- At least one stool sample was obtained for 13 (76%) of the 17 cases identified through active surveillance although only 9 (53%) had complete stool samples
- There were no stool samples collected from the cases identified through hospital discharge audit

The NZPSU has notified 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 exceeded in the 12 months to 30 June 2023 with 2.2 cases per 100,000 children aged 0–14 years. This high detection rate suggests that surveillance is adequate to detect a case of poliomyelitis if it should occur. The rate of complete stool testing (53%) was below the WHO target of 80%. Of note, stool samples were obtained for 4 of the 5 cases reported in 2023 (to 30 June) which suggests that the ongoing education efforts are proving effective. These efforts include regular reminders to paediatricians and other clinicians about the importance of stool samples from children with acute flaccid paralysis, and posts in online discussion groups involving paediatricians in New Zealand.

Congenital Rubella Syndrome (CRS)

Dr Mavis Duncanson
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 and Dr Lesley Voss
Ongoing Study started January 1998

Key Results for 2022

In 2022 there were 4 infants reported to have been born in New Zealand to women infected with HIV who were diagnosed prior to or during their pregnancy. Information has been received on all of these infants.

Of these 4:

- Three were born in Auckland, and 1 in Christchurch.
- All four were born to mothers whose HIV had been diagnosed before their pregnancy.
- The mothers were of Pacific Island, African and European ethnicity (<5 in each group)
- All four of the mothers were given antiretroviral treatment during pregnancy; 2 gave birth by caesarean section and 2 gave birth vaginally; one of the babies was breastfed.

None of the children are believed to be infected with HIV (although most are still awaiting confirmation).

Serious Paediatric Adverse Drug Reactions (ADR)

Assoc. Prof. David Reith, Prof. Michael Tatley, Prof. Keith Grimwood
Ongoing study started August 2007.

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 2022

There were 8 notifications made to CARM from NZPSU during the 2022 year. Two reports were received for the one patient but there was no follow up report received.

At NZPSU's request suspected COVID vaccine related reports of pericarditis/myocarditis were added to the notification card in September 2021. For those reported for the COVID vaccine only 1 has been included in the study (as seen in Table 3). The other 2 have been added to the COVID adverse reaction reporting system (CIR).

The 4 reports included in the study are summarised below in Table 1.

Of the 4 reports included, there were 2 that had not previously been notified to the Centre for Adverse Reactions Monitoring (CARM). These have now been included in the CARM database to further enhance our understanding of serious ADR's in children.

Table 3: Information on the 4 reports of Serious Paediatric Adverse Drug Reactions (ADR) notified through NZPSU in 2022. The column titled "Medical Warning" indicates those added to the national Medical Warning System, and the column titled CARM indicates whether the adverse reaction had also been notified directly to the Centre for Adverse Reactions Monitoring (CARM)..

Suspect Medicine	**Reaction(s)**	**Age**	**Sex**	**Serious/Outcome**	**Medical Warning**	**CARM**
Ceftriaxone	Anaphylaxis	14 years	M	Life threatening/Recovered at the time of reporting	Danger	No
Co-trimoxazole	Serum-sickness like disorder	7 years	M	Required hospitalisation/Not fully recovered at time of reporting	Warning	Yes
Testosterone (Sustanon)	Injection site reactions, anxiety, leg pain and tachycardia	16 years	M	Medically significant/ Recovered at the time of reporting	Warning	Yes
COVID vaccine (Pfizer)	Myocarditis	13 years	M	Required Hospitalisation/Not fully recovered at the time of reporting	Nil	No

This annual report summary will be considered by the Medicines Adverse Reactions Committee (MARC) which is a technical advisory committee to the Minister of Health.

Potential Prenatal Exposure to Syphilis

Dr Leeyan Gilmour, Professor Tony Walls
Ongoing study commenced April 2018

Aim:

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 2022:

- 25 infants born in 2022 were reported, with information available on 23 of these infants
    - 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.
- Of the 23 cases born in 2022 with available data, 7 infants had findings consistent with congenital syphilis, with 3 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.
- All but 3 of the 23 cases from 2022 arose from the North Island of New Zealand, with 9 cases notified from the Counties Manukau region, 3 each from the Canterbury and Waikato region, 2 each from the Waitemata and Auckland regions, and one each from the Bay of Plenty, Capital and Coast, Northland, and MidCentral regions.
- Of the 23 cases from 2022, 13 of the women were of Māori descent, 9 NZ European, 3 of Pacific Peoples and of 1 Latin/Hispanic ethnicity (some women identified with more than one ethnicity).
- Of the 7 infants with confirmed or probable congenital syphilis born in 2022:
    - 4 were born to women who did not receive antenatal care
    - 4 infants had clinical signs, which included syphilis skin rash, jaundice/hepatitis, CNS/eye signs, thrombocytopaenia, and ascites. One infant was severely affected with neurosyphilis and birth asphyxia and died at 11 days of age.
    - 5 had long bone changes visible on X-ray, 3 had CSF findings (elevated WCC, protein, and/or reactive VDRL)
    - 1 had an infant: maternal (at delivery) non-treponemal titres of 4x or greater and 2 had positive placental samples.
    - 4 were born to women who were not treated for syphilis during pregnancy due to not receiving antenatal care, 1 woman was treated in pregnancy with good serological response but likely reinfection, 1 woman was treated in pregnancy but with insufficient time for serological response, and 1 woman was treated, with no information available on whether further serological testing was completed.
    - All of the probable and confirmed cases were treated appropriately with penicillin.

Multi-inflammatory syndrome in children

Dr Amanda Taylor, Dr Mavis Duncanson, Professor Peter McIntyre, Professor Stuart Dalziel
Ongoing study started May 2020

Aims

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.

Key Results

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 with a multi-inflammatory syndrome. This report refers to the first half of 2022.

In March 2022, the condition multi-inflammatory syndrome in children (MIS-C) was added to the New Zealand Paediatric Surveillance Unit electronic report card. MIS-C is a criteria-based, clinical and laboratory diagnosis. It is defined by the World Health Organisation (WHO) as occurring when children meet six criteria:[1]

1. Age 0 to 19 years
2. Fever for >3 days
3. Clinical signs of multisystem involvement (at least 2 of the following):
    - Rash, bilateral non-purulent conjunctivitis, or mucocutaneous inflammation signs (oral, hands, or feet)
    - Hypotension or shock
    - Cardiac dysfunction, pericarditis, valvulitis, or coronary abnormalities (including echocardiographic findings or elevated troponin/Brain Natriuretic Peptide)
    - Evidence of coagulopathy
    - Acute gastrointestinal symptoms (diarrhoea, vomiting, or abdominal pain)
4. Elevated markers of inflammation
5. No other obvious microbial cause of inflammation, including bacterial sepsis and staphylococcal/streptococcal toxic shock syndromes
6. Evidence of SARS-CoV-2 infection which includes any of the following:
    - Positive SARS-CoV-2 PCR
    - Positive SARS-CoV-2 serology
    - Positive SARS-CoV-2 antigen test
    - Contact with an individual with COVID-19

The 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 New Zealand with the Omicron variant.

The study group used the NZPSU report card, the National Minimum Data Set and case- notifications to the MIS-C multi-disciplinary team (MDT) to collect cases notified during the period, 01 January 2022-30th June 2022. Cases were included if they met the WHO MIS-C definition as determined by consensus opinion of the MIS-C MDT.

[1] World Health Organization (WHO). Multi-system inflammatory syndrome in children and adolescents with COVID-19 2020 [updated 15 May 2020]. Available from: https://www.who.int/publications/i/item/multisystem-inflammatory-syndrome-in-children- and-adolescents-with-covid-19

Over this 6 month period, 13 cases were notified to NZPSU. On review, 3/13 had acute COVID-19 rather than MIS-C and were excluded. 10 cases of MIS-C were confirmed across NZ. The incidence of MIS-C in NZ was 0.0010% of the age-specific population with a rate of 1.03/100,000 age-specific population and 0.04/1000 recorded SARS-CoV-2 infections.

The median age of diagnosis was 8 years (range 5-14). 9 out of 10 cases were male. Of those eligible for SARS-CoV-2 vaccination, two children received one or more dose of vaccine >28 days prior to diagnosis. 8 out of 10 children were treated with both intravenous immunoglobulin (IVIG) and steroids and one each with steroids or IVIG alone.

With regards to severity, one child had a coronary artery aneurysm detected. 2 out of 10 children required intensive care unit admission with a median length of ICU stay of 2.5 days (range 2-3). No children required intubation, ventilation or extracorporeal membrane oxygenation. There were no deaths in this cohort. The median length of hospital stay was 7 days (range 4-10).

This study has subsequently been published in the Pediatric Diseases Journal (see reference list at end of this annual report). We concluded that there was a low incidence of MIS-C in NZ, following infection with the Omicron variant of SARS-CoV-2. This incidence is comparable with international reports from the United Kingdom, Denmark, Israel and Australia.[2,3,4,5]

MIS-C currently remains on the NZPSU electronic report card. There is an ongoing discussion amongst NZ Paediatricians as to whether this should be reconsidered given the low incidence of MIS-C demonstrated in this study and internationally.

[2] Cohen JM, Carter MJ, Ronny Cheung C, Ladhani S, Evelina P-TSSG. Lower Risk of Multisystem Inflammatory Syndrome in Children (MIS-C) with the Delta and Omicron variants of SARS-CoV-2. Clin Infect Dis. 2022. Epub 20220705. doi: 10.1093/cid/ciac553. PubMed PMID: 35788276

[3] Holm M, Espenhain L, Glenthoj J, Schmidt LS, Nordly SB, Hartling UB, et al. Risk and Phenotype of Multisystem Inflammatory Syndrome in Vaccinated and Unvaccinated Danish Children Before and During the Omicron Wave. JAMA Pediatr. 2022. Epub 20220608. doi: 10.1001/jamapediatrics.2022.2206. PubMed PMID: 35675054

[4] Miller AD, Yousaf AR, Bornstein E, Wu MJ, Lindsey K, Melgar M, et al. Multisystem Inflammatory Syndrome in Children (MIS-C) During SARS-CoV-2 Delta and Omicron Variant Circulation- United States, July 2021 - January 2022. Clin Infect Dis. 2022. Epub 20220610. doi: 10.1093/cid/ciac471. PubMed PMID: 35684958; PubMed Central PMCID: PMC9214171.

[5] Levy N, Koppel JH, Kaplan O, Yechiam H, Shahar-Nissan K, Cohen NK, et al. Severity and Incidence of Multisystem Inflammatory Syndrome in Children During 3 SARS-CoV-2 Pandemic Waves in Israel. JAMA. 2022;327(24):2452-4. doi: 10.1001/jama.2022.8025. PubMed PMID: 35588048; PubMed Central PMCID: PMC9121298

Acute Self-Harm seen by Paediatrician

Dr Sarah Fortune, Dr Gabrielle McDonald, Ms Linda Hobbs
Ongoing Study started June 2020

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 2022

This ongoing four-year study is collecting sensitive data that will be reported on completion of the study in 2024. In 2021 there were 61 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

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 2022

There were 22 cases of severe acute hepatitis reported to the NZPSU in 2022. In addition, six cases that occurred in 2021 were reported retrospectively.

NZPSU SURVEILLANCE STUDIES and PUBLICATIONS[6]

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 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.

[6] 2022–2023 references in **bold type**

		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.
Inborn Errors of Metabolism	2004–2006	Wilson C, Kerruish N, Wilcken B, Wiltshire E & Webster D. The failure to diagnose inborn errors of metabolism in New Zealand: the case for expanded newborn screening. New Zealand Medical Journal 2008;120:U2727 Wilson C, Kerruish NJ, Wilcken B, Wiltshire E, Bendikson K & Webster D. Diagnosis of disorders of intermediary metabolism in New Zealand before and after expanded newborn screening: 2004–2009. New Zealand Medical Journal. 2012;125(1348):42-50.
Pneumococcal meningitis	2005–2008	Safar A, Lennon D, Stewart J, Trenholme A, Drinkovic D, Peat B & Voss L. Invasive group A streptococcal infection and vaccine implications, Auckland, New Zealand. Emerging Infectious Diseases. 2011;17(6):983-9.
Acute Post Streptococcal Glomerulonephritis	2007–2011	Wong W, Lennon DR, Crone S, Neutze JM & Reed PW. Prospective population-based study on the burden of disease from post-streptococcal glomerulonephritis of hospitalised children in New Zealand: Epidemiology, clinical features and complications. Journal of Paediatrics and Child Health. 2013;49(10):850-855.
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.

Neonatal Bacterial or Fungal Infection	2011–2013	Darlow B A, 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.
Severe Neonatal Hyperbilirubinaemia	2011–2013	
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.
Supratherapeutic Paracetamol Ingestion	2014–2015	
Eosinophilic Oesophagitis	2014–2016	Roberts AJ, Day AS, Sinclair J, Dickson N, Porter J, Wellington G & Evans H. Paediatric eosinophilic oesophagitis in New Zealand: A 3-year prospective study. Journal of Paediatrics and Child Health. 2021;57(2):234-38.
Empyema	2014–2018	Rix-Trott K, Byrnes C, Twiss J, Matsas R, Hamill J, Evans S, Mahon C, Williamson D, Dickson N, Walls T, Voss L. & Best E. Nationwide surveillance of paediatric empyema in New Zealand 2014–2016. Presentation at Australasian Society of Infectious Diseases Annual Scientific Meeting, Leura NSW, March 2018 Rix-Trott K, Byrnes CA, Gilchrist CA, Matsas R, Walls T, Voss L, et al. Surveillance of pediatric parapneumonic effusion/empyema in New Zealand. Pediatric Pulmonology. 2021;56(9):2949-57.
Acute Post-Streptococcal Glomerulonephritis	2007–2015	Vogel AM, Lennon DR, van der Werf B, Diack M, Neutze JM, Horsfall M, Emery D, & Wong W. Post-streptococcal glomerulonephritis: Some reduction in a disease of disparities. Journal of Paediatrics and Child Health. 2019; 5,652-658.
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 Aotearoa. 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 ongoing**	**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**

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

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 ten 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 ten scientific meetings since 2000. Associate Professor Nigel Dickson attended meetings in Ottawa, York, Lisbon and Melbourne. Dr Mavis Duncanson attended the 10th Scientific Conference in Glasgow in 2018. Members communicate regularly with each other and in recent years there has been increasing collaboration in developing surveillance studies. The NZPSU has contributed to international discussions in the development of surveillance methods for SARS-CoV-2 infection, delay in paediatric care due to the COVID-19 pandemic, severe microcephaly

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 5: **Members of the International Network of Paediatric Surveillance Units**

Unit	Acronym	Email	Website
Australia	APSU	SCHN-APSU@health.nsw.gov.au	www.apsu.org.au
Belgium	PediSurv	edisurv@sciensano.be	https://www.sciensano.be/en/projects/network-pediatric-infectious-disease-surveillance
UK	BPSU	bpsu@rcpch.ac.uk	https://www.rcpch.ac.uk/work-we-do/british-paediatric-surveillance-unit
Canada	CPSP	cpsp@cps.ca	https://cpsp.cps.ca/
Germany	ESPED	No further information	No further information
Ireland	IPSU	robert.cunney@hse.ie	
Aotearoa New Zealand	NZPSU	nzpsu@otago.ac.nz	www.otago.ac.nz/nzpsu
Netherlands		nsck@nvk.nl	www.nvk.nl/onderzoek/nsck
Switzerland	SPSU	spsu@bag.admin.ch	https://www.spsu.ch/en/home
Wales	WPSU		www.welsh-paediatrics.org.uk/wpsu

Special thanks to all the paediatricians who regularly contribute every month to New Zealand's Paediatric Surveillance Unit. Your contribution is valued and appreciated.