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Table of Contents

PREFACE: NEW ZEALAND PAEDIATRIC SURVEILLANCE UNIT

Welcome to the 2016 Annual Report of the New Zealand Paediatric Surveillance Unit (NZPSU).

The NZPSU was established with funding from the Ministry of Health in order to undertake surveillance of acute flaccid paralysis (AFP) for the Ministry of Health's National Certification Committee for the Eradication of Poliomyelitis (NCCEP).

The opportunity was taken for the study of other uncommon high impact conditions, most of which has been undertaken by paediatricians with a particular research interest.

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 would like to acknowledge the ongoing funding from the Ministry of Health.

CHANGE OF PERSONNEL

During 2016 the two Co-directors of the NZPSU stepped down from their roles.

Associate Professor Nigel Dickson has been involved since the beginning of the NZPSU in 1997 and been instrumental in the day to day running of the Unit. He retired in December 2016 and his role was taken by Dr Mavis Duncanson.

Professor Barry Taylor was influential in establishing the Unit and is currently the Dean of the Dunedin School of Medicine. The clinical input provided by Professor Taylor has been taken by Dr Ben Wheeler.

The NZPSU welcomes Dr Mavis Duncanson and Dr Ben Wheeler into their roles.

INTRODUCTION

The NZPSU was established in 1997 to facilitate and improve the knowledge of uncommon high-impact 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 is used by some other specialist groups.

The core activities of the NZPSU are funded through a contract with the Ministry of Health 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. Since the establishment of the NZPSU, the number of conditions under surveillance has increased to eight conditions in 2016.

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 WHO.
- To facilitate national surveillance and improve the knowledge of uncommon high-impact childhood conditions in New Zealand.

Paediatricians in New Zealand gave their support to the surveillance system after the concept was discussed at several annual meetings of the Paediatric Society of New Zealand. A database of eligible clinicians, which included all paediatricians and other specialists working predominantly with children, was developed using the specialist register and the membership list of the Paediatric Society. All eligible clinicians were contacted and invited to participate. Those who agreed were provided with study protocols, which included definitions of the conditions under surveillance, specific reporting instructions, and a contact telephone number. Efforts are made to keep up-to-date with the paediatric specialist work force using information received from the Medical Council of New Zealand.

Every month participants are sent either a reply-paid card or an email (depending on their preferred method of reporting) to report whether in the previous month they have seen any cases of the conditions under surveillance. However, cases of AFP are also required to be reported immediately by phone to the NZPSU. When a case of any of the conditions is reported, the reporting clinician is sent a short questionnaire to complete on the case. The identity in most cases remains anonymous. Duplicate notification is recognised by a code derived from the child's initials and date of birth.

How the Surveillance System Works

A Scientific Review Panel (SRP) considers the applications of new conditions into the scheme (see Table 1 for details on members of the SRP) A study is eligible for consideration in the scheme if the condition in the scheme if the condition of interest is:

- A relatively uncommon high-impact childhood condition (or an uncommon complication of a more common disease)
- Of such a low incidence or prevalence as to require ascertainment of cases on a national scale in order to generate sufficient numbers for the study

The SRP may also consider inclusion of short-term or geographically limited studies of more common conditions.

It is important for the success of the scheme that the work-load of the respondents is kept to a minimum. Accordingly, the SRP must be certain that studies conducted through the NZPSU are well designed and worthwhile. The SRP will take into consideration the scientific interest and public health importance of the proposed study, its methodology, and the suitability of the condition for ascertainment through the NZPSU scheme. Studies depending on immediate reporting and/or sample collection, or requiring the participation of other specialties, are less likely to be suitable.

***Table 1*: The Members of the NZPSU Scientific Review Panel (SRP) 2016**

Member	Institution
Associate Professor Nigel Dickson (Chair)	NZPSU, University of Otago, Dunedin
Professor Barry Taylor	NZPSU University of Otago, Dunedin
Dr Pat Tuohy	Ministry of Health
Professor Elizabeth Elliott	Australian Paediatric Surveillance Unit
Dr Jeff Brown	Palmerston North Hospital
Professor Brian Darlow	University of Otago, Christchurch
Professor Diana Lennon	University of Auckland

SURVEILLANCE ACTIVITIES IN 2016

In 2016, 245 clinicians participated in the system. The average response rate to the monthly report card/email was 90%. The ongoing high response rate from the whole of the country is very pleasing. Minimising the extra workload that the system imposes on paediatricians is a key factor for its success. Table 2 shows the percentage of clinicians on the mailing list that reported between 2015 and 2016; in 2016, 206 did not report any cases at all, with 2 reporting 5 or more.

In 2016, the NZPSU monitored eight uncommon childhood conditions *(Table 3)*. Some of the protocols and questionnaires used were adapted from those used by the Australian Paediatric Surveillance Unit.

Table 2: **Respondents' Workload 2015 and 2016**

Notifications	2015		2016	
			No.	%
None	165	68.1	206	84
One	41	16.9	28	11.4
2-4	29	11.9	9	3.7
5 or more	7	2.8	2	0.8

Table 3: **Conditions under surveillance in 2016**

Condition	Surveillance Started	Surveillance Ending	Principal Investigators
Acute Flaccid Paralysis	October 1997	Ongoing	A/Prof Nigel Dickson
Haemolytic Uraemic Syndrome	January 1998	Ongoing	Dr William Wong
Congenital Rubella Syndrome	January 1998	Ongoing	Professor Diana Lennon
Perinatal HIV Exposure	January 1998	Ongoing	A/Prof Nigel Dickson Dr Lesley Voss
Adverse Drug Reactions	May 2008	Ongoing	Dr Desiree Kunac
Pleural empyema	June 2014	May 2016	Dr Emma Best
Complications of Tongue-Tie treatment	July 2016	July 2018	Dr Ben Wheeler
Possible congenial Zika Syndrome and/or severe microcephaly	July 2016	July 2018	Associate Professor Nigel Dickson

BRIEF REPORTS ON ONGOING STUDIES

Acute Flaccid Paralysis

Associate Professor Nigel Dickson
Ongoing study started in January 1998

Introduction

To confirm the absence of poliomyelitis WHO requires a surveillance system to be in place:

1. That captures an annual incidence of acute flaccid paralysis (AFP), not due to poliomyelitis, of at least one per 100,000 children < 15 years.
2. In which 80% of cases of AFP have two stool samples taken at least 24 hours apart within 14 days of onset, tested negative for wild polio virus in a WHO-accredited laboratory.

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

Key Results for 2016

- There were 12 cases notified to the NZPSU in 2016.
- Information has been obtained on all of these children including follow-up information two months after diagnosis.
- 11 were from the North Island, one was from the South Island.
- Three females, nine males.
- Age range 4 years to 15 years
- No seasonal variation.
- The overall incidence was 1.3 per 100,000 children < 15 years.
- All 12 cases have been classified as Non- Polio by the National Certification Committee for the Eradication of Polio (NCCEP).
- Complete and timely collection of stool samples, satisfying the WHO criteria of 2 samples at least 24 hours apart <14 days after onset paralysis, was complete for nine of the 12 children (75.0%).

These findings have been notified to the World Health Organization to fulfill New Zealand's obligation to report on its polio-free status.

***Table 4*: Percentage of AFP cases with adequate (or otherwise) stool samples: 2016**

Category	Stool samples	
	No.	**%**
2 stool samples within 14 days of onset of paralysis	9	75.0
2 stool samples, but one or both not within 14 days of onset of paralysis	1	8.3
1 stool sample	1	8.3
No stool samples	1	8.3

The required rate (of 1.0 per 100,000) expected by WHO in a country without endemic polio was reached in 2016, and the rate of stool testing was 75.0%, just under the WHO target which is 80%.

Thanks must go to the team at Starship Hospital and in particular the Neurology Nurse Specialist, Barbara Woods, who provides leadership in ensuring, where possible, all cases are notified.

We appreciate that this surveillance requirement is a challenge, in the absence of endemic polio. We wish to thank the paediatricians for vigilance in obtaining timely testing in most instances.

Even though the WHO believes polio to have been eradicated from the Western Pacific region, ongoing surveillance of AFP is likely to be required for some years. This will require the continued telephone notification of all cases of AFP, including those with a definitive diagnosis such as Guillain - Barré syndrome (GBS).

Haemolytic Uraemic Syndrome (HUS)

Dr William Wong
Ongoing study started in January 1998

Key Results for 2016

- 14 cases of childhood HUS reported, in which 10 had a diarrhoeal prodrome (D+), 8/10 had E coli 0157H7 isolated.
- Four children with no diarrhoea prodrome (one found to have genetic mutations in complement protein regulators, one had streptococcus pneumoniae and one had autoantibodies to Factor H)
- All but one of the E coli 0157 positive cases were in the North Island.
- No one DHB had any more than two cases (7 DHBs had 1-2 cases)
- Median age at presentation of D(+) HUS was 2.4 years, range 1.7 to 7.4 years
- One patient has multiple parasitic infections: Cryptosporidium, Giardia
- 6/10 diarrhoeal cases had been in contact or lived on a farm in the last 2 weeks before presentation. Three children had been in contact with contaminated water.
- Median time to diagnosis of HUS was 6 days (range 2-9)
- 6/10 in the diarrhoeal group received acute dialysis and all recovered renal function to discontinue dialysis.

Perinatal HIV Exposure

Associate Professor Nigel Dickson and Dr Lesley Voss
Ongoing Study

Key Results for 2016

In 2016, there were 13 reports to the NZPSU of infants/children born in New Zealand to women infected with HIV who were diagnosed prior to or during their pregnancy.

Of these 13:

- 6 were born in Auckland, with other cases from Hawke's Bay, Wellington, Dunedin and Palmerston North.
- 10 were born to mothers whose HIV had been diagnosed before their pregnancy, 3 were born to mothers whose HIV status was diagnosed during pregnancy
- Mothers were of African, Asian, European and Pacific ethnicity
- All of the mothers were given antiretroviral treatment during pregnancy; 5 gave birth by caesarean section and 8 gave birth vaginally and one baby was breastfed.

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

Congenital Rubella Syndrome (CRS)

Professor Diana Lennon
Ongoing study started January 1998

There were no reported cases in 2016.

Serious Paediatric Adverse Drug Reactions (ADR)

Dr Desiree Kunac, Dr Michael Tatley, Associate Professor David Reith, Professor Keith Grimwood

Study commenced August 2007.

Key Results for 2016

There were nine notifications made during 2016; however for 1 of these, no further details were provided, resulting in a total of eight reports received. Of the eight reports received, two were excluded, leaving 6 reports which are summarised below in Table 5:

The two exclusions were:

- An inadvertent household exposure to gamma hydroxbutyrate
- Aponea following 3 month immunisation in a premature infant where the temporal circumstances are unclear

Three of the six cases are new reports that were not previously notified to the Centre for Adverse Reactions Monitoring (CARM). All three cases resulted in a medical danger or warning being entered for the child in the national Medical Warning System and are now included in the CARM database to further enhance our understanding of serious ADRs in children.

Surveillance through the NZPSU has completed 10 years of data. This collection method is still proving to be very useful with new cases being identified that are not otherwise being reported to CARM.

Table 5: Information on the 3 reports of Serious Adverse Drug Reactions (ADR) notified through NZPSU in 2016. The column titled" Medical Warning" indicates those added to the national Medial Warning System, and that titled CARM indicates whether the adverse reaction has also been notified to the Centre for Adverse Reactions Monitoring (CARM).

Suspect Medicine	*Reaction(s)*	*Age (Years)*	*Seriousness/Outcome*	*Medical Warning*	*CARM*
Sildenafil	Agitation Confusion Behaviour abnormal Back arched backward Paroniria	0-4	Medically significant / recovered	Warning	No
Vemurafenib Cotrimoxazole	Fever convulsions Rash Leukocytosis Myalgia Sweet syndrome	5-14	Hospitalised/recovered	Warning	No
Atomoxetine	Suicidal ideation	5-14	Life threatening / recovered	Danger	Yes
Ethosuxamide	Agranulocytosis	5-14	Hospitalised/recovered	Warning	No
Montelukast	Behaviour abnormal Aggressive reaction	0-4	Medically significant / not yet recovered at time of report	Warning	Yes
Omeprazole	Neutropenia	0-4	Life threatening / not yet recovered at time of report	Danger	Yes

Complications of Tongue Tie Treatment

Dr Ben Wheeler
Two year study commenced August 2016

Key Results

In the period of data collection in 2016 (commenced 1st August 2016) we have received 3 reports to the NZPSU of complications of tongue-tie treatment.
Of the three cases:

- Two male, one female
- All three were New Zealand European
- All three had cases had breastfeeding difficulties as the indication for the tongue-tie treatment
- The presenting symptom for 2 cases was poor feeding, for the other case, it was pallor with " greyish black stools"
- One patient each from Auckland, Coromandel and Gisborne
- One patient required a one day admission to hospital
- One case required treatment for bleeding with diathermy and blood product replacement, this baby had an undiagnosed coagulopathy
- Of the two cases where it is known who performed the procedure, both were in private practice, with one by an Ear Nose and Throat surgeon, and the other by a dentist.

Possible Congenital Zika Syndrome and/or severe microcephaly

Dr Nigel Dickson
Two year study commenced August 2016

There were no reported cases in 2016.

Nationwide Surveillance of Paediatric Empyema in New Zealand 2014-2016

Katherine Rix-Trott[1], Catherine Byrnes[1,2], Jacob Twiss[1], Richard Matsas[3], James Hamill[1], Stephen Evans[1], Caroline Mahon[2], Deborah Williamson[4], Nigel Dickson[5], Tony Walls[5], Lesley Voss[1,]Emma Best[1,2]

1. Starship Children's Health, Auckland District Health Board, Auckland, New Zealand
2. Department of Paediatrics, University of Auckland, Auckland, New Zealand
3. KidzFirst Hospital, Counties Manukau District Health Board, Auckland
4. Institute of Environmental Science and Research, Wellington
5. University of Otago

Two year study commenced May 2014

Final Report: Key Results

Background:

- Empyema is a rare yet serious complication of childhood pneumonia
- Mortality in children is low
- Significant morbidity is associated with potential for surgical intervention, prolonged hospital stay and intensive care
- Incidence is increasing worldwide; despite reductions in pneumonia and invasive pneumococcal disease associated with pneumococcal conjugate vaccine (PCV)[1]
- *Streptococcus pneumoniae* is the most common causative organism with *Staphylococcus aureus* also important in NZ [2,3]

Aims:

- To document the burden of empyema in children aged <15 years including infectious aetiology, demographics and underlying conditions
- To describe surgical and medical management, complications and outcomes

Methods:

- Monthly notification of empyema cases in children aged 0-14 years admitted to hospital were notified to the New Zealand Paediatric Surveillance Unit (NZPSU) 1st May 2014 through to 1st June 2016.
- Clinician questionnaires were used to collect demographics, management, laboratory results, complications and outcomes.

Results:

- 127 notifications were received with 109 fulfilling the case definition and complete data available for 101 cases (93%)
- Annual incidence of empyema related hospitalisations was 5.7/100,000 in children <15 years

Demographics:

- Gender distribution 54% male
- Median age 3.8 years (range 2 months to 14.9 years)
- 61% aged < 5yrs
- 46% of cases lived in the greater Auckland area
- Immunisation status; Hib 92%, PCV≥ 3 doses 63%, Influenza <1%
- 26% of children had comorbidities ranging from mild asthma or eczema to immune-compromising conditions (such as Type 1 DM, neuroblastoma or polyarticular JIA on etanercept)

Microbiology:

- Causative organism was detected in 70%
- Of the 71 organisms detected *S. pneumoniae* was the most common organism followed by *S. aureus and S. pyogenes*

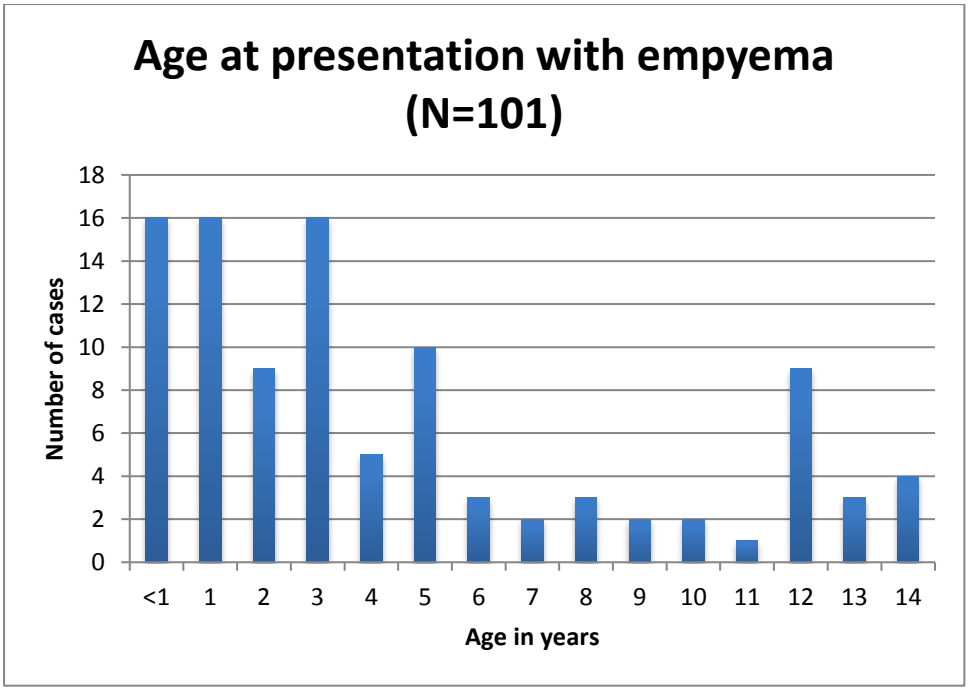
Management:

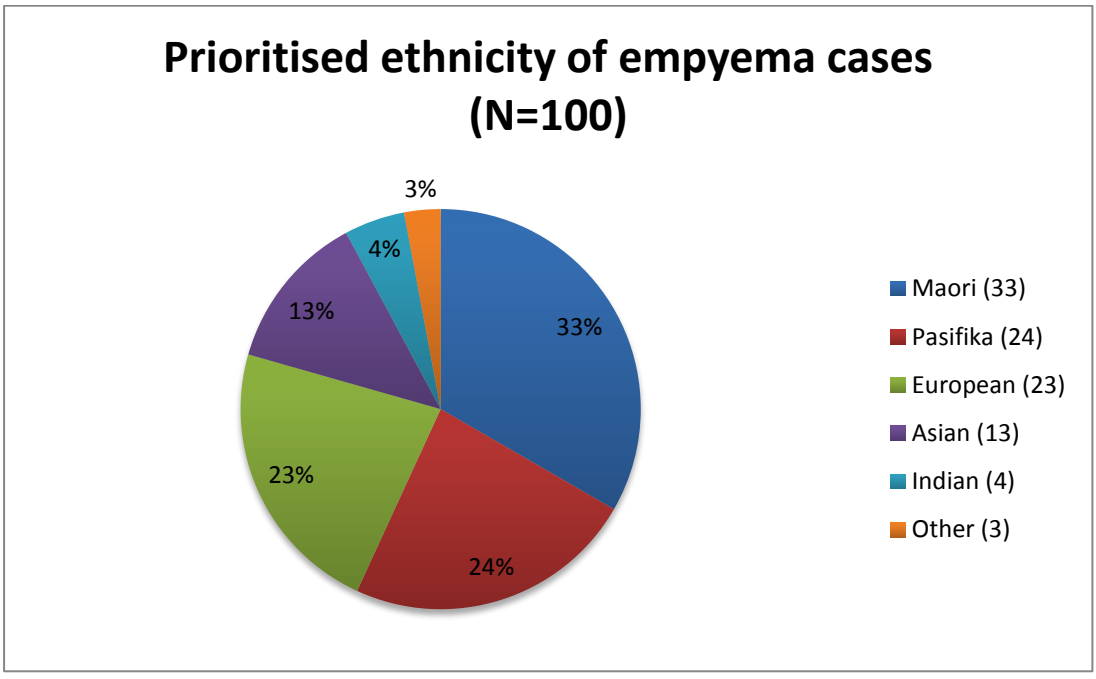
- 81% required surgical intervention including pleural aspirate alone, pleural drain, pleural drain+fibrinolytic, Video Assisted Thorascopic Surgery (VATS) or open thoracotomy
- 19% managed conservatively with IV antibiotics alone
- 87% of cases were treated with empiric antibiotics in line with clinical guidelines [4,5]

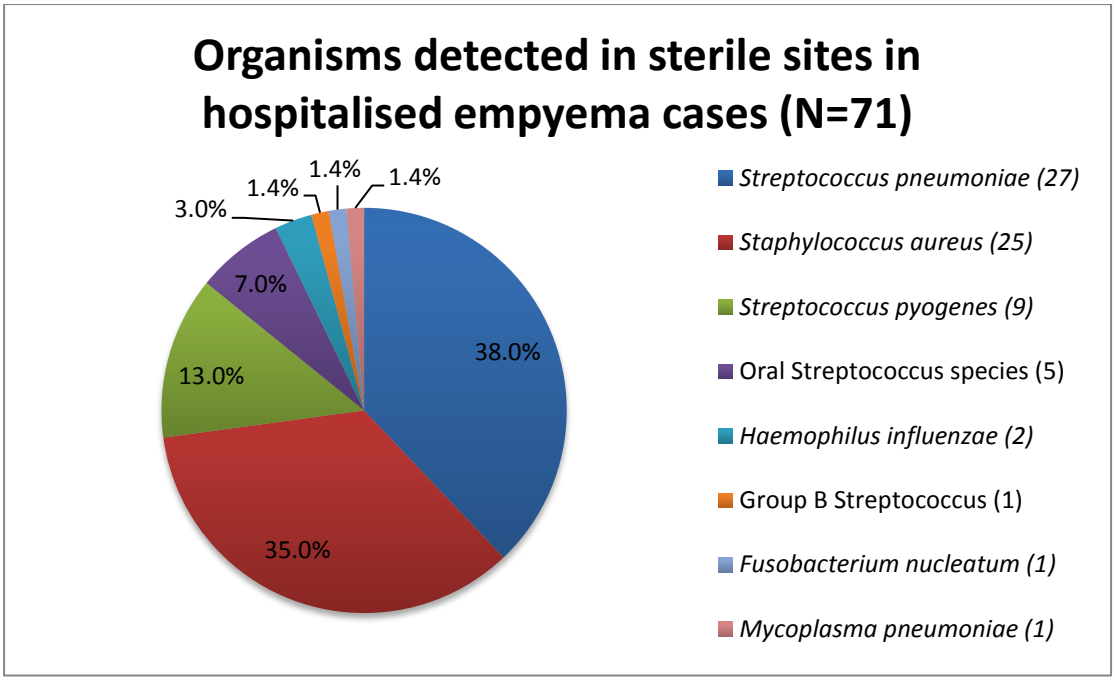
Hospital Stay:

- Mean length of hospital stay: 18 days (range 6 to 56 days)
- 32% of cases required intensive care unit admission
- Mean length of ICU stay: 9 days (range 1 to 36 days)
- No deaths attributed to empyema

Geographic Distribution of Cases by District Health Board (N = 101)


Age at presentation with empyema (N=101)
Number of cases
18
16
14
12
10
8
6
4
2
0
<1
1
2
3
4
5
6
7
8
9
10
11
12
13
14
Age in years


Prioritised ethnicity of empyema cases (N=100)
3%
4%
13%
33%
23%
24%
Maori (33)
Pasifika (24)
European (23)
Asian (13)
Indian (4)
Other (3)



(a) 4/25 (16%) S.aureus isolates were methicillin resistant (MRSA)
(b) Oral streptococci (n=5) consisted of S. constellatus (3), S. oralis (1), S.intermedius (1)

Discussion:

- Paediatric empyema rates in NZ appear higher than the UK (2.7/100,000) and Australia (<1/100,000) at 5.7/100,000
- Maori and Pasifika children were over-represented (33% and 24% of cases respectively)
- Nearly ¾ of empyema cases had a bacterial pathogen identified
- *S. pneumoniae* was the most common organism (38%) followed closely by *S. aureus* (35%) of which 20% were MRSA
- Increasing incidence of MSSA invasive disease is well reported in NZ with stable MRSA proportion but we report high MRSA in this cohort [6]
- Empyema cases reflect significant morbidity with a majority requiring surgical intervention, 1/3 requiring ICU, and prolonged hospitalization (18 days).

References:

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2. Burton C, Walls T, Price N,..Best EJ. Paediatric empyema in New Zealand: a tale of two cities. NZMJ. 2015; 128:25-33.
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Acknowledgements:
- Dr Peter W Reed, Statistician, Children's Research Centre, Starship Children's Health, ADHB
- New Zealand Paediatric Surveillance Unit staff and collaborators

CONDITIONS MONITORED BY NZPSU

Condition	Report Period	Findings Reported
Acute Flaccid Paralysis	1997 - ongoing	Chambers, S. T., & Dickson, N. (2011). Global polio eradication: progress, but determination and vigilance still needed. *The New Zealand Medical Journal (Online).* 124(1337) Desai, S., Smith, T., Thorley, B. R., Grenier, D., Dickson, N., Altpeter, E., & Zurynski, Y. (2015). Performance of acute flaccid paralysis surveillance compared with World Health Organization standards. *Journal of Paediatrics and Child Health*, *51*(2), 209-214.
Empyema	July 2014-July 2016	Rix-Trott, K., Best, E., Walls, T., Dickson, N., McCay, H., Wilson E., (2015) Nationwide surveillance of paediatric empyema in New Zealand 2014-2016. Conference presentation
Haemolytic Uraemic Syndrome	1998 - ongoing	Prestidge, C., & Wong, W. (2009). Ten years of pneumococcal-associated haemolytic uraemic syndrome in New Zealand children. *Journal of Paediatrics and Child Health*, *45*(12), 731-735.
Congenital Rubella Syndrome	1998 - ongoing	
Perinatal HIV Exposure	1998 - ongoing	Dickson, N., Paul, C., Wilkinson, L., Voss, L., & Rowley, S. (2002). Estimates of HIV prevalence among pregnant women in New Zealand. *New Zealand Public Health Reports*, *9*, 17-19.
Fetal Alcohol Syndrome	1999 - 2001	Leversha, A. M., & Marks, R. E. (1995). The prevalence of fetal alcohol syndrome in New Zealand. *The New Zealand Medical Journal*, *108*(1013), 502-505.
Subdural Haemorrhage	1999 - 2002	Kelly, P., & Farrant, B. (2008). Shaken baby syndrome in New Zealand, 2000–2002. *Journal of Paediatrics and Child Health*, *44*(3), 99-107.
Retinopathy of Prematurity (stage III)	1999 - 2000	
Diabetes Mellitus	1999 - 2000	Campbell-Stokes, P. L., & Taylor, B. J. (2005). Prospective incidence study of diabetes mellitus in New Zealand children aged 0 to 14 years. *Diabetologia*, *48*(4), 643-648.
Kawasaki Disease	2001 – 2002	Heaton, P., Wilson, N., Nicholson, R., Doran, J., Parsons, A., & Aiken, G. (2006) Kawasaki disease in New Zealand. *Journal of Paediatrics and Child Health*. 42(4), 184-190.

Bronchiectasis	2001 - 2002	Twiss, J., Metcalfe, R., Edwards, E., & Byrnes, C. (2005). New Zealand national incidence of bronchiectasis "too high" for a developed country. *Archives of disease in childhood*, *90*(7), 737-740. Twiss, J. (2008). *Childhood bronchiectasis: national incidence, disease progression and an evaluation of inhaled antibiotic therapy* (Doctoral dissertation, ResearchSpace@Auckland).
Idiopathic Nephrotic Syndrome	2001 - 2003	Wong, W. (2007). 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. *Journal of Paediatrics and Child Health*, *43*(5), 337-341.
Inflammatory Bowel Disease	2002 - 2003	Yap, J., Wesley, A., Mouat, S., & Chin, S. (2008). Paediatric inflammatory bowel disease in New Zealand. *The New Zealand Medical Journal (Online)*, *121*(1283).
Prolonged Infantile Cholestasis	2004 - 2005	
Pertussis	2004 - 2005	Somerville, R. L., Grant, C. C., Grimwood, K., Murdoch, D., Graham, D., Jackson, P.,& Purvis, D. (2007). Infants hospitalised with pertussis: estimating the true disease burden. *Journal of Paediatrics and Child Health*, *43*(9), 617-622.
Inborn Errors Of Metabolism	2004 - 2006	Wilson, C., Kerruish, N. J., Wilcken, B., Wiltshire, E., & Webster, D. (2007). The failure to diagnose inborn errors of metabolism in New Zealand: the case for expanded newborn screening. *The New Zealand Medical Journal (Online)*, *120*(1262).
Pneumococcal meningitis	2005 - 2008	Safar, A., Lennon, D., Stewart, J., Trenholme, A., Drinkovic, D., Peat, B., & Voss, L. (2011). Invasive group A streptococcal infection and vaccine implications, Auckland, New Zealand. *Emerging Infectious Diseases*, *17*(6), 983-9.
Acute Post Streptococcal Glomerulonephritis	2007 - 2011	Wong, W., Lennon, D. R., Crone, S., Neutze, J. M., & Reed, P. W. (2013). 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*, *49*(10), 850-855.
Adverse Drug Reactions (ADR)	2008-ongoing	Kunac, D. L., Kennedy, J., Austin, N., & Reith, D. (2009). Incidence, preventability, and impact of adverse drug events (ADEs) and potential ADEs in hospitalized children in New Zealand. *Pediatric Drugs*, *11*(2), 153-160.

Neonatal Bacterial or Fungal Infection	2011-2013	Darlow, B. A., Voss, L., Lennon, D. R., & Grimwood, K. (2016). Early-onset neonatal group B streptococcus sepsis following national risk-based prevention guidelines. *Australian and New Zealand Journal of Obstetrics and Gynaecology*, *56*(1), 69-74.
Pertussis	2004 - 2005	Somerville, R. L., Grant, C. C., Grimwood, K., Murdoch, D., Graham, D., Jackson, P.,& Purvis, D. (2007). Infants hospitalised with pertussis: estimating the true disease burden. *Journal of Paediatrics and Child Health*, *43*(9), 617-622.
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Neonatal Bacterial or Fungal Infection	2011-2013	Darlow, B. A., Voss, L., Lennon, D. R., & Grimwood, K. (2016). Early-onset neonatal group B streptococcus sepsis following national risk-based prevention guidelines. *Australian and New Zealand Journal of Obstetrics and Gynaecology*, *56*(1), 69-74.
Severe Neonatal Hyperbilirubinaemia	2011-2013	
Moderate and Severe Neonatal Encephalopathy	2011-2013	Battin, M., Sadler, L., Masson, V., & Farquhar, C. (2016). Neonatal encephalopathy in New Zealand: Demographics and clinical outcome. *Journal of Paediatrics and Child Health*.
Vitamin D Deficiency Rickets	2011-2013	Wheeler, B. J., Dickson, N. P., Houghton, L. A., Ward, L. M., & Taylor, B. J. (2015). 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*, *39*(4), 380-383.
Renal Stones	2011 - retrospective	Dickson, Nigel, Tonya Kara, and Pat Tuohy. "Rapid national survey of renal stones in New Zealand infants." *Journal of Paediatrics and Child Health* 45.11 (2009): 633-635.
Varicella and post-varicella complications	2011-2013	Wen, S. C. H., Best, E., Walls, T., Dickson, N., McCay, H., & Wilson, E. (2015). Prospective surveillance of hospitalisations associated with varicella in New Zealand children. *Journal of Paediatrics and Child Health*, *51*(11), 1078-1083.

Vitamin K Deficiency Bleeding	1998-2008	Darlow, B. A. (2004). 60 Vitamin K Deficiency Bleeding (VKDB) in New Zealand Infants: Results of Surveillance Over Five Years (1998 to 2002). *Pediatric Research*, *56*(3), 474-474. Darlow, B. A., Phillips, A. A., & Dickson, N. P. (2011). New Zealand surveillance of neonatal vitamin K deficiency bleeding (VKDB): 1998–2008. *Journal of Paediatrics and Child Health*, *47*(7), 460-464.
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INTERNATIONAL NETWORK OF PAEDIATRIC SURVEILLANCE UNITS

Establishment of INoPSU

The network was formed in August 1998 at a meeting of 10 Paediatric Surveillance Units expressing a desire to link with each other. This took place at the 22nd International Congress of Paediatrics in Amsterdam, The Netherlands. The first INoPSU conference was held in 2000 in Canada and was attended by representatives of the existing units. Subsequent meetings have been held in York England, Lisbon, Portugal, Munich Germany and Melbourne. Associate Professor Nigel Dickson has attended the meetings in Canada, England, Portugal and Melbourne.

Mission

The mission of INoPSU is the advancement of knowledge of uncommon childhood infections and disorders, and the participation of paediatricians in surveillance on national and international basis so as to achieve facilitating communication and co-operation between existing national paediatric surveillance units;

Aims

- 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 and 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 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 co-operative surveys through each national unit;
- To collaborate with, and provide information to, other interest groups interested in rare childhood diseases such as parent support groups; and
- To respond promptly to international emergencies relating to rare childhood conditions where national and international studies where national and international studies can make a contribution to science or public health.

There are currently 12 surveillance units that form the INOPSU network.

Table 6: **Members of INoPSU**

Country	Unit	Email	Website
Australia	APSU	apsu@chw.edu.au	www.apsu.org.au
Belgium	BSU	*under development*	*under development*
Britain	BPSU	bpsu@rcpch.ac.uk	www.rcpch.ac.uk/bpsu
Canada	CPSP	cpsp@cps.ca	www.cps.ca/cpsp
Germany	ESPED	prof.von.kries@gmx.de	www.esped.uni-duesseldorf.de
Greece and Cyprus	GCPSU	npersianis@cytanet.com.cy	
Ireland	IPSU	gilld@iol.ie	
Netherlands	NSCK	rob.rodiriguepereira@tno.nl	www.nvk.pedianef.nl
New Zealand	NZPSU	nzpsu@otago.ac.nz	www.otago.ac.nz/nzpsu
Portugal	PPSU	uvp-spp@ptnetbiz.pt	www.spp.pf/ingl/index_17.html
Switzerland	SPSU	mirjam.maeusezahl@bag.admin.ch	www.spsu.ch
Wales	WPSU	oconnellHl@cardiff.ac.uk	www.welsh-paediatrics.org.uk/wpsu

Table 7: **Characteristics of the Paediatric Surveillance Units**

Country	Population (x10^6<15 years)	Established	Approximate number of respondents
Australia	4.1	1992	1360
Belgium			
Britain	12.8	1986	3300
Canada	7.5	1996	2500
Germany	12.0	1992	460*
Greece and Cyprus	1.6	2001	
Ireland	1.3	1996	150
Netherlands	3.0	1992	780
Portugal	1.67	2000	1506
New Zealand	0.86	1997	250
Switzerland	1.3	1995	250
Wales	0.56	1994	135*

*Heads of Paediatric Centres

LIST OF CLINICIANS : RETURN RATE 2016

Clinicians who had 100% return rate in 2015 and 2016 are underlined

Aikin, Richard	Asher, Innes	Ayers, Rosemary	Bach, Kitty
Bates, Giles	Battin, Malcolm	Best, Emma	Bishop, Jon
Baker, Nic	Blair, Nikki	Bloomfield, Frank	Bloomfield, Guy
Bond, David	Bradley, Stephen	Bremner, Catherine	Broadbent, Roland
Brooks, Jeanine	Brown, Jeff	Brynes, Cass	Buckley, David
Buskh, Mariam	Campanella, Silvana	Campbell, Moira	Campbell-Stokes, P
Carter, Philippa	Chang, Emily	Chin, Simon	Clark, Philippa
Cole, Nyree	Corban, Jenny	Corbett, Rob	Coulter, Belinda
Craig, Angela	Craine, Karina	Crone, Sonya	Cunningham, Vicky
Currie, Sarah	Dalton, Marguerite	Dalziel, Stuart	Daniel, Alison
Darlow, Brian	Day, Andrew	De Lore, Danny	Dickson, Cameron
Dixon, Bronwyn	Dixon, Joanne	Doocey, Clare	Drake, Ross
Edmonds, Liza	Edward, Kathryn	Elder, Dawn	Evans, Helen
Farrant, Bridget	Fischer, Annette	Ferguson, Janet	Fleming, John
Ford, Rodney	Forster, Richard	Gapes, Stephanie	Garrett, John
Gangkhedkar, Arun	Gavin, Raewyn	Gentles, Tom	Geddes, Janet
Goldsmith, John	Goodwin, Mick	Graham, Dave	Grangaard, Erik
Grant, Cameron	Grant, Shaun	Grupp, Oliver	Gunn, Alistair
Hainsworth, Oliver	Harding, Jane	Hewson, Michael	Hector-Taylor, James
Hegarty, Jo	Hoare, Simon	Hou, David	Hobbs, Vivienne
Hofman, Paul	Hornung, Tim	Hunter, Warwick	Hunter, Wendy
Jellyman, Timothy	Jordan, Nicola	Kamphambe, Willie	Kelly, Andrew
Kelly, Patrick	Laughton, Stephen	Lala, Anita	Law, Michelle
Leadbitter, Philip	Lear, Graham	Lennon, Diana	Liang, Allen
Lynn, Adrienne	Lyver, Amanda	Maulidi, Halima	Marks, Rosemary
Marshall, Andrew	Matsas, Richard	Maxwell, Fraser	McArthur, John
McCarthy,Karen	McCay, Hamish	McFarlene, Scott	McIllroy, Peter
McKie, Jill	Meyer, Michael	Mildenhall, Lindsay	Momsen, Tracey
Moore, Philip	Sarah Mils	Anna Murphy	Morrison, Philip
Munro, Karen	Nair, Arun	Neas, Katherine	Nelson, Nicola
Nicholson, Ross	Nolan, Melinda	Nutthal, Gabrielle	Orr, Nigel
Ostring, Genevieve	Pattemore, Philip	Perira, Nicola	Purvis, Diana
Raithatha, Meera	Pinnock, Ralph	Ramadas, Ram	Reith, David
Robertson, Stephen	Robinson, Stephen	Robertshaw, Kate	Rowley, Simon
Sadlier, Lynette	Selby, Roslyn	Schmidt Uli, Meia	Sharpe, Cia
Shaw, Ian	Shaw, Robyn	Shepherd, Michael	Shillito, Paul
Sinclair, Jan	Siversten, Louise	Skeen, Jane	Skinner, Jon
Smiley, Richard	Smith, David	Sommerville, Rebecca	St John, Martyn
Stanley, Thorsten	Stanley, Clare	Steinmann, Kai	Stonehouse, Mary
Taylor, Barry	Thomson, Janine	Trani, Paul	Trenholme, Adrian

Tomlinson, Paul	Townsend, Tom	Tsang, Bobby	Tuck, Katie
Tuck, Roger	Twiss, Jacob	Van de Boom, Jutta	Vogel, Alison
Voss, Lesley	Walls, Tony	Walker, Wendy	Webster, Diane
Webster, Nicky	West, Clare	Weston, Phil	Wheeler, Ben
Wilde, Justin	Williams, Gregory	Wilson, Callum	Wilson, Elizabeth
Wilson, Nigel	Wilson, Ross	Wilson, Toni	Wiltshire, Esko
Winstanley, Mark	Wong, Sharon	Wong, William	Yan, Jacqui