SUPPORT FOR NEW PARENTS AND BABIES IN NEW SOUTH WALES

Organisation:	NSW Ombudsman
Name:	Professor John McMillan
Position:	A/Ombudsman Convenor, NSW Child Death Review Team
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ABN 76 325 886 267





Level 24, 580 George Street, Sydney NSW 2000

T 02 9286 1000 | **F** 02 9283 2911 **Tollfree** 1800 451 524 | **TTY** 02 9264 8050

www.ombo.nsw.gov.au

The Hon. Kevin Conolly MP Chair Committee on Community Services Parliament House Macquarie Street Sydney NSW 2000

By email: communityservices@parliament.nsw.gov.au

Dear Mr Conolly

Inquiry into support for new parents and babies in NSW

Thank you for the opportunity to make a submission to the Inquiry into support for new parents and babies in New South Wales by the Committee on Community Services.

As the Committee is aware, the NSW Child Death Review Team and NSW Ombudsman have a broad range of functions aimed at preventing or reducing the likelihood of child deaths in NSW. Our work informs the submission attached here.

I trust that the information provided will assist the Committee in conducting its Inquiry. If further information is required, please do not hesitate to contact Monica Wolf, Director, Reviews, Inquiries and Complaints on

Yours sincerely

Professor John McMillan Acting Ombudsman Convenor, NSW Child Death Review Team

November 2017

Submission to the Committee on Community Services Inquiry into support for new parents and babies in New South Wales

November 2017

1. Background: the NSW Child Death Review Team

Since 1996, the NSW Child Death Review Team (CDRT) has been responsible for registering, reviewing and reporting to the NSW Parliament on all deaths of children aged from birth to 17 years in NSW.

The work of the CDRT is governed by Part 5A of the *Community Services (Complaints, Reviews and Monitoring) Act 1993* (CS CRAMA).

CDRT membership is prescribed by the Act. Members are:

- the NSW Ombudsman, who is the Convenor of the Team
- the Advocate for children and young people
- the Community and Disability Services Commissioner
- two persons who are Aboriginal
- representatives from NSW government agencies, including NSW Health, NSW Police Force, Department of Family and Community Services, Department of Education, and Department of Attorney General and Justice
- experts in health care, research methodology, child development or child protection, or persons who are likely to make a valuable contribution to the Team.

The Ombudsman, the Advocate and the Commissioner are statutory appointments.

Separately, and under Part 6 of CS CRAMA, the NSW Ombudsman is responsible for reviewing the deaths of children in circumstances of abuse or neglect, or in suspicious circumstances, and children who die in care or detention ('reviewable deaths').

The purpose of both functions is to prevent or reduce the deaths of children in NSW. To this end, we:

- maintain a register of child deaths in NSW
- classify deaths in the register according to cause, demographic criteria and other relevant factors, and identify trends and patterns relating to those deaths
- undertake research either alone or with others that aims to help prevent or reduce the likelihood of child deaths, and to identify areas requiring further research, and
- make recommendations as to legislation, policies, practices and services that can be implemented by government and non-government agencies and the community to prevent or reduce the likelihood of child deaths.

Our reviews

The main purpose of our review work is to identify opportunities for preventing the deaths

of children and young people. This is at two levels:

- at an individual level the circumstances of death may highlight a particular risk.
- at a population level we may be able to identify trends that point to the need for action to prevent deaths in certain demographic groups or from certain causes.

The NSW Registry of Births, Deaths and Marriages provides us with initial information about the deaths of children. Under CS CRAMA, certain agencies and individuals are required to provide information that we reasonably require to fulfil our functions. We seek and receive records from a wide range of sources, including health providers, forensic services, the State Coroner, the Department of Family and Community Services and other government and non-government agencies as relevant.

Information gained from reviews is placed on the child death register. The register informs our reports of child deaths to the NSW Parliament, and research initiatives that focus on the prevention of deaths of children in NSW.

Our reports

Both the CDRT and the Ombudsman are required to prepare a biennial report to the NSW Parliament about our work. Our functions also include research focused on prevention of child deaths. Below are links to reports relevant to your inquiry:

- Child Deaths from Vaccine Preventable Infectious Diseases, NSW 2005-2014 (August 2016) <u>https://www.ombo.nsw.gov.au/__data/assets/pdf_file/0019/39412/NCIRS-</u> <u>child-deaths-from-infectious-diseases-report-2016-NSW-Ombudsman-final-1.pdf</u>
- Child death review report 2015 (November 2016)
 https://www.ombo.nsw.gov.au/_data/assets/pdf_file/0009/39474/CDRT_review_report_2015_final.pdf
- Report of Reviewable Deaths in 2014 and 2015, Volume 1: Child Deaths (June 2017) https://www.ombo.nsw.gov.au/_data/assets/pdf_file/0004/45805/Report-of-reviewable-deaths-2014-and-2105_Child-deaths_Vol1_June17.pdf
- Childhood injury prevention: Strategic directions for coordination in New South Wales (November 2017)
 https://www.ombo.nsw.gov.au/__data/assets/pdf_file/0009/50130/Childhood-injury-prevention-strategic-directions-for-coordination-in-New-South-Wales.pdf

This submission

The following information provides:

- An overview of deaths of infants, drawn from the NSW Child Death Register
- Issues for consideration by the Inquiry, based on our recent work relating to vaccine preventable infectious disease, Sudden Unexpected Death in Infancy, and abuse and neglect-related deaths of infants.

2. Overview: deaths of infants under one year

Over the past 10 years, the NSW child death register has recorded the deaths of 5501 children aged from birth to 17 years.¹ Over this period, there has been an ongoing decline in mortality rates for children across all age groups, primarily due to a significant decline in the rate of death of children from natural causes.

The majority of children who die in NSW are infants aged less than 12 months. Consistent with the overall decline in child mortality rates, infant mortality rates in NSW have also declined considerably.

Of the 5501 child deaths, infants less than 12 months of age accounted for more than half (3392, 61.7%) of these deaths.

Information from the NSW Child Death Register shows that:

- nearly three-quarters of the infants (2477, 73.02%) died in the neonatal period within 28 days of their birth; of these, more than half (2044, 60.3%) died within the first week of life.
- just over half the infants (1925, 56.8%) were male; and 1467 (43.2%) were female. The mortality rate for male infants has been significantly higher than female infants over the past decade.
- while Aboriginal and Torres Strait Islander infants represent around five per cent of all infants,⁴ they accounted for approximately ten per cent (10.2%) of infant deaths. The mortality rate for Aboriginal and Torres Strait Islander children in NSW, including infants, has consistently been significantly higher than comparable rates for non-Indigenous children.
- over half of the families of infants who died (53.3%) resided in areas of the greatest socio-economic disadvantage.⁵
- most infants die from natural causes of the 3149 cases where a cause of death was identified, almost all (3063, 97.3%) the infants died as a result of natural causes. Conditions arising in the perinatal period (such as prematurity; respiratory and cardiovascular disorders; and maternal factors) and congenital and chromosomal conditions (for example, heart and neural tube defects and developmental disorders) accounted for most (2628, 85.8%) of these deaths; with the majority occurring in the first 28 days of life (neonatal period).
- eighty-six infants (2.7%) died from external causes, including abuse (12), drowning (10) – primarily in bathtubs, transport incidents (9) and other unintentional injury-related causes (55) – mainly accidental suffocation or strangulation in an unsafe sleeping environment (43 of the 55).
- a cause of death was not able to be identified for 210 infants (6.2%), even after thorough investigation including post-mortem examination.⁶

¹ Deaths that occurred between 1 January 2007 and 31 December 2016.

⁴ Australian Bureau of Statistics (2013), *3101.0 Australian Demographic Statistics (TABLE 51. New South Wales, 2013)*, Canberra: ABS; Australian Bureau of Statistics (2012), *Indigenous experimental population projections by age, by sex – Reference period 2011*, Canberra: ABS.

⁵ Calculated on data for the period 2011-2015.

⁶ Final coronial information/cause of death information is not yet available for 33 infants.

3. Issues for consideration

Vaccine preventable infectious disease

Infectious diseases are caused by organisms such as bacteria, viruses, parasites or fungi and can be passed directly or indirectly from person to person. Examples include bacterial diseases such as pertussis (whooping cough), meningococcal infection and sepsis; and viral infections such as viral encephalitis, viral meningitis, and measles.

While child deaths due to vaccine preventable diseases are now rare in Australia, small numbers of deaths due to pneumococcal disease, meningococcal disease, pertussis, influenza and varicella have been reported in recent years. Over the last 15 years, 155 children in NSW died from infectious and parasitic diseases. The majority of children who died from this cause in the period were under five years of age, and male children consistently outnumbered females.

In 2014, the CDRT commissioned the National Centre for Immunisation Research and Surveillance (NCIRS) to analyse data held in the NSW Child Death Register regarding deaths from infectious diseases, over the 10-year period 2005-2014. A copy of the final report is appended to this submission.

The review found that despite the existence of a successful national immunisation program, deaths of children from potentially preventable infectious diseases continue to occur in NSW, particularly among infants. The review made a number of recommendations, including that:

- General practitioners and other immunisation providers should ensure that they
 are aware of the recommendations on influenza and meningococcal B vaccination
 in the Australian Immunisation Handbook, including that influenza vaccination is
 recommended for infants aged from six months, and meningococcal B vaccination
 is recommended for infants and young children.
- Immunisation of person's in contact with, and caring for, infants under 6 months at high risk of influenza, pertussis and varicella is recommended and should be promoted, particularly if vaccination has not been received in pregnancy; and also that comprehensive immunisation programs for workers in facilities that provide health care or child care services for high risk children and infants should be implemented.
- Pertussis and influenza vaccination during pregnancy should be promoted and encouraged by general practitioners, obstetricians and midwives to reduce the risk of disease in young infants.

It is worth noting that free seasonal influenza vaccine is currently only available for certain people, including Aboriginal and Torres Strait Islander children aged 6 months to 5 years, pregnant women, and people aged 6 months and over with medical conditions predisposing to severe influenza (such as cardiac disease, chronic respiratory conditions, and impaired immunity).

Influenza infection during pregnancy can lead to premature delivery and even death in newborns and very young babies. NSW Health reports that while influenza vaccination

represents the best protection pregnant women and their newborn babies have against influenza, vaccination rates remain low with only 1 in 3 pregnant women receiving the vaccine. Detailed further information in relation to influenza vaccination can be found at: http://www.health.nsw.gov.au/immunisation/pages/seasonal_flu_vaccination.aspx

Sudden Unexpected death in Infancy

In recent years the CDRT has undertaken considerable work in relation to this issue.

SUDI is a classification rather than a cause of death. The CDRT defines SUDI as the death of an infant aged less than 12 months that is sudden and unexpected, where the cause was not immediately apparent at the time of death. Excluded from this definition are infants who died unexpectedly as a result of injury – for example, transport fatalities – and deaths that occurred in the course of a known acute illness in a previously healthy infant.

The infant mortality rate for SUDI has, overall, declined since 2001. Notably, however, the rate has not changed significantly since 2008. In addition, the overall decline reflects a change in post-neonatal SUDI (infants older than 28 days).

Over the past 10 years, 497 of the 3392 infant deaths (14.7%) have been classified as SUDI. The majority of these infants had been placed for sleep, either on their own or with others. Other infants died after being placed for the purpose of feeding or settling, which in most cases resulted in unintentional bed sharing. A small number of infants were suddenly taken ill and were attended by emergency services.

Our reviews have found that many of the infants whose deaths are classified as SUDI were in unsafe (non-infant specific) sleep environments when they died, including infants who were sharing a sleep surface or who had been placed for sleep in an adult bed or on a couch. Other infants died in circumstances where risk factors such as prone sleeping and/or loose bedding were evident. The majority of infants were also found to have been exposed to tobacco smoke.

It is critical that clear messages about safe sleep and safe environments are developed and delivered effectively, and that resources are made available to support families to make choices that avoid exposing babies to external factors associated with increased risk of SUDI. Health professionals who have contact with babies, infants, expectant parents, or families with babies, have a significant role in the reduction of the incidence of SUDI by providing and promoting consistent information and modelling safer sleeping practices. The Team has made recommendations to NSW Health in relation to the promotion of safe sleeping practices, and are actively monitoring the progress of initiatives.

SUDI is disproportionately affecting infants in disadvantaged and vulnerable families

SUDI affects families from all socio-economic backgrounds; however increasingly, it is families residing in areas of low socio-economic advantage; families with a child protection history; and Aboriginal and Torres Strait Islander families that are over-represented in SUDI. Over the five years from 2011 to 2015, almost 50% of SUDI were from families living in areas of greatest socio-economic disadvantage.

The CDRT have identified there is a clear need to better target initiatives to work effectively with vulnerable families to promote safe sleeping and other preventative practices. Red Nose (formerly SIDS and Kids) has also identified the area of vulnerable populations in high income countries as a key area for priority to improve outcomes in child mortality and to prevent SUDI.

These findings highlight the important role of NSW Health and FACS to target safe sleeping and other risk-related messages specifically to disadvantaged families. The CDRT have recommended that FACS and NSW Health should jointly consider the applicability of relevant initiatives in other jurisdictions that target high risk populations. The CDRT has also recommended agencies review strategies targeted to young mothers, including use of alternative avenues of advice through social media and parenting blogs, and targeting grandmothers for safe sleep education.

Our work, and that of FACS, has also highlighted the need for child protection caseworkers to focus on SUDI risk factors in families caring for an infant, particularly when assessing risk in the context of parental drug use

The proportion of explained SUDI is unacceptably low

Deaths classified as SUDI are either:

- explained SUDI deaths where a cause is found after investigation, or
- unexplained SUDI deaths where the cause remains unidentified after all investigations are completed. This includes deaths that are classified as Sudden Infant Death Syndrome (SIDS).

Most (326, 65.6%) of the 497 deaths classified as SUDI are unexplained; with explained SUDI accounting for less than one-third (145, 29.2%) of sudden and unexpected infant deaths. In cases where a cause of death is subsequently identified, most (90, 62.1%) are found to be due to natural causes following post-mortem examination. Other explained SUDI are, in the main, due to external causes such as unintentional threats to breathing, as well as rarely, assault and drowning.

Identifying a cause of death for SUDI is important for a number of reasons:

- for parents and carers, to understand their loss
- to provide information about possible medical or genetic implications for the family
- to learn from untimely deaths and help prevent future deaths, and
- to identify any possible suspicious deaths.

In NSW, a cause of death is able to be determined (on average) in less than one-third of SUDI. This is much lower than best practice, which indicates the proportion of explained SUDI should be closer to half.⁹

Identification of a cause of death requires a timely, expert-led and comprehensive

⁹ Garstang J, Ellis C, Sidebotham P (2015), An evidence-based guide to the investigation of sudden unexpected death in infancy, *Forensic Science, Medicine and Pathology* DOI.1007/s 12024-015-9680, Springer, New York.

investigation following the sudden and unexpected death of an infant.

SUDI investigation in NSW involves the NSW Police Force, NSW Health (including forensic services), and the State Coroner; however, there is currently no whole-of-government policy to direct the cross-agency coordination of responses to SUDI.

The CDRT has identified significant gaps in investigation of SUDI in NSW. In order to improve identification of cause of death, and therefore to potentially help to prevent SUDI in the future, the CDRT has recommended a clear whole-of-government directive should govern SUDI investigation in NSW. A revised model, drawing on contemporary recognised best practice, should incorporate strategies that are not part of the current approach, including:

- Expert paediatric assistance in death scene investigation and interviews with the family (noting that investigation of any suspicious deaths would be the responsibility of police).
- Specialised training and development of resources for police in SUDI investigation.
- The conduct of SUDI post mortems by specialist paediatric pathologists, or minimally, consultation with paediatric specialists.
- The introduction of multi disciplinary review following post mortem to consider all available information and provide advice to assist the Coroner in determining cause of death, to advise on possible genetic issues and necessary investigations for surviving children and parents, and prevention strategies for the family in the context of identified risks.

At the time of writing, we note there is broad support for a change in the approach to SUDI investigation across agencies with a role in responding to SUDI. The NSW Government has advised it is currently consulting with agencies on options to improve the whole-of-government response to SUDI. The CDRT welcomes this support and will continue to actively monitor and report on progress in this area.

Abuse and neglect

Child protection history

In 2014, the CDRT tabled a special report to Parliament on the causes of death of children with a child protection history between 2002 and 2011. The analysis for this report was undertaken by the Australian Institute of Health and Welfare.¹⁰

In relation to infants under one year of age, the research found that a child protection history significantly increased the odds that a baby would die:

• suddenly and unexpectedly (SUDI)

¹⁰ NSW Child Death Review Team (2014) *Causes of death of children with a child protection history 2002-2011*, report by the Australian Institute of Health and Welfare. NSW Ombudsman, Sydney. The report can be accessed from our website - <u>https://www.ombo.nsw.gov.au/news-and-publications/publications/reports/child-death-review-team/causes-of-death-of-children-with-a-child-protection-history-2002-2011-special-report-to-parliament</u>

- from external (injury-related) causes, including unintentional causes such as accidental suffocation or strangulation in bed, and drowning; and from intentional causes (abuse)
- from respiratory illnesses, such as influenza and pneumonia.

In addition, the analysis found a higher proportion of deaths of babies with a child protection history remained unexplained, compared with babies without a child protection history.¹²

Children with a child protection history are, by definition, a vulnerable group. Identifying both natural and external causes of death where these children have a significantly higher risk of death is important for progressing work related to the prevention of future deaths. Of relevance to the current Inquiry, the findings highlight the potential importance of universal early intervention services in identifying families where additional supports may be required, and point to possible opportunities for future work in the targeting of prevention strategies. The research also supports the findings and recommendations of the Team in relation to SUDI, and underscores the importance of this work.

Abuse and neglect-related deaths of infants

The NSW Ombudsman's work in relation to 'reviewable' child deaths has established that very young children (0-4 years) are over-represented in abuse and neglect-related deaths.

Abuse and neglect-related deaths represent a small but significant proportion of child deaths in NSW – approximately four percent of all child deaths.

Over the past 10 years, 210 children died in circumstances of abuse or neglect. Just over one-quarter of these deaths (60, 28.6%) involved infants under the age of 12 months; 43 infants died in circumstances of neglect, and 17 due to abuse.¹⁴ The majority (47) of these infants had a child protection history.

Neglect-related deaths

Cases are considered neglectful because the actions of a carer are identified as significantly careless or an intentional or reckless failure to adequately supervise, or result from the failure to provide for a child's basic needs, including food, shelter and medical care.

Most neglect-related infant deaths (36 of 43) are classified as SUDI. The seven infants whose deaths were not classified as SUDI died from drowning (5), in a transport incident (1) and from injuries sustained during an unassisted birth (1).

For the 36 infants where cause of death was not immediately apparent at the time of the fatal incident, a cause of death was subsequently identified for one-third (12) of the infants: four infants died from natural causes (mainly pneumonia-related); the remaining eight deaths were due to external causes, primarily accidental suffocation or strangulation in an unsafe sleep environment.

¹² NSW Child Death Review Team (2014), *Causes of death of children with a child protection history 2002-*2011, special report to Parliament, Sydney: NSW Ombudsman.

¹⁴ Including deaths that occurred in circumstances that were 'suspicious' of abuse or neglect.

A context of unsafe sleeping was also a key factor in almost all the cases which remained unexplained after investigation (22 of the 24 cases); in most (16) instances infants were co-sleeping with a drug and/or alcohol affected parent(s), and an element of accidental asphyxia could not be excluded with certainty. In other cases infants were left to sleep overnight in bouncers, placed to sleep in broken cots or bassinettes filled with excessive bedding or other objects that posed a clear suffocation risk, or were left unattended for excessive periods of time in unsafe situations.

Regardless of whether a cause of death was identified, the cases raise strong themes of severe environmental neglect beyond the immediate circumstances of death, and a lack of attention to the needs of very young infants by their carers which is often associated with parental drug or alcohol use, but also with transience, overcrowding, and other family dysfunction.

Abuse-related deaths

Unlike neglect, only a small number of abuse-related infant deaths are classified as SUDI. This is because in most cases (12 of 17), the infant was presented to health professionals with obvious life-threatening non-accidental injuries, or the circumstances surrounding the fatal incident clearly indicated intentional harm. For those cases where no signs of intentional injury were immediately apparent, evidence of suspicious injury was found during autopsy, and/or concerns about abuse were identified by police during their investigation.¹⁵

Parents, or a person acting in a caring role, are almost always (16 of the 17 cases) found to be responsible in cases of infant homicide. In some (3) cases, both parents are implicated; however in most (9) instances the father or male defacto partner of the mother was identified as having caused the fatal injuries. A mother was responsible for the death of her infant in four cases, including one case where the mother was suffering from a severe undiagnosed mental illness.

Our reviews of abuse-related deaths have found, amongst other things, that young children are most vulnerable to fatal abuse; that the nature and extent of risk is not always recognised or understood; and that frontline services, particularly maternity and early childhood services, have a key role in identifying and responding to child protection issues in vulnerable families, particularly in response to physical injury and mental health.

Observations in relation to abuse and neglect

Maternal mental health

The issue of maternal mental health, and support to children of parents with mental illness, is one area where the NSW Ombudsman has undertaken considerable work.

In 2014-15, we investigated the actions of agencies in response to concerns about the safety and welfare of a toddler who died in circumstances of abuse. The child and family had complex needs, and as a result, the family was provided with a high level of support from a number of agencies. In this context, it was important that the actions of all involved agencies were coordinated and informed by the interventions, strategies,

¹⁵ Includes two cases where final coronial information is not yet available.

identified issues and outcomes of work by other involved agencies. Our investigations found that this was not the case. We found that:

- Despite the family's significant contact with services, none of the involved agencies sought to bring all of the parties together to:
 - clarify the roles and responsibilities of each agency
 - discuss the child protection risks and how these would be monitored and escalated if required
 - discuss what and when information needed to be shared between the agencies, and
 - o agree on a plan for coordinating the provision of services.
- There was inadequate communication between relevant services about the progress and outcome of respective service interventions as a result, it appeared that agencies often made assumptions about the nature, effectiveness and protective impact of work by other agencies.
- Some practitioners tended to respond to changes in family circumstances by making new referrals, rather than reviewing the effectiveness of existing interventions or therapeutic strategies, and adjusting the intensity or focus as indicated. Although it was not always evident what improvements were being achieved by the involvement of multiple services, it appeared that for some practitioners, the number of services involved was in and of itself considered protective for the child.

The circumstances of the child's death resulted in internal reviews by involved agencies, and interagency discussions to identify barriers to good practice and strategies for change.

The issues identified in this case in relation to the need for a coordinated approach by agencies are relevant in many cases, and are closely linked with the concept of shared responsibility, a hallmark of the NSW child protection system since 2010. It refers to the principle that child protection is the collective responsibility of the whole-of-government and the community.

Our previous reports of reviewable child deaths have noted the ongoing and significant challenges for agencies in engaging and responding effectively to families with complex needs. We have also highlighted the importance of early assessment and intervention, and effective coordination and collaboration between agencies working with these families.

Drug and alcohol misuse

The risks to infants and children associated with carer substance abuse are well known, and where parenting capacity is affected, the impact on babies and young children can be significant. Carer substance abuse was a significant issue in reviews of abuse and neglect-related deaths.

In 2015, we reported on initiatives by FACS and NSW Health to improve responses to risks to children in the context of parental substance abuse, and strengthen guidance for workers. We note that NSW Health funds Drugs in Pregnancy Services across NSW, which are designed to improve the management of substance use in pregnancy and to

improve follow up services for families.

In 2017, we undertook a review of children who died in neglect-related circumstances over the ten-year period 2006-2015. The group included 49 infants under 12 months old (over one-third of all cases considered), reflecting the vulnerability of very young children and their strong reliance on carers to meet their basic needs and to keep them safe. Our review identified that alcohol and/or other drug abuse was the most significant single risk factor contributing to the neglect-related deaths of children, and the predominant risk in the background of the children who died.

Following on from the cohort review and our previous work in this area, we are currently undertaking a further research project focusing specifically on the role of alcohol and other drugs in reviewable child deaths. We plan to publish the results of this work in 2018 or 2019.

Domestic violence

In 2015, we conducted a review of familial abuse-related child deaths in NSW over a 10year period, 2004-2013. One of the issues we identified was that new partners (male intimate partners who had formed a relatively new relationship with a birth mother) represented a significant proportion – almost one-third – of all persons of interest / offenders.

The identification and assessment of risk presented by new partners is an issue that FACS also recognises is important, and a *New Partners and New Household Members Practice Tool* is in place with accompanying practice advice to guide caseworkers.

Contact: Monica Wolf, Director Reviews, Inquiries and Complaints



Child Deaths from Vaccine Preventable Infectious Diseases, NSW 2005–2014

FINAL REPORT

Prepared by National Centre for Immunisation Research and Surveillance 2016

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Authors

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Abbreviations used in this document

7vPCV	7-valent pneumococcal conjugate vaccine
13vPCV	13-valent pneumococcal conjugate vaccine
ACIR	Australian Childhood Immunisation Register
BDM	Registry of Births, Deaths and Marriages
CDR	Child Death Register
CDRT	Child death review team (NSW)
COD	Cause of death
ICD-10-AM	International classification of diseases, 10th revision, modified for Australia
IPD	Invasive pneumococcal disease
NCIRS	National Centre for Immunisation Research and Surveillance
NCIMS	Notifiable Conditions Information Management System
NIP	National Immunisation Program
NSW	New South Wales
PBS	Pharmaceutical Benefits Scheme
PBAC	Pharmaceutical Benefits Advisory Committee
VPD	Vaccine preventable disease

1 Executive Summary

1.1 Aims

This report was commissioned by the New South Wales (NSW) Child Death Review Team (CDRT) to:

- Describe child deaths in NSW from diseases for which a vaccine is currently available in Australia, over the period 2005 to 2014; and
- Provide recommendations to improve prevention of child deaths due to vaccine-preventable diseases.

1.2 Background

Immunisation has been successful in dramatically reducing the number of childhood deaths from infectious diseases in Australia. The current National Immunisation Program (NIP) provides funded vaccination to protect against 16 infectious diseases. Most of these vaccines are available for all children, although a small number of vaccines or doses are funded for specific high-risk groups. Other vaccines are available for private purchase in Australia.

While child deaths due to vaccine preventable diseases (VPDs) are now rare in Australia, small numbers of deaths due to pneumococcal disease, meningococcal disease, pertussis, influenza and varicella have been reported in recent years. Although vaccines are provided through the NIP for these diseases, deaths can occur due to disease subtypes not included in current vaccines (for example pneumococcal or meningococcal subtypes), among infants too young to be vaccinated or in unvaccinated older children. Children with some underlying medical conditions are more likely to be affected by severe disease and may have inadequate immune responses to vaccines.

1.3 Methods

For the purposes of this review, a *disease of interest* was defined as a disease caused by a pathogen (virus or bacterium) for which a vaccine is currently provided by the NIP. Cases were identified from the Child Death Register (CDR), which is a database of all child deaths in NSW maintained by the CDRT under the *Community Services (Complaints, Review and Monitoring) Act 1993.* In order to validate this data source, cases were also identified from the Notifiable Conditions Information Management System (NCIMS). NCIMS is maintained by the Communicable Diseases Branch, Health Protection NSW, and captures notification of VPDs by laboratories and doctors in NSW under the *NSW Public Health Act 2010.* Data from the two sources were matched to determine how many cases were identified in both databases versus one only. Data was requested for deaths among children resident in NSW occurring in neighbouring states.

For each case of the disease of interest identified, all available records were reviewed including medical records, post-mortem examinations, laboratory results and coronial findings. To ascertain whether death was due to the disease of interest, cases were classified as definite, probable or uncertain depending on the strength of evidence for the disease and cause of death. Cases considered as definite or probable were then further classified according to whether the death was considered preventable through vaccination. Deaths were considered preventable, potentially preventable or not preventable depending on the disease subtype, age and medical conditions of the child, and the availability of the relevant vaccine and recommendations for its use prior to the time of the child's death.

1.4 Results

Of 788 cases in the CDR, 55 cases were assessed as likely to be due to a disease of interest. Thirty-five cases were successfully matched to an NCIMS record and a further 18 cases were identified from NCIMS only. Of the resulting 73 cases, 54 were classified as confirmed or probable.

Among all 54 confirmed and probable cases, the highest number of deaths was in infants under six months of age, with male children overrepresented. While most deaths occurred in major cities, the highest per capita mortality rate was in inner regional areas. Meningococcal disease deaths tended to occur more in children residing in regions of greater disadvantage, whereas influenza deaths tended to occur more in children residing in less disadvantaged regions. Two thirds of confirmed and probable deaths were in previously healthy children, not known to have an underlying high-risk medical condition. One third had medical conditions affecting the lungs, heart or brain, or impaired immune function, that put them at increased risk of severe disease, which was significantly more than expected from the community prevalence of these conditions.

Twenty-three deaths were considered preventable or potentially preventable by vaccination, with influenza and meningococcal disease the most common causes of preventable or potentially preventable deaths. Five preventable influenza deaths occurred in children with high-risk medical conditions, and seven in children without documented high-risk conditions. Two further influenza deaths in children at high risk were not considered preventable as an influenza vaccine against the applicable subtype was not available. In addition, for three infants for whom a cause of death could not be determined at post-mortem, there was evidence of influenza by laboratory testing. Of twelve meningococcal deaths identified, eight were due to meningococcal subtype B, for which a vaccine was not available until 2014. Only one death occurred in 2014. Two cases occurred due to meningococcal subtype C after the introduction of a catch-up program with this vaccine in 2003.

Thirty deaths were considered not preventable through immunisation, predominantly because the subtype was not covered by the vaccine, the relevant vaccine was not available prior to the time of the child's death, or the child was too young to be eligible for vaccination. Nine deaths were in children too young to be vaccinated (infants aged two months of age or less). Although not preventable through immunisation of the child, pertussis and influenza deaths (four cases) may have been preventable through immunisation of the mother during pregnancy. Three of these infants died of pertussis prior to the NSW government-funded program to vaccinate pregnant women, which commenced in 2015. Vaccination of pregnant women aims to protect infants in the early months through the transfer of maternal vaccine-acquired antibodies, and also by reducing the chance that the mother will develop pertussis infection and pass it on to her infant. Of 16 deaths from pneumococcal disease, seven were due to subtypes not covered by the vaccine at the time of the child's death. In addition, one death caused by a vaccine strain occurred in a fully vaccinated child.

Identification of some cases from the CDR was limited by lack of information about the specific type of the pathogen causing some disease syndromes, for example whether a case of pneumonia was due to a vaccine preventable pathogen. The use of NCIMS, which contains data on disease types, increased the identification of cases for this review.

1.5 Conclusions and recommendations

Deaths in children from potentially preventable infectious diseases continue to occur in NSW, particularly in young infants. This review makes the following recommendations:

- 1 Immunisation of children at high risk is recommended and provided free under the NIP:
 - General and specialist practitioners who care for children with medical conditions or compromised immune systems placing them at increased risk of influenza, invasive pneumooccal disease, meningococcal disease or Haemophilus influenzae type b disease should put mechanisms in place to ensure that additional vaccines specifically recommended in the Australian Immunisation Handbook are received.
 - General and specialist practitioners providing care for children with predisposing medical conditions should ensure responsibilities for immunisation are clear.
 - Examples of relevant mechanisms may include flags in hospital electronic records, amendments to medical practice software to issue alerts to general practitioners, configuration of immunisation registers to issue alerts to parents and providers, and routine provision of information to parents.
- 2 Vaccines against influenza and meningococcal B disease are recommended for all Australian children although not provided free of charge in 2016:

- Parents wishing to reduce their child's risk of influenza and meningococcal B should discuss this with their general practitioner or other immunisation provider.
- General practitioners and other immunisation providers should ensure that they are aware of the recommendations on influenza vaccination in the Australian Immunisation Handbook, including that influenza vaccination is recommended for infants and children aged from six months to less than five years due to the increased risk of hospitalisation and death in this group.
- General practitioners and other immunisation providers should ensure that they are aware
 of the recommendations on meningococcal B vaccination in the Australian Immunisation
 Handbook, including that meningococcal B vaccination is recommended for infants and
 young children, particularly those aged <2 years, due to their higher risk of serogroup B
 meningococcal disease.
- 3 Immunisation of contacts is recommended for children at high risk of influenza, pertussis and varicella:
 - General practitioners and specialists who care for infants aged under 6 months should be aware of the recommendation in the Australian Immunisation Handbook for pertussis vaccination of household contacts and carers of these infants, and should promote immunisation to these groups, particularly if vaccination has not been received in pregnancy.
 - General practitioners and specialists who care for children at high risk of influenza (particularly those with a high-risk medical condition) should be aware of the recommendations in the Australian Immunisation Handbook to vaccinate household contacts and carers of these children and should actively promote immunisation to these groups.
 - Facilities that provide health care or child care services for children who are at high risk of influenza or infants at risk of pertussis should take steps to provide comprehensive occupational immunisation programs for their workers as per the recommendations in the Australian Immunisation Handbook.
 - Specialists who care for children at risk of severe varicella infection should be aware of the recommendation in the Australian Immunisation Handbook to ensure household contacts without a history of varicella receive two doses of varicella vaccine and actively promote immunisation to this group.

- 4 Immunisation against pertussis and influenza is recommended during pregnancy and provided free in NSW:
 - Health practitioners providing antenatal care should be aware that pertussis and influenza vaccine is provided free for pregnant women in NSW and that detailed information about this program can be obtained from the NSW Health website.^{1,2}
 - Pertussis and influenza vaccination during pregancy should be promoted and encouraged by general practitioners, obstetricians and midwives to reduce the risk of disease in young infants.
- 5 Children should receive vaccines for which they are eligible under immunisation catch up programs:
 - Immunisation providers should ensure children receive all vaccines for which they are eligible under funded immunisation catch-up programs, for example through the use of electronic alerts or flags on medical records.
 - Catch-up programs should be widely promoted to parents when new immunisation programs commence.
- 6 Travel immunisation should be provided as recommended:
 - General practitioners should be aware of recommendations on vaccination for international travel in the Australian Immunisation Handbook that are relevant to children, including hepatitis A and BCG vaccines, and these should be actively promoted to parents.
- 7 Data collections on child deaths in NSW should be enhanced and cross-checked between sources:
 - The CDRT should implement measures to improve identification and coding in the CDR of specific pathogens and isolation sites associated with VPDs to facilitate review of child deaths from infectious diseases in NSW.
 - The CDRT and Health Protection NSW should engage in regular communication and crosschecking regarding child deaths from VPDs.
 - The CDRT and Health Protection NSW should work with the NSW State Coroner in regard to standard protocols for testing for and notification of infectious diseases identified following a child's death.

2 Background

The NSW Child Death Review Team (CDRT) was established under the *Community Services (Complaints, Review and Monitoring) Act 1993* with a mandate to prevent and reduce child deaths in New South Wales (NSW). Within this role, the CDRT have commissioned the National Centre for Immunisation Research and Surveillance (NCIRS) to complete a report on child deaths in NSW from 2005 to 2014, focussing on recommendations to prevent or reduce deaths from vaccine preventable diseases (VPDs).

2.1 Aims

This report aims to:

- Describe child deaths in NSW, from diseases for which a vaccine is currently available in Australia, over the period 2005 to 2014; and
- Provide recommendations to improve prevention of child deaths due to vaccine-preventable diseases.

2.2 Immunisation in Australia

There has been a significant decline in the absolute number of deaths due to a range of vaccine-preventable diseases in Australia, compared with relevant pre-vaccination baselines, despite substantial increases in the Australian population.³ Although smallpox, plague and typhoid vaccines were used in the 1800s, the first vaccination programs at state level commenced in the 1930s with diphtheria vaccine.⁴ The first immunisation schedule adopted at national level commenced in 1975.⁴ The Immunise Australia 'Seven Point Plan' was launched in 1997, to address low coverage for recommended childhood vaccines (estimated to be 53% for "fully immunised" among children under 6 years). The plan, which included incentive payments for parents and general practitioners, monitoring of immunisation targets through the Australian Childhood Immunisation Register (ACIR), and the introduction of school entry requirements, drove increases in the proportion of children fully immunised at 6 years at the national level to around 93%. ⁵

The current nationally funded childhood schedule (Appendix A), known as the National Immunisation Program (NIP), protects against 16 infectious diseases. Most vaccines are funded for all children, although a small number of additional vaccines or additional doses are funded for specific high-risk groups. During the period of this review, nationally funded immunisation programs were introduced against pneumococcal disease, hepatitis A, rotavirus, varicella and influenza (Table 1). Table 1 Nationally funded immunisation programs for children, by disease and year of funding^{4,6}

Disease	Funded group	Vaccine recommended or local programs	National childhood vaccination funded
Measles		1969	1975
Mumps		1981	1983
Rubella		1969	1971 ¹
Polio		1956	1975
Diphtheria		1932	1975
Tetanus		1953	1975
Pertussis	All children	1942	1975
Haemophilus influenzae type b		1993	1993
Hepatitis B		1980s	2000
Meningococcal type C		2003	2003
Varicella		2003	2005
Rotavirus		2006	2007
Pneumococcal disease	At-risk medical conditons and Aboriginal and Torres Strait Islander children ²	2001	2001
	All children	2003	2005
Hepatitis A	Aboriginal and Torres Strait Islander children 12-24 months in (NT, QLD, SA and WA)	2005	2005
Human	Females	2007	2007
Papillomavirus	Males	2011	2013
	Children 6 months or older medically at risk for severe influenza ³	Pre-1991	2010
Influenza	Aboriginal and Torres Strait Islanders 15 years and over	2008	
	Aboriginal and Torres Strait Islander children 6 months to 5 years	2013	2015

¹ School based program (funded for young children in 1989)

² These groups have an additional vaccine dose funded under the NIP in addition to the three-dose course available to all children

³ Subsidised under the PBS pre-2010

In addition to vaccines included in the nationally funded program, some vaccines registered for use in Australia are available only through private purchase (Table 2). The *Australian Immunisation Handbook* provides recommendations about the use of these vaccines.⁷

Table 2 Vaccines recommended for specific groups in the Australian Immunisation Handbook, not NIP funded^{6,7}

Disease	Current handbook recommendation for children	Year recommended
Meningococcal type A, C, W and Y	At risk individuals (including high-risk medical conditions and travel)	1991
Hepatitis A	Travellers to endemic areas aged one year and over	2000
Influenza	All children 6 months to 5 years	2013
Meningococcal type B	Infants and young children, particularly ages less than 2	2014

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	years, and adolescents 15-19 years	
Varicella	Second dose	2008
Tuberculosis	Aboriginal and Torres Strait Islander neonates in some regions; travellers	
Japanese encephalitis	Travellers, residents of outer Torres Strait Islands	1994
Cholera	Travllers at risk, aged 2 years and over	
Typhoid	Travellers aged 6 years and over	
Yellow fever	Travellers aged 9 months and over	
Q fever	Adolescents 15 years and over at risk of infection from animals	1989
Rabies	Travel, bat handling	

2.3 Child deaths from vaccine preventable diseases

While child deaths due to VPDs are rare in Australia, some deaths do occur. Table 3 summarises deaths in children less than five years of age reported in various VPD surveillance reports prepared by the NCIRS. Reported deaths are based on data obtained from both the National Mortality Database held by the Australian Institute of Health and Welfare (AIHW), which is in turn derived from death certificate data coded by the Australian Bureau of Statistics; and the National Notifiable Diseases Surveillance System (NNDSS).^{3,8-13} While these data provide background to the national picture of vaccine preventable deaths and allow historical comparison, reported deaths are not subject to individual review and death certificates are known to under-report certain diseases.¹⁴

Table 3 Child deaths (< 5 years of age) due to vaccine preventable diseases (death certificate (AIHW) and notification (NNDSS) data)*, Australia ^{3,8-13}

	1993- 1997	1998- 2000	2001- 2002	2003- 2005	2005- 2007	2008-2011
Diphtheria	0	0	0	0	0	0
Invasive <i>Haemophilus influenzae</i> 1 disease	13	1	1	1	1 ⁵	1
Influenza	NR	12	3	5	6 ⁶	3
Measles	2	0	0	0	0	0
Invasive Meningococcal disease ²	NR	33	26	12	15 ⁶	15
Pertussis	9	1	5	14	1 ⁵	8
Pneumococcal septicaemia, meningitis and pneumonia ^{2,3}	25	17	8	13	6 ⁵	23
Poliomyelitis	0	0	0	0	0	0
Rotavirus	NR	NR	NR	0	0	0
Tetanus	0	0	0	0	0	0
Varicella	8	1	1	3	1 ⁵	1

*The data source documenting the highest number of deaths for each disease is reported; NR: not reported

¹Deaths are reported for any deaths identified as *Haemophilus* meningitis, not specifically type b. Deaths from acute epiglottis were also identified prior to 2003.

²Deaths are reported regardless of whether the disease was caused by a type contained in the vaccine.

³Deaths due to pneumococcal pneumonia were not included from 1993-1998

⁴2003-4 data; ⁵2005-6 data; ⁶2006-7 data

2.3.1 Influenza

Influenza causes epidemics of illness each winter, with symptoms in children including cough, fatigue, muscle aches and high fever. Although symptoms in young children may be non- specific, infection may be complicated by middle ear infections, pneumonia and febrile seizures.⁹ Children with high-risk medical conditions are more likely to suffer severe disease.¹⁵ However, rates of hospitalisation are high in healthy children under five years of age ^{7,9,16-18} and deaths occur.¹⁹

Influenza vaccine is recommended annually for anyone aged six months or older who wishes to reduce the liklihood of becoming ill with influenza. The vaccine available in each year is matched as closely as possible to the subtypes predicted to cause disease in that year. The Australian Immunisation Handbook highlights the increased risk of severe disease and hospitalisation in children less than five years of age. Population groups at higher risk of severe disease (all persons with heart and lung disease, neurological conditions, immune system compromise and Down Syndrome and pregnant women) have been funded for influenza vaccine since 2010 and all Aboriginal and Torres Strait Islander Children (hereafter referred to as Indigenous) since 2015.^{6,7}. Influenza vaccine is not funded under the NIP for all children, but in Western Australia, has been funded by that state for children aged 6 months to 5 years since 2008.²⁰

Nationally, a background rate of one to six influenza deaths, with an average of 2.6 deaths, per year was reported for children under five years of age between 1997 and 2005.²¹ In 2005-6, there were five deaths in children under five, and two in children aged 5 to 14 years.³ During the 2007 influenza season, 7 deaths in children under five were reported.²¹ During the 2009 influenza season (often referred to as the H1N1 2009 pandemic), when a large proportion of the population was infected, 11 children were reported to have died due to influenza.²²

2.3.2 Pneumococcal disease

Streptococcus pneumoniae (pneumococcus) causes a diverse range of diseases, from middle ear infection to pneumonia, septicaemia and meningitis. Invasive pneumococal disease (IPD), defined as isolation of *Streptococcus pneumoniae* from the blood or another sterile site, has a reported mortality of around 1%.²³ Pneumococcal disease can be caused by ninety different serotypes (strains or subtypes), but a small number of strains cause a large proportion of IPD in most populations; pneumococcal vaccines to date have covered serotypes causing the majority of disease in the United States at the time they were developed.²⁴

There are two different types of pneumoccocal vaccine – pneumococcal conjugate vaccine (PCV) and pneumococcal polysaccharide vaccine (PPV). Unlike polysaccharide vaccines, conjugate vaccines are able to induce immune responses in children under the age of 2 years and to set-up the immune system to respond to later exposure to pneumococcal serotypes included in the vaccine.^{6,7} The serotypes included in PCVs increased from seven serotypes (7vPCV) in 2001 to 13 serotypes (13vPCV) in 2011 (Table 4). In 2001, 7vPCV

was funded under the NIP for medically at-risk and Indigenous children, extended to all children in 2005 and replaced by 13vPCV in 2011. Following introduction of 7vPCV, the overall rate of IPD has substantially declined in Australia, even after accounting for increases in some types not contained in the vaccine, a phenomenon known as 'serotype replacement'.²⁵

The polysaccharide vaccine (23vPPV) contains 23 serotypes. It was funded as a booster dose at 12 months of age for children with certain high risk medical conditions from 2001 to 2005, and for 4 to 5 year olds from 2004. Indigenous children in some states (not NSW) had a dose of 23vPPV at 18 to 24 months of age funded under the NIP from 2001 to 2011.²⁶

Table 4 Vaccine for pneumococcal disease and serotypes covered ²⁴
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Vaccine	Availability	Serotypes
23vPPV	2001	1 2 3 4 5 6B 7F 8 9N 9V 10A 11A 12F 14 15B 17F 18C 19A 19F 20 22F 23F 33F
7vPCV	2001 ¹	4 6B 9V 14 18C 19F 23F
	2005 ²	
13vPCV	2011	1 3 4 5 6A 6B 7F 9V 14 18C 19A 19F 23F
1	ممثله محبر امحرم المحالة والم	0 · · · · · · · · · · · · · · · · · · ·

¹Indigenous children and medically at-risk children ²All children

Deaths from IPD in Australian children aged less than five between 2005 and 2012 are shown in table 5.

 Table 5 IPD deaths in children less than 5 years, Australia (Data from Invasive Pneumococcal Disease surveillance program)

Year	2003 - 2004	2005-2006	2007-2008	2009-2010	2011-2012	2013
Vaccine availability	Pre universal vaccine	7vPCV				13vPCV
Deaths	28	14	11	13	7	*

*Data not yet available

Figure 1 IPD deaths in children less than 5 years, Australia, 2003-2012



2.3.3 Pertussis (whooping cough)

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Pertussis is a bacterial infection caused by *Bordetella pertussis*; typical clinical symptoms are respiratory infection characterised by paroxysmal cough. Infants who have received less than 2 vaccine doses are at greatest risk of severe disease, with complications including pneumonia, apnoea (stopping breathing for periods of time), seizures, encephalitis (inflammation of the brain) and death.³⁶

State-based vaccination programs for pertussis commenced in the 1940s⁴, and even prior to national programs using the combined diphtheria-tetanus-pertussis (DTP) vaccine in 1954, had resulted in substantial decreases in pertussis deaths.³ The first of three infant doses of vaccine is given at 6 to 8 weeks of age. ³⁷ The current acellular vaccine, given as combination with other infant vaccines, has been used since 1999. It provides good protection against severe illness but lesser protection against mild illness; importantly, immunity declines within 2 years following the initial vaccine doses given at 2, 4 and 6 month of ages. Three to 4 year old siblings are well known to be a source of infection for younger siblings who are too young to be immunised. ³⁷⁻³⁹ In 2015, vaccination of pregnant women against pertussis (maternal vaccination) was recommended in the Australian Immunisation Handbook and funded in all states and terriroties, with the aim of protecting babies less than 3 months of age through the transfer of vaccine-derived antibodies from their mother.^{7,40}

Pertussis is the most commonly notified vaccine preventable disease in Australia,³⁹ with epidemics every three to four years. This high rate of notification is in part due to our easy access to diagnostic tests and the requirement for positive results to be notified to the laboratory. Between 2006 and 2012, 10 of 11 notified pertussis deaths in Australia were in infants less than 2 months of age, ³⁹ and between 2004 and 2013, eight of twelve identified pertussis deaths were in infants less than 2 months of age.⁴¹

2.3.4 Meningococcal disease

Meningococcal disease is a bacterial infection caused by *Neisseria meningitidis*, which can result in septicaemia (blood poisoning) or meningitis. It has a high case fatality rate (which varies by age and subtype but can be as high as 10-15%), despite advances in treatment. ²³ Disease is caused by a range of different subtypes (serogroups) of the meningococcal bacteria, with five serogroups (A, B, C, W and Y) causing most disease worldwide.⁷ Since the success of the immunisation program for meningococcal C, introduced from 2003, most cases in Australia are now due to meningococcal type B disease (80% overall in 2014, with a higher proportion in children under the age of 10).⁴²

A conjugate vaccine against meningococcal type C has been included in the NIP at 12 months of age since 2003.³ In August 2013, a new vaccine effective against meningococcal type b became available in Australia. In 2014, it was recommended in the Australian Immunisation Handbook for infants and young children, particularly those aged <24 months, for adolescents aged 15-19 years, and those with high-risk medical conditions; however, the vaccine is not funded under the NIP. ⁴³ Conjugate vaccines that include types A, W

and Y in addition to C are available and recommended for those with high-risk medical conditions and travellers to high risk areas.⁷

Meningococcal disease can occur in any age group, but children less than 5 years of age and adolescents 15-19 years have the highest incidence. ⁴⁴ In Australia, 15 deaths in children under five years were reported between 2005 and 2007, and 15 between 2008 to 2011. There were also deaths in older children aged 5 to 14 years (two 2005-7 and one in 2008-11) and in adolescents and young adults aged 15 to 24 years (three in 2005-7 and nine in 2008-11).^{3,10} The mortality rate per million population was in infants under one year.^{3,10}

2.3.5 Measles

Measles is a highly infectious disease with symptoms including cough, fever and rash. Complications can include pneumonia and encephalitis.⁴⁵ A single dose of measles vaccination was funded in the 1970s, with two doses funded since 1993. Two doses of measles vaccination are currently given at 12 and 18 months under the NIP.⁷

Deaths from measles encephalitis in Australia occurred at an average of 3.3 per year between 1979 and 1985, decreasing to two deaths per year 1986-1992.⁴⁶ Elimination of locally circulating measles was declared in Australia in 2014, but cases acquired overseas may cause outbreaks in Australia, mostly among people who are not vaccinated.^{3,45,47} The last measles death in Australia was recorded in 1995,^{3,45} and no deaths were reported during an outbreak of 168 cases in Sydney in 2012.⁴⁷

2.3.6 Mumps

Mumps is a viral infection with symptoms ranging from mild cold-like symptoms to fever, fatigue and facial swelling. It can be complicated by meningitis, encephalitis and testicular swelling, with death resulting from 1.5% of encephalitis cases.⁴⁸ Mumps vaccination has been funded under the NIP since 1983, initially as mumps-rubella vaccine and since 1988 as MMR.⁴ While outbreaks of mumps do occur in Australia, only adult deaths were reported from 2001 to 2006 in Australia, ^{3,8,9} and no deaths were reported from 2008 to 2011.^{10,49}

2.3.7 Rubella

Rubella infection is generally mild and complications are rare. The main concern is infection in pregnant women, which can cause birth defects (congenital rubella syndrome).^{7,49} Childhood vaccination has been funded under the NIP since 1989.⁴ No deaths were recorded in death certificates in Australia from 2001 to 2006 ^{3,8,9} or from 2008 to 2011.^{10,49}

2.3.8 Varicella (chickenpox)

Varicella infection can vary from mild to severe, with complications including secondary bacterial skin infection, pneumonia, or encephalitis. Risk factors for severe varicella include older and younger ages, and

impaired immune function (immunocompromised). From US studies, the case-fatality rate is reported as 2.6 per 100,000 cases. ²³

Varicella vaccine was registered for use in Australia in 2002 and in 2005 a single dose of varicella vaccine at 18 months of age was funded under the NIP. Varicella vaccine has been given in a combined measles, mumps, rubella and varicella (MMRV) vaccine since 2013. It is a live vaccine so is unable to be given to children who have siginificant immune system problems.⁷ Prior to 2005, studies reported between 5 and 8 deaths per year in Australia, most occurring under five years of age.^{50,51} One death was reported nationally in children under 5 years of age in each of 2005-7 and 2008-11, compared to three between 2003 and 2004.³ Among four Australian childrens' hospitals, no deaths were identified in any hospital between 2007 and 2010, compared to two from one hospital between 1999 and 2001.⁵².

2.3.9 Haemophilus influenzae

Haemophilus influenzae type b (Hib) is a bacterial infection that may cause meningitis, epiglottitis (swelling in the respiratory tract) and pneumonia, among other conditions.⁵³ Hib meningitis has a high case-fatality rate and risk of long term complications. ⁷ While most cases of severe disease are caused by subtype b, other types (A,C,E,F) and occasionally non-typeable *Haemophilus influenzae* (NTHI) can cause severe disease, although NTHI in particular is more likely to cause respiratory infection or milder diseases such as middle ear infections.⁷

Infant Hib vaccination was introduced to the NIP in 1993 and is only effective against this type.⁷ Prior to the vaccination program, it was estimated that up to 19 child Hib deaths occurred per year in Australia.⁵⁴ Following the introduction of the program, eight Hib deaths were reported nationally in children under five between 1993 and 1996, with two of these being Indigenous children. Five of these deaths occurred in the second half of 1993, with one each subsequent year until 1996.⁵⁵ Between 1993 and 2007, the NNDSS reported five Hib deaths and was one infant death from Hib reported between 2005 and 2007 in an Indigenous infant.³

2.3.10 Rotavirus

Rotavirus causes gastroenteritis, predominantly in infants and young children. The disease can range from mild to severe diarrhoea with fever, dehydration and death. The case-fatality rate is estimated to be approximately 1 in 200,000 cases of rotavirus gastroenteritis in developed countries like Australia.²³

There has been a substantial decrease in severe rotavirus disease since the vaccine was introduced in 2007.⁵⁶ Prior to 2007, one study reported 13 rotavirus deaths in all ages between 1990 and 2002 (approximately one death per year), with most occuring in infants under one year of age. There were three

deaths reported overall between 2001 and 2007,³ and from 2008-2011, there was one death reported in a child under five years of age in Australia.¹⁰

2.3.11 Tetanus

Tetanus is caused by a toxin produced by the bacterium *Clostridium tetani*, which leads to painful generalised spasms which are often fatal through effects on the respiratory system. Tetanus vaccines were introduced in 1939, included in state immunisation programs since 1953 and funded under the NIP since 1975.⁷ Tetanus occurs at very low rates in Australia, mostly following injury in adults over the age of 70 years who are not fully vaccinated or have not had booster vaccinations.³ Tetanus deaths were reported only in adults in between 2001 and 2007.^{3,8,9} Tetanus among newborns has effectively been eliminated in developed countries like Australia but is a significant problem in developing countries.⁷

2.3.12 Diphtheria

Diphtheria is a bacterial disease causing either respiratory or skin infection, with heart and neurological complications.⁵⁷ Disease is usually caused by the strain of the *Corynebacterium diphtheriae* bacteria that carries a toxin, although may occur from non-toxin containing strains in some circumstances.⁵⁷ Vaccination has been available since the 1930s.⁷ Previously the most common cause of infectious death in Australia, vaccination programs have virtually eliminated diphtheria,⁵⁷ although cases may be acquired from overseas.³ No deaths in Australia were reported from 1996 to 2005,³ however one death occurred in 2011 in an unvaccinated adult who acquired the disease from someone who had returned from overseas.⁵⁷

2.3.13 Poliomyelitis

Paralytic polio occurs as a complication of infection with poliovirus.⁷ Mass vaccination with polio vaccine has occurred since the 1950s in Australia, with the last locally acquired case in 1972. Australia was declared free of polio in 2000.^{3,7} Cases may be acquired overseas with the last case imported into Australia in 2007.^{3,58} No deaths were reported from 1986 to 2005.³

2.3.14 Hepatitis

A number of hepatitis viruses cause liver disease, and vaccination is available for two types - Hepatitis A and B.

Hepatitis A

Hepatitis A virus often causes no symptoms or mild disease in children, while adults are more likely to have symptoms. Typically initial fever is followed by nausea, vomiting and liver impairment with jaundice; severe liver disease associated with liver failure occurs uncommonly. It is transmitted from contaminated food or water, or person to person.⁷

Hepatitis A vaccination has been funded for Indigenous children, who are at increased risk of severe disease, since 2005. It is also available but not funded for travellers to high risk countries.⁷ Although cases and outbreaks may occur in Australia,⁵⁹ the disease has been declining in recent years.³ It is considered the most common and potentially preventable disease of international travellers.⁶⁰ Hepatitis A deaths were reported only in Australian adults between 2005 and 2007.³ One death was reported in an Indigenous child aged under five between 2000 and 2002.⁶¹

Hepatitis **B**

Hepatitis B is transmitted via blood or body fluids, and can be transmitted from mother to child around the time of birth. Infection in infants and children is usually without symptoms, but death can occur in adulthood following chronic infection, due to liver damage and cancer.⁷ Groups at higher risk of infection and chronic disease include Aboriginal and Torres Strait Islander people and some migrant groups.⁷ Vaccination has been recommended for high risk groups since 1987 and funded for all newborns since 2000.⁴ Hepatitis B deaths were reported only in Australian adults between 2005 and 2007.³

2.3.15 Human Papillomavirus

Infection with human papillomavirus (HPV) may cause a range of cancers, including cancer of the cervix. While vaccination is given as part of the adolescent immunisation program, the impact of this disease is experienced in adulthood.⁶²

3 Methods

For the purposes of this review, a disease of interest was defined as a disease caused by a pathogen (virus or bacteria) for which a vaccine is currently available on the NIP. Diseases were included regardless of whether the vaccine covered that specific subtype of disease (Table 6). We excluded HPV because this causes disease in adulthood.

Table 6 Diseases of interest

Diseases of interest		
Haemophilus influenzae	Meningococcal disease	Rotavirus
Diphtheria	Mumps	Rubella
Hepatitis A & B	Pertussis	Tetanus
Influenza	Pneumococcal disease	Varicella
Measles	Poliomyelitis	

3.1 Case identification

3.1.1 Databases

We identified deaths due to diseases of interest through the NSW Child Death Register (CDR), maintained by the Child Death Review Team (CDRT). The CDR records all deaths in NSW among children less than 18 years of age, with cause of death coded based on a combination of death certificates and coroner's reports using International Statistical Classification of Diseases and Related Health Problems (ICD) system, 10th revision, modified for Australia (ICD-10-AM).

In order to validate the data available on the CDR and determine how many cases were not identified from the CDR data alone, we also identified deaths due to the diseases of interest from the Notifiable Conditions Information Management System (NCIMS), which is the state-based version of NNDSS. NCIMS is maintained by the Communicable Diseases Branch, Health Protection NSW, and captures notification of vaccine preventable diseases by laboratories and doctors in NSW under the *NSW Public Health Act 2010*. Case definitions for each disease are described here:

http://www.health.nsw.gov.au/Infectious/controlguideline/Pages/default.aspx

CDR data was provided by the CDRT (for the NSW Ombudsman) to allow completion of this report under their mandate to prevent and reduce child deaths in NSW, as outlined in the *Community Services (Complaints, Review and Monitoring) Act 1993.* NCIMS data access was approved and data released to the NSW Ombudsman by Health Protection NSW.

3.1.2 CDR data

From all infectious causes of death in the CDR (2005 to 2014), we identified cases of diseases of interest using CDRT-applied ICD-10-AM coding for cause of death (COD) and associated COD (ACOD) codes. The following ICD-10-AM codes were of particular interest: diphtheria (A36), *Haemophilus* disease (G00.0 – *Haemophilus* meningitis, J14 – *Haemophilus* pneumonia, A41.3 - *Haemophilus* sepsis, J05.1 - Epiglottitis), hepatitis A (B15), hepatitis B (B16), influenza (J10, J11), measles (B05), meningococcal disease (A39), mumps (B26), pertussis (A37), pneumococcal disease (G00.1 – pneumococcal meningitis, A40.3 – pneumococcal septicaemia, and J13 pneumococcal pneumonia), acute poliomyelitis (A80), rotavirus (A0.80), rubella (B06, P350), tetanus (A34, A35), varicella zoster virus infection (B01 – chickenpox, B02 – shingles). We also identified cases based on any mention of the diseases of interest in the Registry of Births, Death and Marriages (BDM) COD (coded from death certificates) or coroner's report COD fields or notes.

CDR assessment process

Cases in the CDR were assessed as being either a) *highly likely* or b) *moderately likely* to be associated with a disease of interest if the disease was mentioned in any field in the CDR Dataset, either by ICD code or text

(Appendix B). Cases were assessed as c) *possible* or *d*) *unlikely* to be associated with the disease of interest if any field identified a clinical syndrome known to be associated with the disease of interest, without identifying the specific disease. Syndromes of interest are listed in Appendix B. Full case notes were only obtained for cases that were assessed as *highly* or *moderately likely* to be associated with the disease of interest were not reviewed further.

3.1.3 NCIMS data

From NCIMS, we identified notified cases of child deaths under the age of 15 years due to diseases of interest between 2005 and 2014. Data were extracted if the disease was listed in the notifiable 'condition' field and a death was also recorded. To compare NCIMS and CDR data, cases identified through the CDR were matched to cases in NCIMS using date of birth and last name, or date of birth and death. A manual review of other personal identifiers was then conducted to ensure that the matched case was in fact the same individual child.

3.1.4 Interstate data

The Child Death Review Team requested data on deaths of children from NSW from neighbouring jurisdictions in Queensland, the Australian Capital Territory and Victoria. This was to account for the possibility that children may have travelled interstate before their death, and that those living close to state borders may have been transferred to a hospital in another state.

3.2 Data extraction

For each of the cases identified for further review either through the CDR or NCIMS, the CDRT provided medical records, post-mortem examinations and coronial findings if available. Some laboratory results were also recorded on NCIMS. A standard set of information was collected on case demographics (age, sex, Indigenous status, and residential postcode), clinical presentation and history (medical comorbidities, vaccination status, clinical presentation and management) and laboratory results.

3.3 Case definition

Cases of each disease of interest identified from each database were classified as *confirmed, probable* or *uncertain* depending on the strength of evidence for the disease and cause of death (Table 7). Two authors (JC and AP) reviewed available medical documentation in order to classify the likelihood that the death was attributable to a disease of interest according the case definitions. Complex cases were reviewed by an expert panel (KM, PM and FB).
Table 7 Case definitions for deaths due to diseases of interest

	Laboratory & Enidomialogical ovidence		Clinical & Dect martem ovidence
Confirmed	Laboratory & Epidemiological evidence Laboratory definitive evidence ¹ of pathogen ² of interest from a clinical specimen	AND	Clinical & Post-mortem evidence Post-mortem or clinical evidence of severe disease consistent with the disease of interest
Probable	Laboratory suggestive evidence of pathogen of interest from a clinical specimen OR Laboratory evidence of a pathogen of interest from a post-mortem specimen ³ OR Epidemiological ⁴ link to a case of disease of interest	AND	Post-mortem or clinical evidence of severe disease consistent with the disease of interest
Uncertain	Laboratory evidence (clinical or post- mortem specimen) of a pathogen ² of interest OR epidemiological link to a case of disease of interest	AND	<i>Absence</i> of post-mortem or clinical evidence of severe disease consistent with the disease of interest
Not a case	No laboratory evidence of pathogen of interest		

¹Laboratory evidence is consistent with National notifiable diseases case definitions, where available

² A pathogen of interest refers to the bacteria or virus that causes the disease on interest and is detectable in the laboratory

³Expert panel reviewed cases where second pathogen was identified at post-mortem examination but was unlikely to be clinically relevant. Where two organisms of interest were identified with consistent clinical or post-mortem findings (e.g. S.pneumoniae and H.influenzae) the case was ascribed a probable status.

⁴Epidemiological evidence refers to a contact with another known case of the disease in an appropriate timeframe, consistent with national notifiable diseases case definitions

Post-mortem samples were considered relevant although lesser evidence of infection with the pathogen of interest. In the presence of relevant clinical or post-mortem findings, these cases were given a probable classification and therefore included with confirmed cases in the initial analysis.

3.4 Descriptive analysis

All confirmed and probable cases due to the diseases of interest were included in the initial analysis. Further analyses focused on preventable and potentially preventable deaths only. Data were analysed using STATA (StataCorp. 2015. Stata Statistical Software: Release 14. College Station, TX: StataCorp LP) and Microsoft Excel (2010). Death rates were presented as annual average rates per 100,000 child population.

Postcode data were linked to the Socio-Economic Indexes for Areas (SEIFA) and Australian Standard Geographic Classification (ASGC) Remoteness Structure data provided by the Australian Bureau of Statistics (ABS) in order to describe deaths by socioeconomic status and remoteness. Population data by remoteness was obtained from the Centre for Epidemiology and Evidence, NSW Ministry of Health.⁶³

3.5 Assessment of preventable deaths

Confirmed and probable cases were classified as preventable through vaccination according to the framework below (Figure 2).





¹Where the pathogen of interest has not been further subtyped by the laboratory, it is not possible to know whether the subtype is in the vaccine

4 Results

4.1 Cases identified

Of 788 cases in the CDRT Infectious Disease dataset, 55 cases were assessed as highly or moderately likely to be due to a disease of interest. Thirty five cases were successfully matched to an NCIMS record. A further 18 cases were identified from NCIMS only (Table 8 and Figure 3). A total of 73 cases were included.

Figure 3 Cases identified



Table 8 Sources of cases

Source	Number	Per cent
Both	35	48.0
CDRT only	20	27.4
NCIMS only	18	24.7

Of the 73 included cases of diseases of interest, 54 were classified as confirmed or probable based on the case definition (Table 9).

Table 9 Classification of cases

Classification	Number	Per cent
Confirmed	41	56.2
Probable	13	17.8
Uncertain	10	13.7
Not a case	9	12.3
Total	73	100.0

Confirmed cases were more likely to have been identified from both data sources, while uncertain cases were more likely to have been identified from NCIMS only. The CDR database identified a high proportion of probable cases (Figure 4).





Of the 18 cases identified by NCIMS only, seven were classified as confirmed or probable. This included two cases who had died in Queensland so were not recorded in the NSW CDR. Two pneumococcal cases identified from NCIMS and classified as probable were not in the original CDR database. Two cases were triaged as possible or unlikely in the initial CDR review but later classified as confirmed or probable. One of these was originally assessed as possible based on an ICD code of bacterial meningitis was classified on review of medical records to be a confirmed case of pneumococcal meningitis. The other was assessed as unlikely based on an ICD code of birth asphyxia was later classified as a probable case of neonatal pneumococcal disease. One case was identified from NCIMS only but was matched to re-extracted CDR data showing deaths in 2014 as not all deaths were registered at the time of initial data extraction.

Of the cases identified by the CDR only, 14 were classified as confirmed or probable. Most of these were not recorded on NCIMS as the cases did not meet the criteria for notification under the *Public Health Act 2010*, such as *S. pneumoniae* isolated from a non-sterile site, or *Haemophilus influenzae* not further typed. Two were deaths from varicella, which is not notifiable in NSW. Two influenza cases and one hepatitis A case were not notified to NCIMS, although laboratory reporting of all detections of these pathogens should be routine.

We identified NSW residents who died in neighbouring states. Two cases of pertussis identified from Queensland were captured in NCIMS with sufficient information provided by the Queensland Family and Child Commission and NCIMS to allow inclusion in the review. For 13 infectious disease deaths in Victoria among children who usually reside in NSW, only ICD-10 codes were provided with no further information. Three of these ICD-10 codes were among the codes used to identify cases in the NSW CDR data (two cases coded as meningococcal disease and one as influenza with pneumonia). We were unable to access more

detailed information on these cases and so they were not included. From the ACT, no deaths were triaged as highly or moderately likely to have been caused by a disease of interest.

4.2 All confirmed and probable cases of diseases of interest4.2.1 Post mortem

Of the 52 cases with information on whether a post-mortem had been conducted, 22 had a post mortem performed (42%) (Figure 5). Children with high-risk medical conditions were less likely to have a post mortem performed. Of 18 children with high-risk conditions, 6 had a post-mortem (33%), while of 34 children without documented high-risk conditions, 16 had a post-mortem (47%).





4.2.2 Child deaths by Indigenous status, sex and county of birth

Among all 54 confirmed and probable cases, male children were overrepresented. Deaths among Indigenous children identified accounted for 5.6%, similar to the proportion of Indigenous children residing in NSW (5.5%)⁶⁴ (Table 10). However, Indigenous status may not have been adequately identified.

Table 10 Demographic information

	Number	Percentage
Indigenous	3/53	6%
Male	39/54	72%
English speaking family	48/52	89%

The number of deaths was highest in infants under six months of age. The death rate was 2.1 per 100 000 infants under 12 months (Figure 6) and 0.33 per 100 000 children overall.

Figure 6 Deaths by age, confirmed and probable cases, 2005-2014





4.2.3 Median age at death, by disease

The average age of death due to *H.influenzae*, meningococcal disease and pertussis was under 12 months of age, while the average age of pneumococcal deaths was 16 months. Influenza deaths had a median age of seven years (Table 11).

Disease [*]	Observations	Median age (years)	Median age (months)	
H.influenzae	4			6
Influenza	15		7	
Meningococcal	12			9
Pertussis	4			2
Pneumococcal	16			16
Varicella	2	11	.5	

Table 11 Median age at time of death by disease, confirmed and probable cases, 2005-2014

* Median age for diseases with only one case are not reported.

4.2.4 Deaths over time

Over time, the rate of death due to meningococcal disease appeared to decrease, while the rate of deaths due to influenza appeared to increase (Figures 7 and 8). The increase in influenza deaths may be partly attributable to increased testing following the 2009 H1N1 pandemic season.





Figure 8 Rate of child deaths by disease, confirmed and probable cases, 2005-2014



4.2.5 Child deaths by remoteness

While most deaths (n=31) occurred in major cities, the highest rate of death was in inner regional areas (Figure 9). Because of small numbers, deaths in outer regional, remote and very remote areas were combined. There were no deaths in children from very remote areas.

Figure 9 Deaths per 100,000 population by remoteness, confirmed and probable cases, 2005-2014 (number of cases shown labelled for each region)*



* Population data were only available for age 0 to 14. Given that only 3 of 53 cases were aged over 14 years (5.7%), this data may slightly overestimate rates. Population data for 2014 are population projections based on data from the NSW Department of Planning and Infrastructure (SAPHaRI). Centre for Epidemiology and Evidence, NSW Ministry of Health.

Of the four outer regional and remote deaths, half were in Indigenous children, both of whom died from meningococcal B disease, and one was a visiting Pacific Islander child (Figure 10). During the 2011 census, 17% of children aged up to 14 living in outer regional, remote and very remote areas were Indigenous.⁶⁵





4.2.6 Child deaths by level of disadvantage

Child deaths were analysed by level of socioeconomic disadvantage using SEFIA deciles based on postcode of residence, where 1 represents the most disadvantaged areas and 10 represents the areas of greatest social advantage (Figure 11).



Figure 11 Number of child deaths by level of disadvantage and disease, confirmed and probable cases, 2005-2014

Meningococcal deaths tended to occur more in children residing in more disadvantaged regions, whereas influenza deaths tended to occur more in children residing in less disadvantaged regions (Figures 12 a. and b.).





4.2.7 High risk medical conditions

Two thirds of confirmed and probable deaths were in children without a documented high-risk medical condition. One third (n=18) had medical conditions that put them at increased risk of severe disease (Table 12). For 12 of these children, their high-risk medical conditions meant that they were eligible for NIP funded vaccine or additional vaccine doses for the disease of interest, although not all children died from strains that were covered in the relevant vaccine. All children who died from influenza were eligible for the vaccine due to their medical conditions and all children who died from pneumococcal disease were eligible for

additional vaccine doses. Some children were eligible for vaccines based on their age rather than their medical condition (Table 12).

All children with conditions of the brain had both seizures and cerebral palsy; three also had scoliosis and two had microcephaly. Of eight children with impaired immune function, two who died from pneumococcal disease just before two years of age were born without a spleen, but this had not been diagnosed before death. Four children were on immune suppressive treatment and two had medical conditions that suppressed the immune system.

Table 12 High-risk medical conditions, by disease

Disease	Lung	Heart	Brain	Impaired immune function
Influenza	1		4	2
H. influenzae			1 ¹	
Pneumococcal		2		3
Meningococcal		1 ²		1 ³
Varicella				2 ⁴
Pertussis		1 ⁵		

¹All children are eligible for *H.influenzae* type b vaccine, but this *H.influenzae* type was unknown and the child was too young to be vaccinated ²Recommended but unfunded for meningococcal B vaccine on basis of age, not medical condition

³Funded for meningococcal C vaccine catch up program based on age, not medical condition

⁴Not recommended to be vaccinated due to immune compromise

⁵Funded under NIP for vaccination based on age not medical condition

4.3 Disease subtypes

4.3.1 Meningococcal disease

Most meningococcal deaths were due to meningococcal B disease, in keeping with the prevalence of serotype B meningococcal disease in NSW. Three meningococcal C deaths occurred in the early years of the review following introduction of the meningococcal C immunisation program (Figure 13).



Figure 13 Meningococcal disease subtype by year

4.3.2 Pneumococcal disease

Pneumococcal disease subtype also varied by year (Figure 14). Most deaths were due to non-vaccine serotypes. Three deaths occurred following 7vPCV introduction due to infection with serotypes contained in 13vPCV but not 7vPCV (19A and 3). One death from 19A occurred after the introduction of 13vPCV and one death occurred due to type 9V, present in the 7vPCV, six months after this vaccine was introduced.





4.3.3 Influenza

Influenza deaths were predominantly due to Influenza A (Figure 15).



Figure 15 Influenza subtypes by year

4.4 Preventable and potentially preventable deaths

There was one death from pneumococcal disease in a fully vaccinated child, which was considered a vaccine failure that was not preventable by vaccination. Of all confirmed and probable deaths, the number of deaths considered preventable by vaccination is shown in Figure 16.



Figure 16 Number of deaths of confirmed and probable cases considered preventable by vaccination 2005-2014

Twenty-three deaths were considered preventable or potentially preventable by vaccination. The distribution of these deaths over the review period is shown in Figure 17.



Figure 17 Preventable and potentially preventable deaths, 2005 – 2014^{*}

^{*}Eleven of twelve influenza cases were positive clinical samples; one was a post-mortem sample

4.4.1 Preventable deaths

Five deaths occurred in children eligible under the NIP for the relevant vaccine and were considered preventable under the framework in Figure 2. These included two meningococcal deaths (aged 5 and 17 years), one pneumococcal death (aged 14 months), one influenza death (aged 12 years) and one pertussis death (aged 8 months). These children were either unvaccinated (n=3) or had unknown vaccination status

(n=2). Overall, three cases were eligible for vaccination through catch-up programs, including both meningococcal cases who were eligible for the meningococcal C catch up from 2003 and one case who was eligible for pneumococcal vaccine catch up. One influenza death occurred in a child with a high risk medical condition eligible for influenza vaccination. While parental views on immunisation are not always recorded, objection to immunisation was formally documented in one case.

4.4.2 Potentially preventable deaths

A further 18 deaths were considered potentially preventable as defined by the framework (Figure 2). For four deaths from influenza A, there was no additional subtyping so it was not possible to confirm whether the subtype was the same as the vaccine type. These deaths occurred in children aged five and over with high risk medical conditions and unknown vaccination status. Four had cerebral palsy along with other conditions. Among children without documented high risk medical conditions, five influenza deaths occurred in children aged between two and five years and two occurred in children over the age of five. Influenza deaths appeared to increase over the last few years of the study period, but this could be partially due to increased testing following the 2009 H1N1 pandemic season.

Two deaths occurred due to untyped *Streptococcus pneumoniae* (pneumococcal disease), one in a vaccinated but immunocompromised child. One hepatitis A death occurred following travel to a country for which vaccination was recommended. Three meningococcal deaths occurred: one type B after meningococcal B vaccine was available, and type Y and C when vaccines covering these subtypes were available but not recommended.

4.4.3 Non preventable deaths

Thirty deaths were considered not preventable through immunisation (Table 13). Two deaths from varicella were in children unable to be vaccinated due to impaired immune function, although it is unknown whether their family members were vaccinated. Seven deaths from pneumococcal disease occurred due to subtypes not covered by the 7vPCV then available. This included two deaths from non-vaccine serotypes and three deaths (before 2011) from serotypes in the 13vPCV but not the 7vPCV. Two deaths occurred due to strains in the 23vPPV in children with high-risk medical conditions. Two deaths from H1N1 influenza occurred in 2009 prior to the availability of the specific vaccine; both children were over the age of five but had high risk medical conditions so would have been eligible for the vaccine under the NIP.

Deaths from untyped *H.influenzae* were not considered preventable due to the low likelihood that the infecting strain was type b (Hib). The six meningococcal deaths were due to meningococcal B disease and occurred before the meningococcal B vaccine was available. Five of these six deaths were in infants under 12 months of age. Nine deaths were in children too young to be vaccinated (infants aged two months of age

or less) (Table 12). Although not preventable through immunisation of the child, pertussis and influenza deaths may have been preventable through immunisation of the mother during pregnancy.

 Table 13 Reasons children could not be vaccinated for the disease of interest

	H.influenzae	Influenza	Meningococcal	Pertussis	Pneumococcal	Varicella
Medical exemption						2
Non-vaccine serotype		2 ¹			7 ³	
Too young		1^{4}	1	3	4	
Vaccine not available	4		6 ²			

¹ These deaths would now be preventable as the H1N1 pandemic strain is now included in the vaccine

² All of these deaths were from meningococcal B, for which a vaccine is now available

³ Three of these deaths would now be preventable through 13vPCV vaccination

⁴These deaths may be preventable through maternal immunisation

4.5 Deaths in cases classified as uncertain

The deaths described as preventable and not preventable above were a subset of cases classified as confirmed or probable. In cases classified as uncertain according to the case definition in Table 7, seven were coded as possible influenza and three as possible pneumococcal disease. Of the influenza cases, three were in three month old infants where the post mortem could not determine a clear cause of death but influenza was detected in respiratory swabs taken post-mortem. Four older children had other underlying causes of death likely to be primary, including bacterial infection (two cases), epilepsy and injury.

One of the pneumococcal cases was a three month old infant with a positive post-mortem lung culture sample but no evidence of pneumonia or meningitis. The two other pneumococcal cases had also sustained significant injury prior to death which was considered likely to be the primary cause of death, with pneumococcal disease a potential contributing cause

4.6 Deaths in children classified as non-cases

Nine cases were identified from the databases but then excluded as cases. These included cases with no laboratory evidence of the pathogen of interest. One death due to gastroenteritis with dehydration did not have any laboratory evidence to confirm the pathogen so it was not possible to determine whether this was due to rotavirus.

5 Discussion

5.1 Diseases causing the most deaths

5.1.1 Influenza

A large proportion of preventable and potentially preventable deaths were due to influenza. Five deaths occurred in children aged five and over with high-risk medical conditions who were eligible for funded vaccination. In addition, two children with high-risk medical conditions died from the H1N1 pandemic strain of influenza in 2009 prior to the specific vaccine becoming available (these deaths were considered not preventable as the vaccine was not available).

While influenza vaccination is recommended and funded under the NIP for children with high-risk medical conditions, who are at greater risk of severe disease and death,^{7,66} studies have found low vaccine coverage in this group of around 40%.^{15,67} The Australian Paediatric Surveillance Unit reported no vaccinated children among high-risk cases admitted with severe disease during September 2007.⁶⁸ One survey reported the main reason children did not receive the vaccine is that parents were not aware it was needed, although some did not get around to it or were advised not to have it. Of those children with high-risk medical conditions who were vaccinated, the most important factor was advice from a medical practitioner.⁶⁷

Seven influenza deaths in our review occurred in children with no documented high-risk medical conditions, six of whom were under five years of age. Studies of influenza hospitalisation have shown high rates of admission, including to intensive care, in previously healthy young children.^{16,17,19,69} A study of influenza deaths during the 2009 H1N1 pandemic showed that, in Australia and overseas, a high proportion of children under 10 years did not have high-risk medical conditions.⁷⁰ One US study reported that children without high-risk medical conditions were more likely to die from influenza before hospital admission or within three days of symptom onset, compared to those with high-risk medical conditions.⁶⁶ Of all confirmed and probable cases of influenza in our review, four died before arrival at hospital; all of these cases were under five years of age and had no documented high-risk conditions.

While influenza vaccination is currently recommended in Australia for children under five years of age, it is not funded under the NIP, except for children with high risk medical conditions.⁷ Coverage is known to be low outside WA (where it is funded), and in one NSW study was reported to be 14%.¹⁵ None of 12 healthy children hospitalised with severe influenza nationally in September 2007 was vaccinated.⁶⁸ While the funded influenza vaccination program in Western Australia led to coverage of 40% in children under five in 2008 and 2009, this dropped to around 5% following an increase in adverse reactions to a specific brand of influenza vaccine in 2010.²⁰ This vaccine brand is no longer recommended in young children.⁷¹ The high proportion of healthy children among those suffering severe complications of influenza has led to calls for the vaccine to be funded for children under five.¹⁷

Among cases where it was 'uncertain' (as per the case definition in Table 7) whether death was due to influenza, three deaths occurred in previously healthy infants under six months of age. At post-mortem examination, a cause of death for these three infants was not able to be determined, although all had

laboratory evidence of influenza. These kinds of sudden deaths in infancy are thought to be due to many contributing causes. Although signs of infection are often found at autopsy in these cases, minor respiratory infection in infants are common and in many cases infection is not considered to be the only factor contributing to death.⁷²⁻⁷⁴ The CDRT has completed a review of sudden unexplained death in infancy and is considering the process for investigation of these deaths in NSW.

These infants would have been too young to be vaccinated because the influenza vaccine cannot be given under 6 months of age. However, they may have been protected by immunisation of their mother during pregnancy (maternal vaccination) with antibody transfer and reduced influenza-related hospitalisation well documented among infants born to such mothers.⁷ Influenza vaccination is currently recommended for pregnant women, both to reduce severe disease during pregnancy and to protect infants for six months after birth, and has been nationally funded since 2010.^{6,7} Vaccination is also recommended for people who may transmit influenza infection to high risk groups, including household contacts, healthcare workers and childcare workers.⁷

5.1.2 Meningococcal disease

We identified 12 deaths from meningococcal disease which was consistent with the NSW VPD reports, based on NCIMS data, which are available for 2009 to 2013.⁷⁵⁻⁷⁹ This is substantially less than the 26 deaths identified in NSW in children less than 15 years between 2000 and 2007; ⁸⁰ the reduction in deaths is attributable to the meningococcal C vaccination program.⁴²

Most cases of meningococcal disease in Australia are now caused by subtype B⁴² and a vaccine is now available and recommended for young children, particularly those aged <24 months, adolescents aged 15-19 years, and those with specific high-risk medical conditions.⁷ In our review, one case of meningococcal B disease was potentially preventable, as it occurred after the vaccine was available and recommended in Australia. Another six were not considered preventable as the vaccine was not available at that time. While the vaccine is currently available for private purchase, it has not been funded under the NIP because of uncertainties about the effectiveness of the vaccine when delivered as part of an immunisation program, particularly with regard to long-term protection and cost-effectiveness.⁸¹

While meningococcal disease is now rarely caused by subtype C, two deaths in our review occurred in children eligible for the catch-up program after the introduction of the meningococcal C vaccination program. Catch-up programs are offered when an immunisation program is first introduced, and offered to children outside the targeted age group. Coverage has been noted to be low in catch-up programs for other vaccines.⁸²⁻⁸⁴

5.1.3 Pertussis

One death in an eight month old, unvaccinated infant was considered preventable. Three infant pertussis deaths were not considered preventable at the time of death, as the infants were too young to be vaccinated. The two deaths occurring in 2011 and 2012 were also captured in the NSW vaccine preventable diseases reports.^{75,76} Various strategies are recommended to reduce the risk of pertussis in young infants, including vaccination of close contacts to reduce exposure of the infant to pertussis (known as cocooning) and maternal vaccination.³⁹

Vaccination of close contacts including household contacts and carers, healthcare workers and childcare workers is recommended in the Australian Immunisation Handbook.⁷ Maternal vaccination leads to the transfer of antibodies to the newborn, providing protection in the early months before vaccination, and also reduces the chance that the mother will contact pertussis and pass it on to her infant.⁷ It is considered the best strategy for protecting vulnerable infants from infection.⁴⁰ Maternal pertussis immunisation was recommended in the Australian Immunisation Handbook in April 2015 and subsequently provided free of charge by all states and territories, but was not funded nationally through the NIP.^{7,40}

5.1.4 Pneumococcal disease

We reported 16 pneumococcal deaths, consistent with those reported in NSW Vaccine Preventable Disease reports based on NCIMS data for 2009 to 2013.⁷⁵⁻⁷⁹ One death occurred in a fully vaccinated child, caused by a vaccine strain. This is a case of vaccine failure, which can occur as a result of an ineffective immune response.⁷ This case was also reported in the NSW vaccine preventable disease report.⁷⁷ One death was considered preventable as it occurred due to strain 9V, which is present in the 7vPCV vaccine. The child was eligible for a catch-up program which commenced six months prior to the child's death. Four cases occurred in infants too young to be vaccinated.

Seven deaths were due to subtypes not present in the vaccine that was available at that time. Two deaths in our review were due to subtypes not present in any pneumococcal vaccine. Three deaths, occurring between 2007 and 2010, were due to subtypes (19A and 3) not present in the 7vPCV (available from 2005) that were later included in the 13vPCV vaccine, which was only available from 2011. An increase in IPD due to certain non-vaccine subtypes, particularly 19A, following introduction on 7vPCV is well documented as a serotype replacement phenomenon.²⁵ Despite this increase, the overall number of cases and deaths due to pneumococcal disease dramatically reduced since the introduction of the vaccine. In NSW, 27 children under five died from pneumococcal disease between 1998 and 2004, with only 3 deaths between 2005 and 2010.⁸⁵

Two deaths in our review were due to subtypes (22F and 33F) that were not present in either 7vPCV or 13vPCV, but were present in the 23vPPV. For children with high-risk medical conditions, the 23vPPV was funded as a booster dose at 12 months of age from 2001 to 2005, and at 4 to 5 years of age from 2003. A

booster dose was funded for Indigenous children in some states (not NSW) from 2001 to 2011.²⁶ Both deaths in our review occurred after 2005 and were in children under five years who had high-risk medical conditions, although in one case this condition was not diagnosed until after death. In one case the child was also Indigenous.

5.2 Risk factors

Fifteen of the 54 confirmed and probable cases occurred in infants under six months of age, reflecting both those too young to be vaccinated (10 infants), and the increase risk of severe infectious disease in that age group. Males were disproportionately affected, and other studies have shown that male sex is a risk factor for infant infectious disease deaths.⁸⁶ One third of deaths occurred in children with medical conditions known to increase the risk of severe disease.⁷ However, it is concerning that two thirds occurred in children with no known high-risk medical conditions.

Deaths from meningococcal disease tended to occur in children residing in more disadvantaged regions. An association was shown between socio-economic status (including low education and income) and hospitalisation for infectious diseases in pre-school children in Denmark, despite universal health care and social benefits available in that country.⁸⁷ This association may be due to increased exposure to infection (for example, through crowding), decreased resistance to infection (for example, due to parental smoking) or access to care in groups with lower socioeconomic status.⁸⁷⁻⁸⁹

5.3 Data completeness

Review of deaths from any data source is limited by whether cases have been tested and diagnosed within the health system. Cases may die due to complications of an initial infection, and these complications may be diagnosed and recorded as the cause of death. Laboratory testing may not always be required at the time the patient receives care, and infections may not always be detected in the laboratory.¹⁴

Various data sources are available in Australia to examine deaths, but all have limitations.³ We used two separate data sources for our review: the CDR (through the NSW Ombudsman) and NCIMS (through Health Protection NSW).

The CDRT applied ICD codes based on information gained from death certificates (from BDM), coroner's reports and other records. Classification of deaths using ICD coding is known to provide limited information.¹⁴ Although we identified information from additional fields, specific infectious disease or laboratory data was not always available. Due to the large number of cases in the original CDR database, we assessed cases and included only those most likely to be due to diseases caused by a pathogen of interest. This assessment system only captured deaths where a specific pathogen was mentioned and

excluded cases where a disease syndrome such as pneumonia or sepsis was identified without specific reference to the relevant pathogen. As a result, we may have underestimated of the number of deaths from the database. Collection of specific pathogen information in CDR fields would improve case ascertainment.

The use of NCIMS data to match information for the CDR cases and identify additional cases improved our ascertainment of relevant deaths over this period. Cases on NCIMS are classified using standardised case definitions based on laboratory, clinical and epidemiological criteria and allow for the accurate identification of vaccine preventable diseases caused by specific pathogens. Although this addresses a major limitation of the CDR database, recording of death in NCIMS is inconsistent. We noted that our cases were consistent with those reported in NSW vaccine preventable disease reports, which provides confidence that cases were adequately captured.⁷⁵⁻⁷⁹ Confirmed cases were more likely to have been identified from both sources, suggesting that use of two sources increase the accuracy of case identification.

6 Conclusion

Deaths in children from potentially preventable infectious diseases continue to occur in NSW, particularly in young infants. There is scope to prevent further severe disease and death, particularly from influenza, meningococcal B and pertussis. In particular, it is important that clinicians are aware of recommendations for influenza and pneumococcal vaccination for high-risk children as well as maternal influenza and pertussis immunisation programs. These findings demonstrate that review of child deaths is important to inform future policy and practice.

7 Recommendations

- 1 Immunisation of children at high risk is recommended and provided free under the NIP:
 - General and specialist practitioners who care for children with medical conditions or compromised immune systems placing them at increased risk of influenza, invasive pneumooccal disease, meningococcal disease or Haemophilus influenzae type b disease should put mechanisms in place to ensure that additional vaccines specifically recommended in the Australian Immunisation Handbook are received.
 - General and specialist practitioners providing care for children with predisposing medical conditions should ensure responsibilities for immunisation are clear.
 - Examples of relevant mechanisms may include flags in hospital electronic records, amendments to medical practice software to issue alerts to general practitioners, configuration of immunisation registers to issue alerts to parents and providers, and routine provision of information to parents.

- 2 Vaccines against influenza and meningococcal B disease are recommended for all Australian children although not provided free of charge in 2016:
 - Parents wishing to reduce their child's risk of influenza and meningococcal B should discuss this with their general practitioner or other immunisation provider.
 - General practitioners and other immunisation providers should ensure that they are aware of the recommendations on influenza vaccination in the Australian Immunisation Handbook, including that influenza vaccination is recommended for infants and children aged from six months to less than five years due to the increased risk of hospitalisation and death in this group.
 - General practitioners and other immunisation providers should ensure that they are aware
 of the recommendations on meningococcal B vaccination in the Australian Immunisation
 Handbook, including that meningococcal B vaccination is recommended for infants and
 young children, particularly those aged <2 years, due to their higher risk of serogroup B
 meningococcal disease.
- 3 Immunisation of contacts is recommended for children at high risk of influenza, pertussis and varicella:
 - General practitioners and specialists who care for infants aged under 6 months should be aware of the recommendation in the Australian Immunisation Handbook for pertussis vaccination of household contacts and carers of these infants, and should promote immunisation to these groups, particularly if vaccination has not been received in pregnancy.
 - General practitioners and specialists who care for children at high risk of influenza (particularly those with a high-risk medical condition) should be aware of the recommendations in the Australian Immunisation Handbook to vaccinate household contacts and carers of these children and should actively promote immunisation to these groups.
 - Facilities that provide health care or child care services for children who are at high risk influenza or infants at risk of pertussis should take steps to provide comprehensive occupational immunisation programs for their workers as per the recommendations in the Australian Immunisation Handbook.
 - Specialists who care for children at risk of severe varicella infection should be aware of the recommendation in the Australian Immunisation Handbook to ensure household contacts

without a history of varicella receive two doses of varicella vaccine and actively promote immunisation to this group.

- 4 Immunisation against pertussis and influenza is recommended during pregnancy and provided free in NSW:
 - Health practitioners providing antenatal care should be aware that pertussis and influenza vaccine is provided free for pregnant women in NSW and that detailed information about this program can be obtained from the NSW Health website.^{1,2}
 - Pertussis and influenza vaccination during pregancy should be promoted and encouraged by general practitioners, obstetricians and midwives to reduce the risk of disease in young infants.
- 5 Children should receive vaccines for which they are eligible under immunisation catch up programs:
 - Immunisation providers should ensure children receive all vaccines for which they are eligible under funded immunisation catch-up programs, for example through the use of electronic alerts or flags on medical records.
 - Catch-up programs should be widely promoted to parents when new immunisation programs commence.
- 6 Travel immunisation should be provided as recommended:
 - General practitioners should be aware of recommendations on vaccination for international travel in the Australian Immunisation Handbook that are relevant to children, including hepatitis A and BCG vaccines, and these should be actively promoted to parents.
- 7 Data collections on child deaths in NSW should be enhanced and cross-checked between sources:
 - The CDRT should implement measures to improve identification and coding in the CDR of specific pathogens and isolation sites associated with VPDs to facilitate review of child deaths from infectious diseases in NSW.
 - The CDRT and Health Protection NSW should engage in regular communication and crosschecking regarding child deaths from VPDs.
 - The CDRT and Health Protection NSW should work with the NSW State Coroner in regard to standard protocols for testing for and notification of infectious diseases identified following a child's death.

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A. Appendix: National Immunisation Schedule



Australian Government Department of Health

National Immunisation Program Schedule From February 2016

Child programs			
Age	Vaccine		
Birth	• Hepatitis B (hepB)ª		
2 months	 Hepatitis B, diphtheria, tetanus, acellular pertussis (whooping cough), Haemophilus influenzae type b, inactivated poliomyelitis (polio) (hepB-DTPa-Hib-IPV) Pneumococcal conjugate (13vPCV) Rotavirus 		
4 months	 Hepatitis B, diphtheria, tetanus, acellular pertussis (whooping cough), <i>Haemophilus influenzae</i> type b, inactivated poliomyelitis (polio) (hepB-DTPa-Hib-IPV) Pneumococcal conjugate (13vPCV) Rotavirus 		
6 months	 Hepatitis B, diphtheria, tetanus, acellular pertussis (whooping cough), <i>Haemophilus influenzae</i> type b, inactivated poliomyelitis (polio) (hepB-DTPa-Hib-IPV) Pneumococcal conjugate (13vPCV) Rotavirus^b 		
12 months	 Haemophilus influenzae type b and meningococcal C (Hib-MenC) Measles, mumps and rubella (MMR) 		
18 months	 Diptheria, tetanus, pertussis (whooping cough) (DTPa) Measles, mumps, rubella and varicella (chickenpox) (MMRV) 		
4 years	 Diphtheria, tetanus, acellular pertussis (whooping cough) and inactivated poliomyelitis (polio) (DTPa-IPV) Measles, mumps and rubella (MMR) (to be given only if MMRV vaccine was not given at 18 months) 		
School programs			
10–15 years (contact your State or Territory Health Department for details)			
At-risk groups			
Aboriginal and Torres Strait Isla	nders		
12–18 months (in high risk areas)*	Pneumococcal conjugate (13v PCV)		
12–24 months (in high risk areas) ^r	• Hepatitis A		
6 months to less than 5 years	• Influenza (flu)		
15 years and over	 Influenza (flu) Pneumococcal polysaccharide (23vPPV) (medically at risk) 		
50 years and over	Pneumococcal polysaccharide (23vPPV)		
Other at-risk groups			
6 months and over (people with medical conditions placing them at risk of serious complications of influenza)	cal conditions placing them k of serious complications of		
12 months (medically at risk) ^e	Pneumococcal conjugate (13vPCV)		
4 years (medically at risk) ^e)e Pneumococcal polysaccharide (23vPPV)		
Pregnant women (at any stage of pregnancy)	• Influenza (flu)		
65 years and over	 Influenza (flu) Pneumococcal polysaccharide (23vPPV) 		

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Footnotes to the National Immunisation Program (NIP) Schedule

- a. Hepatitis B vaccine: should be given to all infants as soon as practicable after birth. The greatest benefit is if given within 24 hours, and must be given within 7 days.
- Rotavirus vaccine: third dose of vaccine is dependent on vaccine brand used. Contact your State or Territory Health Department for details.
- c. Varicella vaccine: contact your State or Territory Health Department for details on the school grade eligible for vaccination.
- d. HPV vaccine: is for all adolescents aged between 12 and 13 years. Contact your State or Territory Health Department for details on the school grade eligible for vaccination.
- e. Pneumococcal vaccine:
 - i. Medically at risk children require a fourth dose of 13vPCV at 12 months of age and a booster dose of 23vPPV at 4 years of age.
 - ii. Aboriginal and Torres Strait Islander children require a fourth dose of pneumococcal vaccine (13vPCV) at 12-18 months of age for children living in high risk areas (Queensland, Northern Territory, Western Australia and South Australia). Contact your State or Territory Health Department for details.
- f. Hepatitis A vaccine: two doses of Hepatitis A vaccine for Aboriginal and Torres Strait Islander children living in high risk areas (Queensland, Northern Territory, Western Australia and South Australia). Contact your State or Territory Health Department for details.

Further information

Further information and immunisation resources are available from the Immunise Australia Program website at **www.immunise.health.gov.au** or by contacting the infoline on **1800 671 811**.

You should contact your State or Territory Health Department for further information on the program specific to your State or Territory:

State/Territory	Contact Number
Australian Capital Territory	(02) 6205 2300
New South Wales	1300 066 055
Northern Territory	(08) 8922 8044
Queensland	13 HEALTH (13 4325 84)
South Australia	1300 232 272
Tasmania	1800 671 738
Victoria	1300 882 008
Western Australia	(08) 9321 1312



11178 February 2016

www.immunise.health.gov.au

All information in this publication is correct as at February 2016

B. Appendix: Infectious Diseases CDRT Data Assessment Protocol

What is the likelihood that the case is associated with a disease of interest?

- 1. Highly Likely
- 2. Moderately Likely
- 3. Possible
- 4. Unlikely
- 1. Highly Likely
 - i. ¹Any field on the Infectious Disease CDRT dataset names a specific disease of interest or pathogen or interest
- 2. Moderately Likely
 - i. As above <u>but</u> further clinical review is required to confirm that it is a disease of interest
- 3. Possible
 - Any field names a ²syndrome of interest without identifying a causative agent AND the individual is > 2 months of age
- 4. Unlikely
 - i. Any field names a ²syndrome of interest without identifying a causative agent AND the individual is < 2 months of age
 - ii. A disease of interest does not appear in any field and if a syndrome of interest is present, a cause is identified

¹any field incorporates the following: International Classification of Disease (ICD) Chapter Description, BDM cause of death (COD), additional cause of death (ACOD), Coroner COD and Case Notes

²syndrome of interest refers to a collection of syndromes that may be associated with a VPD and includes (but is not limited to) the following;

Syndro	ome	Potential VPD	
1.	gastroenteritis	rotavirus	
2.	pneumonia, bronchopneumonia,	influenza, pneumococcal, meningococcal,	
	respiratory tract infection, bronchitis,	varicella, Hib, measles, pertussis, varicella,	
	bronchiolitis	diphtheria	
3.	meningitis	pneumococcal, meningococcal, varicella, Hib,	
		polio	
4.	encephalitis	pertussis, measles, mumps, rubella, varicella,	
		polio	
5.	septicaemia, sepsis	pneumococcal, meningococcal, Hib, varicella	
6.	myocarditis, endocarditis	influenza, mumps, viral hepatitis, varicella,	
		streptococci, meningococci, rubella, diphtheria	
7.	enterovirus	polio	