

Privacy Policy

Setting out the
Management of Health
Information contained in the
National Immunisation Register

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MANATŪ HAUORA

Abbreviations

AEFI	Adverse events following immunisation
BCG	Bacille Calmette-Guérin vaccine for tuberculosis
CARM	Centre for Adverse Reactions Monitoring
DHB	District Health Board
HIPC	Health Information Privacy Code
LMC	Lead Maternity Carer
MeNZB™	Group B Meningococcal vaccine
NHI	National Health Index
NIR	National Immunisation Register
NZHIS	New Zealand Health Information Service
NZPhvC	New Zealand Pharmacovigilance Centre
PMS	Practice Management System
SBVS	School Based Vaccination System

The National Immunisation Register Privacy Policy was developed with the assistance of Elisabeth Harding, Solicitor, Counties Manukau District Health Board.

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National Immunisation Register Privacy Policy

The framework for the collection, exchange and management of health information about identifiable individuals held on the National Immunisation Register (NIR) falls within the provisions of the Health Act 1956, the Privacy Act 1993 and the Health Information Privacy Code 1994 (HIPC). The HIPC, in particular, provides a broad framework of controls for the management of information about identifiable individuals.

The purpose of this document is to set out the Privacy Policy in relation to the management of the health information held on the NIR.

1. Introduction

New Zealand needs to improve its immunisation rates, which are lower than in many comparable countries. Along with access to clean water, immunisation is recognised as the public health intervention that has had the greatest impact on health globally. In order to monitor the level of immunisation provided to a defined group, immunisation intervention needs to be measured and relevant information needs to be made available at the point of care.

The development of a national register to record immunisation information about identifiable individuals is driven by several perspectives. The expectations of each of these groups may be different but are not necessarily incompatible:

- Minister of Health
- Ministry of Health
- individuals/parents/guardians/caregivers
- providers of health services
- funders of health services
- public health analysts
- Centre for Adverse Reactions Monitoring (CARM) a unit within the New Zealand Pharmacovigilance Centre (NZPhvC)
- auditor and monitors of quality assurance
- researchers.

The function of the NIR is to record accurately immunisation status of both the individual and the identified population (cohort). The NIR is a tool that will assist providers in improving immunisation rates by providing relevant health information at the point of care. This has to be done in conjunction with informing and educating the public on the importance of immunisation and ensuring the full participation of providers of immunisation services. The quality, including accuracy and completeness, of any data collection is contingent on the support of both these groups. Therefore, the justification for obtaining health information about identifiable individuals to hold within the NIR needs to be transparent and linked to the defined objectives.

2. Current problems – why do we need a register?

Immunisation coverage in New Zealand is lower than is required to prevent epidemics of some vaccine-preventable diseases such as pertussis and measles. Improved immunisation coverage will offer individual protection against vaccine-preventable disease, and protection for the community against recurring epidemics. Achieving higher coverage in Māori and Pacific children is a priority, as data suggests coverage in these populations is significantly lower than in other New Zealanders. Improving coverage in these groups would contribute to reducing health inequalities.

Immunisation in childhood is an integral part of the Well Child Schedule. The implementation of the Child Health Information Strategy 2003 includes the collection and sharing of childhood immunisation data in its scope.

The National Immunisation Schedule recommends childhood vaccines, the annual influenza vaccine for high-risk children and adults, and tetanus and diphtheria boosters for adults at 45 and 65 years of age. (See Appendix for 2002 Schedule.)

New Zealand has obligations to meet present and future global disease targets that require high immunisation coverage (such as the eradication of polio and elimination of measles).

Current problems contributing to New Zealand's low immunisation coverage rates include:

- failure to follow-up individuals who have missed or are late for immunisations
- inability to follow up mobile and hard to reach families
- isolated (practice level) record keeping
- lack of a reliable source of immunisation history for individuals
- inaccurate estimates of the number of children currently immunised¹
- risk of over-immunisation where immunisation status is unknown.

3. National strategies

The demands and justification for the development of the NIR can be found in the following Ministry of Health strategies.

Child Health Strategy 1998

The Child Health Strategy represents the collective wisdom of the child health sector on what is required to improve child health services and ultimately improve the health status of New Zealand children from 1998 to 2010. The Strategy identifies directions to improve health outcomes for New Zealand children/tamariki and their families/whānau. These directions include:

- a greater focus on health promotion, prevention and early intervention

¹ To quantify immunisation coverage it is necessary to accurately define the numerator (the number of children immunised in a specific cohort) measured against the denominator (the number of children in the specified cohort).

- better co-ordination
- development of a national child health information strategy (see below)
- improvement in child health evaluation and research.

New Zealand Health Strategy 2000

The New Zealand Health Strategy sets the platform for the Government's action on health. It identifies the Government's priority areas and aims to ensure that health services are directed to those areas that will ensure the highest benefits for our population, focusing in particular on tackling inequalities in health. One of the thirteen population health objectives is to:

- ensure access to appropriate child health care services including Well Child and family health care and immunisation.

Many indicators of child health show that New Zealand has a low international ranking of child health. Vaccine-preventable diseases are an important cause of morbidity and mortality for all communities. The adoption of the National Health Committee's² advice on immunising children most in need by outreach services is an essential component, along with ensuring that each newborn child has a Well Child provider.

An Integrated Approach to Infectious Diseases – Priorities for Action 2002–2006 (IAID) 2001

The goal of the IAID is to address the New Zealand Health Strategy objective to reduce the incidence and impact of infectious disease. The control or elimination of vaccine preventable disease through the delivery of safe and effective vaccination programmes across all communities is high priority in the IAID. The targets to achieve this IAID objective are:

- 95 percent of children are fully vaccinated at age two years by 2005
- 75 percent or more of the defined high-risk adult population are vaccinated annually against influenza.

The IAID strategies (extracts) identified to meet these targets include:

- establishing and maintaining a national immunisation register that can supply providers across New Zealand with accurate data on a child's immunisation status, as well as information on local, regional and national immunisation coverage. In development of electronic individual immunisation records, maintenance of databases of immunisation status through into adulthood should be considered
- continuing to improve access to immunisation services and remove immunisation disparities among socioeconomic and ethnic groups, through:
 - increasing the range of service provision
 - implementing policies to ensure that providers are motivated to immunise hard-to-contact groups and to provide information

² National Health Committee, *Review of the Wisdom and Fairness of the Health Funding Authority Strategy for Immunisation of 'Hard to Reach' Children*, October 1999.

- providing accessible services for adult immunisation
- ensuring that appropriate information is available to address needs of providers and communities for knowledge about immunisation, through a co-ordinated, consistent communication strategy at the national, regional and local levels
- enhancing surveillance for vaccine-preventable diseases in the community, including integration of laboratory notification and serosurveillance data, disease incidence, immunisation coverage and vaccine adverse event data.
- auditing and evaluating services/providers for effectiveness in improving coverage and disease control
- supporting research on immunisation and means of improving coverage.

Well Child Framework 2002

The Framework has been developed for delivering Well Child care to achieve the population health strategy for child health services as identified in the New Zealand Health Strategy. The aim of the Framework is to ensure a total package of care is delivered to all New Zealand children, and that additional care is provided where there is additional need. The Framework:

- requires the Well Child provider to ‘refer’ the child and their family/whānau to their primary care provider for the six-week physical and developmental examination and the first immunisation
- recognises that 15–25 percent of New Zealand children are not being fully immunised and encourages Well Child providers working with high-need families to either facilitate immunisation with the primary care provider or provide immunisation themselves
- accepts that, traditionally, primary care providers have successfully delivered the immunisation portion of the ‘health protection and clinical assessment’ component to 75–85 percent of children, and does not attempt to change this.

Child Health Information Strategy 2003

The Child Health Information Strategy is an overarching plan to guide the development, collection and use of information about the health of children and young people. The fundamental purpose of the Strategy is to improve the health of our children by making clinically useful, appropriate, up to date, and accurate health information available at every contact between a child and a health professional.

Other Ministry of Health strategies that are relevant to child health but do not specifically refer to immunisation are:

- *He Korowai Oranga* – Māori Health Strategy 2002
- Pacific Health and Disability Plan 2002
- Reducing Inequalities in Health 2002
- Primary Health Care Strategy 2001.

4. Expectation of the use of the information held on the NIR

There are a range of expectations by different groups on how the information held on the NIR will be used. These expectations may not necessarily be in conflict with each other.

Individual/parent/caregiver expectations

- Awareness of how their (or their child's) health information will be used and with whom it may be shared.
- A centralised accurate source of information about immunisations provided.
- Assistance with recalls and reminders.
- A record of individual choice to immunise or not to immunise.
- A record of individual choice about having their immunisation information collected on the NIR or not (note the collection of immunisation information for those immunised as part of the Meningococcal B Immunisation Programme will be mandatory).
- A record of adverse events following immunisation (AEFI) to inform future immunisation decisions.³

Providers of health services requirements

- Relevant clinical information is available at the point of care to ensure the right care at the right time to the right person.
- Information on AEFI.
- Evaluation and audit of immunisation related services.
- Aggregate information for providers about their delivery of immunisation services, AEFI, and the percentage of their enrolled eligible patients receiving immunisation services.
- Providers will also be interested in the use of their identifiable information held on the NIR.

Funders of health services requirements

- Aggregate information about immunisation status for planning, targeting, funding, monitoring and assessment of the delivery of immunisation services
- Evaluation and audit of immunisation related services to assist them in meeting their responsibilities to improve health status, reduce inequalities and ensure optimum use of health funding.

³ Health professionals are professionally and ethically responsible for reporting serious or unexpected adverse events that occur after all medicines, including vaccines, to the NZ Pharmacovigilance Centre (NZPhvC). The NIR will have the capacity for health professionals to flag an AEFI on an individual's record.

Public health requirements

- Analysis of immunisation coverage and impacts on health status.
- Surveillance of vaccine preventable diseases for the prediction and early detection of epidemics.
- Efficient monitoring of immunisation intervention programmes.
- Assessment of the safety and efficacy of vaccines.
- Information on AEFI.
- Evaluation of immunisation programmes.

Research and evaluation requirements

- Assessment of the safety and efficacy of vaccines.
- Information on AEFI.
- Evaluation of immunisation programmes.

Most research and evaluation will use aggregated, non-identifiable information. For some purposes, identifiable information will be provided (eg, CARM, vaccine safety and monitoring, and the Child and Youth Mortality Review Committee).

5. Justification for collecting ethnicity data

The purpose of collecting accurate and consistent ethnicity data is to improve health providers and policy makers ability to analyse, compare and integrate health needs, healthcare service delivery and the development of more appropriate services.

The implementation of a process that is used by collectors, recorders and users of ethnicity data is important and must be undertaken in a standard manner and be informed by a continuous process of quality control involving feedback, review, education and training.

Within the context of Health and Disability Policy, the Treaty of Waitangi, He Korowai Oranga (Maori Health Strategy) and Reducing Inequalities all identify and commit to improving health services to Māori. The improved collection and accuracy of ethnicity data will support government to assist and provide for health priorities of specific ethnicities.⁴

6. What is the scope of the NIR?

In the future it is anticipated that details of all immunisations provided under the National Immunisation Schedule (including adult immunisation events) will be collected on the NIR. Initially, the immunisation information that will be included on the NIR will be:

- the National Childhood Immunisation Schedule events given or declined at 6 weeks, 3, 5 and 15 months, 4 and 11 years of age (see appendix for the 2002 Schedule)

⁴ Ministry of Health, *Ethnicity Data Protocols for the Health and Disability Sector*, 2004.

- the New Zealand strain specific group B meningococcal vaccine (MeNZB™) given or declined within the Meningococcal B Immunisation Programme. The pilot and national rollout (for individuals aged up to 20 years) is planned for 2004 and 2005. Collection of information on the NIR following MeNZB™ immunisation will be mandatory in order to monitor the safety of the new vaccine. If an individual declines MeNZB™ they may have this recorded on the NIR or “opt off” the collection of the decline information on the NIR (see section 10).
- hepatitis B vaccine and immune globulin when given at birth to babies born to hepatitis B surface antigen positive mothers as defined by the National Immunisation Schedule
- BCG vaccine given to babies at risk of tuberculosis as defined by the National Immunisation Schedule.

Information will be collected on all individuals born after a specified date (the birth cohort). The NIR will be implemented via a phased rollout by district health boards (DHBs) from the north of New Zealand to the south. Thus, the birth cohort for each DHB will be different until the NIR is operational throughout New Zealand. To ensure the birth cohort information remains comprehensive, immunisation information about new immigrants who fall within the birth cohort will be added to the NIR when they access a primary care provider for an immunisation event. There will not be any backfilling of historical immunisation information for those who are added to the birth cohort at a later date or who have received an immunisation event overseas.

For the Meningococcal B Immunisation Programme, many individuals who fall outside of the birth cohort will have their information included on the NIR. As the previous immunisation events of these individuals will not be collected, the NIR will not hold a complete immunisation record for these individuals. The NIR will not provide a complete denominator for the Meningococcal B Immunisation Programme population (census data will be used in this case) but importantly, will assist in identifying the MeNZB™ vaccine status of individuals, assist in their recall, and in the monitoring of the safety and efficacy of this new vaccine.

In time, it is anticipated that other immunisation events could be included on the NIR, such as adult immunisation events, future school based immunisation programmes or travel vaccines. Any future immunisation information held on the NIR will be collected with the knowledge of the individual concerned.

7. NIR information flows and who holds the information

The Director General of Health will be responsible for the NIR, with operational management of the NIR being undertaken by the National Immunisation Programme within the Ministry of Health (Ministry).

The NIR will be implemented on a DHB by DHB basis. Each DHB will have access to the information for their population. The DHB will work with its providers to ensure that immunisation information is transmitted to the NIR accurately to nationally consistent

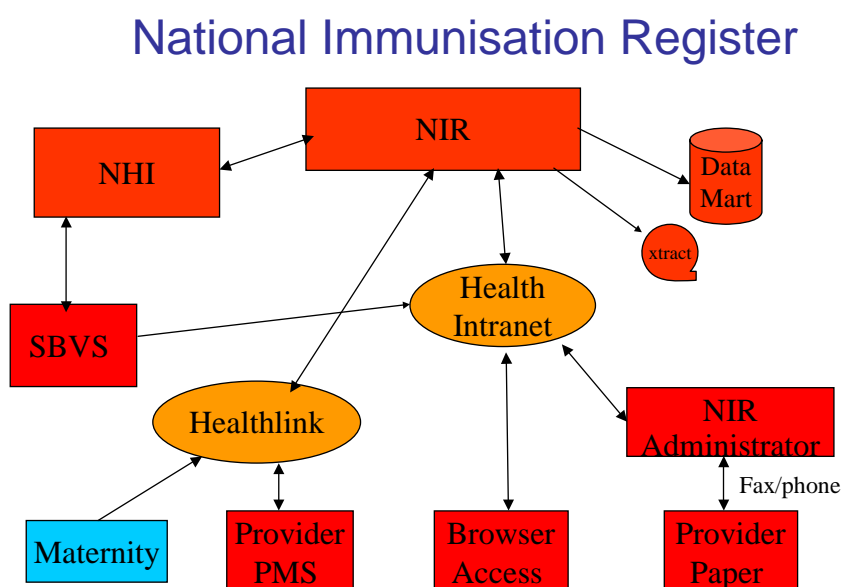
standards. The DHB will use, analyse and monitor the data about their own population and providers, to inform their planning and delivery of immunisation services.

The district immunisation information will be held on the national NIR server, managed by the New Zealand Health Information Service (a unit within the Ministry of Health). By consolidating the information on all the district populations, the NIR holds the immunisation information of the entire child population of New Zealand registered on the NIR and enables communication of information between all DHBs.

The NIR IT system is based on the immunisation component of the Kidslink software, which is already functioning in Counties Manukau DHB and as WestKids in West Auckland. The NIR will use the Orion International Soprano Disease Management application for the NIR database, and a new application for school-based vaccination programmes.⁵ Communications will occur via web-based protocols, via HL7 (HealthLink) messaging protocols and by telephone, fax and paper transfers. The aim is to move to predominantly electronic transfer in the future.

At each DHB, NIR administrator(s) will manage the flow of information about individuals to and from providers in their DHB.

Figure 1: NIR information flow diagram



Registration on the NIR

For the birth cohort, parents are informed about the NIR in the antenatal and birthing period. For children born in hospital, the child's registration information, including NHI, is sent to the district register from the maternity information system at discharge. For

⁵ The School Based Vaccination System (SBVS) has been developed to support the collection of immunisation information within school settings, particularly for the Meningococcal B Immunisation Programme. Health information for an individual will be sent to the NIR following consent and vaccination at school.

children born at home, lead maternity carers (LMCs) will be requested to send information to the NIR. Once the child is registered the primary care provider identified by the parent is notified of the nomination, so that they can accept or decline the ongoing care of the child.

Migrant children and children born to New Zealand citizens overseas, whose date of birth falls within the initial birth cohort, will be registered at their first point of contact with primary care services. This will require health providers to inform the individual/parent about the NIR and send their information to the NIR. The same process will be used for any other birth cohort children who are not captured during the antenatal and birth period.

All individuals immunised as part of the Meningococcal B Immunisation Programme (primarily by primary care providers and school-based vaccination programmes), will be required to be registered on the NIR so that vaccine safety and coverage can be evaluated. Those individuals who decline MeNZB™ will have this information recorded on the NIR or may choose to 'opt off' the collection of the decline information on the NIR (see section 10).

Immunisation event

After an immunisation provider has given a vaccination, they will send the event information (and any changes to demographic information) to the NIR. Providers with computerised practice management systems (PMS) will send electronic messages via HealthLink (a secure password protected messaging system already used by health providers to send messages to and from Ministry of Health and Accident Compensation Corporation systems). Providers without electronic messaging capacity will send information to the NIR by paper/telephone. DHB NIR administrators will then enter this information on the NIR. Information from school-based vaccinations programmes will be sent from public health units to the NIR via HealthLink.

The NIR will send information to immunisation providers (eg, notifying the provider to recall an individual for a late or missed immunisation event) using the same channels ie, via electronic messages to PMSs, or via paper/telephone to non-electronic messaging practices.

Where an immunisation provider does not already know an individual, they will need to obtain information about the individual's immunisation status. Providers with PMSs will send a query using electronic messages via HealthLink or via the Health Intranet. Providers without electronic messaging capacity and those providing school based immunisations will obtain this information by telephoning the DHB NIR Administrator.

The School Based Vaccination System (SBVS) will send individual and immunisation event information to the NIR following vaccination in a school setting. The NIR will not be sending any information to the SBVS.

When a child becomes overdue for an immunisation event

If a child becomes overdue for a childhood immunisation schedule event, the provider will initiate recall, as happens currently. If the overdue period is prolonged beyond the defined 'intervention period' the NIR will flag this. The DHB NIR Administrator will take appropriate action, contacting the provider and offering assistance with recall, as necessary. If the provider is unsuccessful in finding the child, the DHB NIR Administrator will then offer referral to a Well Child provider, outreach or facilitation service to try and find the child, and offer immunisation (firstly by facilitating access to the primary care provider; and if this is unsuccessful, outreach vaccinators may be required). The result of this will be that the child either receives his or her scheduled immunisation and it is recorded on the NIR, or that the provider obtains a reason for the loss of contact, such as relocation, emigration, parents/caregivers deciding to decline immunisation or 'opt-off' immunisation data collection⁶ on the NIR, or the death of the child.

Other information flows

The information collected on the NIR will be used to update the demographic information held on the NHI database for that individual. Individuals will be informed about this use of their information. NHI information on an individual will not be used to update the NIR, except for details used to validate an individual's death and for information on merged or linked NHIs.

In the event that an individual or their parent/caregiver does not know their NHI number or the individual has not been registered on the NIR, an electronic provider may use the NIR to search the NHI database for that individual's NHI. (This search will only use the individual's name, gender and age range. Note no other identifiable information will be required.) If the individual does not have an NHI number the existing procedures will need to be followed to assign an NHI to that individual as per the NHI User Agreement.

The NHI dataset will be regularly matched against the NIR denominator, and the proportion of NHIs not entered on the NIR will be calculated to determine the completeness of the NIR denominator. The NIR will not seek identifiable information about individuals with NHIs who are not enrolled on the NIR.

Reports will be designed specifically for the purpose for which they will be used, for example, DHB coverage information by age, ethnicity and antigen. An extract is a computer file of information with identifiable or non-identifiable data required for specific analysis. For example, CARM may require identifiable information held within the NIR for the purpose of monitoring vaccine safety and sending an individual's immunisation history following an AEFI. Requests for non-standardised reports or use of extracts will be confirmed by the NIR national governance body or via the Ministry of Health's National Immunisation Programme.

⁶ Refer to Section 10: Opting off the NIR.

The NIR will be used to provide national, district and local reports (which will generally contain non-identifiable, aggregated information). Any requests for non-anticipated information will be managed via the NIR national governance body.

Table 2 in the appendix identifies the NIR users, the NIR objectives their role fulfils and the types of information they require to meet the purpose for their use and disclosure of the information held within the NIR.

The historical data held on Kidslink for Counties Manukau District Health Board (CMDHB) and Westkids will be transferred on to the NIR for both immunisation and Well Child information. This data migration will allow the existing Kidslink cohort to have future information collected on the NIR. There will be no backfilling of historical immunisation information, and all future immunisation events for the Kidslink historical cohort as well as the “new” birth cohort will be required to meet the mandatory data collection requirements of the NIR. The NIR will also collect and hold the Well Child information for the existing Kidslink cohorts and future CMDHB cohort. (See Appendix for more details on the migration of Kidslink information onto the NIR).

8. Assumptions

The Ministry has considered the assumptions and justifications of the collection of personal health information for the NIR, including the following questions:

- What is the purpose of the information collection?
- Will the collection achieve a compelling public health purpose?
- Will collection result in effective health policy (eg, people might avoid immunisation if they fear the consequence of disclosure)?
- Who will have access to the information? Can it be disclosed by force or law? What will be the effect of negligent disclosure?
- What impact will it have on human rights? Is there stigma to individuals or communities?
- Are there less invasive alternatives?
- What safeguards are available to reduce the risk?

The Ministry is satisfied that these questions have been addressed, as outlined in this document.

9. Governance of information on the NIR

The Director-General of Health will take overall responsibility for the stewardship of the NIR. A national governance body for the NIR will be established to represent the interests of the different parties and to provide advice to the Director-General on policy matters affecting the operation of the NIR. This body will provide ongoing governance of the NIR information and policy advice as Kaitiaki/caretakers of the NIR. The

selection of the appropriate structure and membership for the NIR national governance body will be finalised following a process of consultation.⁷

It is likely that there will be district immunisation governance bodies in some or all DHBs to provide input to the NIR national governance body and from the interested parties into the operation of the NIR. The decisions made by future district governance bodies will be within the scope of the NIR policy. Each DHB in consultation with its community will identify if it wishes to have a district governance body, its proposed structure and membership.

Final responsibility for the NIR will rest with the Director-General and the national governance body.

10. Opting off immunisation data collection on the NIR

Most individuals in the birth cohort will have their information sent to the NIR directly from the maternity discharge systems. This information will generate the registration of the individual on the NIR. At any time, these individuals or their parent/caregiver may choose not to have any further health information collected on the NIR (ie, they opt-off immunisation data collection). When an individual chooses to opt-off the NIR, the following information will be retained by the NIR: their NHI, date of birth, the DHB they are resident in, the date of opting off, and any immunisation events recorded before they opted-off. All other information will be removed from the NIR. The purpose for retaining this data is to provide an accurate denominator for coverage calculations and to prevent inappropriate recall and referral to outreach immunisation services.

An individual may still receive immunisation events as part of the National Immunisation Schedule despite having chosen to opt-off the NIR.

All individuals immunised as part of the Meningococcal B Immunisation Programme will be required to register on the NIR so that vaccine safety and coverage can be evaluated.

If an individual declines MeNZB™ immunisation, this information may be recorded on the NIR or the individual may choose to “opt off” the collection of the decline information (ie, only their NHI, date of birth, the DHB they are resident in, the date of opting off, and any immunisation events recorded before they opted-off is retained on the NIR).

11. Privacy policy for the NIR

The management of health information including collection, holding, use and disclosure of such information in addition to the individual’s right to access and correct their information, is governed by the framework found in the HIPC.

⁷ *Paua Interface Report for the Ministry of Health on Issues and Options for a Governance-Kaitiaki Board for the National Immunisation Register, 5 May 2003.*

Note that references to a mother, parent, guardian, caregiver or representative are references to the same person unless specified otherwise.

Although the rules and policies relating to the management of health information are considered under each rule, the rules are inextricably interlinked and should not be considered in isolation.

Collecting information

Rule 1 – Purpose of collecting the information⁸

Rule 1 states that health information can only be collected by a health agency if it is collected for a lawful purpose connected with the function or activity of the agency, and the collection of the information is necessary for that purpose.

The overall purpose of the NIR is as a tool to benefit individuals by facilitating the delivery of immunisation services and providing an accurate record of their immunisation history (individual gain). In addition it will provide national and regional level information on the immunisation coverage of the specified population and assist in achieving New Zealand coverage targets,⁹ thus improving individual and population health through the control or elimination of vaccine preventable diseases (public health gain).

The Ministry of Health considers that collecting personal health information on the NIR is a lawful purpose connected with Ministry and DHB functions of improving individual and population health, and is necessary for that purpose.

The Ministry considers that the creation of a reliable source of immunisation history for each individual at a local and regional level across New Zealand, available to vaccinators and other authorised health professionals, will assist in reaching the national immunisation targets.

The objectives of the NIR are to:

1. accurately record all immunisations on the current and future Immunisation Schedule given to individuals, and retain this information throughout the lifespan of that individual (this information must be available to that individual (or parent, in the case of a child), through their health provider)
2. provide immunisation status and contact information to assist with the recall and follow up of individuals by health providers at the local and district level
3. provide a readily available, accurate immunisation history on each individual to approved health providers, support opportunistic immunisation (eg, at after hours clinics, via outreach services and hospitals), and assist vaccinators to give the correct immunisation(s)

⁸ Note: The rules have been abbreviated in this document and the Health Information Privacy Code 1994 should be consulted for the complete wording of each rule.

⁹ Ninety-five percent of children are fully vaccinated at age two years by 2005 and 75 percent or more of the defined high-risk adult population are vaccinated annually against influenza.

4. provide information to vaccinators that an individual has declined a vaccination or vaccinations and that follow up is not required
5. provide reliable information to ensure safe administration of vaccines to individuals including contraindications to their immunisation
6. provide accurate local, district and national immunisation coverage data by antigen, age and ethnicity
7. identify populations who are not accessing immunisation services so that services and resources can be targeted to assist those people to access immunisation services, and thus improve coverage in areas of low coverage
8. provide accurate information so providers may evaluate/audit their services
9. provide an information base to improve immunisation programme policy and delivery of services
10. record and assist with the evaluation of the delivery of new vaccines, including the delivery of a strain-specific meningococcal B vaccine planned for 2004 and 2005
11. assist in control of vaccine-preventable disease outbreaks
12. aid research and evaluation of vaccines and immunisation programmes.

To support and achieve these objectives the NIR has been developed with the following functions:

- Facilitate enrolment at birth to ensure all children are enrolled by the time of the first immunisation schedule event at six weeks.
- Enrolment of the individual on the NIR along with the nominated primary care provider, and in the case of a child, the Well Child provider and LMC.
- Following the individual's progress against the relevant immunisation schedule/programme, including updating progress as vaccinations are completed or declined.
- Consolidate an individual's immunisation records from multiple providers and ensure data accuracy and completeness.
- Ensure access is made available to authorised users including primary care providers, LMCs, public health nurses and immunisation coordinators, so that they can query (ie, retrieve information) electronically, or by telephone/paper, the immunisation record of an individual at the time of encounter.
- Permit authorised users to submit electronically via the PMS, or via paper and telephone, information on all immunisation encounters on the same day that vaccination occurs.
- Produce lists locally of all individuals who are overdue for vaccinations in order to facilitate recall and referral to outreach immunisation services.
- Provide a record of immunisation history for individuals and parents.
- Flag individuals with medical contraindications and known adverse reactions.
- Flag individuals who have declined immunisation (partial or total).

- Produce population based coverage reports by age cohort, vaccine, location, ethnicity and other parameters for authorised users (at local, DHB and national levels).
- Produce data extracts (a computer file of information with identifiable or non-identifiable data).
- Provide population-based non-identifiable data to authorised users for reporting, audit or evaluation and planning.
- Updating demographic information on the NHI database.
- Source of information for funders to monitor provider behaviour as under objectives 9 and 10.

To achieve these objectives the Ministry considers it necessary to obtain information about the individual being immunised, that individual's parent(s)/caregiver(s) if under 16 years of age, and their primary care and Well Child providers (see Table 1 in Appendix).

The health information about identifiable individuals that will be obtained is:

- National Health Index (NHI)
- full name
- date of birth
- place of birth
- date of death
- gender
- address
- phone number
- ethnicity
- immunisation events (including date given, vaccine code, dose, body injection site, vaccine batch and expiry code, event status (ie, scheduled or overdue) and AEFI and contraindications)
- DHB code
- date of NIR registration.

Identifiable information will be collected on the parent/caregiver and the alternative parent/caregiver for the purpose of maintaining accurate contact details for the individual if under 16 years of age. This information includes:

- NHI of mother for those within the birth cohort (to ensure the child's information is accurately recorded from the maternity discharge system)
- full name of parent/caregiver
- address
- phone number

- relationship to child.

Identifiable information on providers will be collected for the purposes of assisting with recall and follow up of individuals, maintaining an accurate immunisation history, and assisting with targeting, audit and evaluation. This information will be collected on the primary care provider, vaccinator, Well Child provider and LMC, and includes:

- name
- clinic name (physical location of practice and/or place where an immunisation event occurs)
- clinic address (including mailbox address for electronic messaging)
- provider ID (ie, New Zealand Medical Council or Nursing Council of New Zealand professional registration numbers, or future NPI number)
- DHB of clinic
- individual–provider relationship (provides link of the individual to the clinic electronic mailbox for NIR messaging to the provider)
- Independent Practice Association/Primary Health Organisation (optional)
- the name of the vaccinator, responsible clinician (eg, GP) and clinic will be recorded for each immunisation event.

Rule 2 – Source of information

Rule 2 of the HIPC requires that where a health agency collects health information, it must collect the information directly from the individual. There are exceptions, including where the agency believes on reasonable grounds that the individual concerned authorises collection of the information from someone else having been made aware of the information in Rule 3. Another exception includes where compliance with Rule 2 is not reasonably practicable in the circumstances of the particular case.

As the health agency managing the NIR the Ministry will not be collecting the information directly from individuals. The Ministry is reliant on maternity, primary care, Well Child and immunisation providers to obtain an individual's health information from individuals/parents/caregivers on the Ministry's behalf. The Ministry will ensure that these providers have sufficient information to ensure that they are able to meet the requirements of Rule 3 (below) in making individuals/parents/caregivers aware of how their information is to be used. LMCs and DHB midwives will play a key role in informing new parents/caregivers of the NIR during the antenatal period.

Information to be contained in the NIR will be collected from:

Maternity providers (for the period the baby is in their care)

1. Health information (defined in Rule 1) will be sent to the NIR on all birth cohort babies born in hospital from their maternity discharge data. This information will be used to generate the NIR registration for this individual.

2. Health information (defined in Rule 1) will be sent to the NIR on all birth cohort babies born outside of maternity facilities by the LMC. This information will be used to generate the NIR registration for this individual.
3. LMCs and DHB midwives will be requested to provide the NIR with information about hepatitis B immunisation following birth on children of hepatitis B surface antigen positive mothers.

Primary care providers

1. Primary care providers will assist in identifying birth cohort children and other individuals (eg, during the Meningococcal B Immunisation Programme) who have not been registered on the NIR and if necessary create their registration by sending information to the NIR from their PMS or via fax/paper forms.
2. Primary care providers (including vaccinators) will be able to update an individual's health information on the NIR including immunisation events from their PMS or via paper/paper forms.

Well Child providers

1. Well Child providers will assist in identifying birth cohort children who have been registered on the NIR by undertaking a NIR status query for that individual. If registration has not occurred, they will provide the DHB NIR administrator with the information to create a registration.
2. Well Child providers who provide immunisation services (including some outreach immunisation services) will be able to update the information on contact details and immunisation events on the NIR via the DHB NIR Administrator.

School Based Vaccination Systems providers¹⁰

1. Health information will be collected for the NIR from school immunisation programme consent forms, which must be completed and signed by the parent/guardian before a child can be immunised in this setting. This information will be sent to the NIR via the SBVS once the immunisation event has occurred.

NHI

1. The NHI index may send specific information to the NIR to update an individual's information (eg, provide an NHI number as a result of a electronic based status query on the NIR, used to validate an individual's death and for information on merged or linked NHI numbers). See Section 7, subsection "other information flows".

¹⁰ The School Based Vaccination System is held at Public Health Nursing Services and used by public health nurses to record the demographic details and immunisation events for individuals who are vaccinated in school settings.

Provider information

1. Identifiable information held on the NIR about individual providers will be obtained directly from the provider via DHBs.

Rule 3 – Collection of information from individuals

Rule 3 requires that where a health agency collects health information directly from an individual, it must take reasonable steps to ensure the individual is aware of the information flows and the purpose of those flows.

The HIPC requires that the individual whose information is being collected is made aware that their information is being collected and how their information might be used and with whom it may be shared. This will include the individual (or parent/guardian on behalf of a child) and the provider of immunisation services.

As noted under Rule 2, the Ministry will be relying on maternity, Well Child and primary care providers to ensure that individuals (both children and their parents/guardians) are informed about the NIR and the information being collected. The Ministry and DHBs (as the collectors of the individual's information from the provider) will ensure that providers are aware of the anticipated purposes for which that information may be used.

The Ministry will require that DHBs and providers ensure that the individual (or their representative) is well informed about the NIR, its purpose, the benefits that registration will bring to the individual and the community, the data that will be collected, and how it will be used. The Ministry will provide training packages for DHBs to assist in their responsibility to inform and train NIR users and ensure competent use of the NIR. The Ministry will work with provider professional bodies, similarly, to assist in informing providers about the NIR and its appropriate use.

NIR policies and business processes are being established to ensure that compliance with the HIPC is maintained. These processes include informing individuals about the NHI unique identifier and the updating of information between the NIR and NHI index.

When providers collect health information, which will be contained within the NIR, directly from an individual (or their representative) the individual must have been informed about the following:

- the fact that the information is being collected (it is not always obvious that information is being collected, or that it is being collected in a particular way)
- the purpose of collecting the information (this may be explained directly, or by way of posters, pamphlets or brochures)
- the intended recipients of the information (individuals will be told about NIR practices and any particular disclosures that will be made)
- the contact details for the agency who will collect and hold the information locally and nationally (this allows people to alert the NIR to changes of address)
- whether the supply of the information is voluntary or mandatory (for children, this will mean informing their parents of their right to opt-off having immunisation information on the NIR)

- the consequences if the information is not provided (if immunisation information is not entered on the NIR this will not affect their entitlement to immunisation services).

The LMC or hospital midwife will give NIR information to the mother during the antenatal period. If information is not received during the antenatal period, the maternity facility will be expected to provide the parents/caregivers with information on the NIR during the postnatal stay.

For individuals outside the birth cohort the required information will be provided to individuals/parents/caregivers at the time of consent for an immunisation event (eg, within the primary care setting when immunising an individual, or via a school immunisation programme consent form). This will be applicable to immigrant children of eligible birth cohort age and those immunised as part of the Meningococcal B Immunisation Programme.

Individuals (or a child's representative) will be sent written information advising of their registration on the NIR, providing a copy of the health information held by the NIR and inviting them to check the accuracy of the information (refer to Rule 8). Because of the high volumes immunised as part of the Meningococcal B Immunisation Programme written information will not be sent. These individuals will be informed of the NIR and of the mechanisms to access and correct their information prior to consent for or decline of MeNZB™ vaccination.

An individual or their representative may chose not to have their future immunisation data collected by the NIR (ie, to opt off the NIR) - (with the exception of MeNZB™ vaccination as part of the Meningococcal B Immunisation Programme). If an individual opts off, the only information retained by the NIR will be their NHI, date of birth, the DHB they are resident in, the date of opting off, and any immunisation events recorded before they opted-off. This data is retained to provide an accurate denominator for coverage calculations and to prevent inappropriate recall and referral to outreach immunisation services.

It is also intended that information will be collected and held on the NIR about the providers of immunisation services and parents/caregivers. In both cases, the providers and parents as representatives will be made aware of the purposes for which their information is being collected.

The collection of information about individual providers will be governed by the provisions of the information privacy principles in the Privacy Act 1993 (refer to Rule 1).

Those whose information is obtained will be made aware of their rights to access, and request correction of their information (see Rules 6 and 7).

Rule 4 – Manner of collection

Rule 4 states that health information must not be collected by unlawful means or by means that in the circumstances of the case are unfair or intrude to an unreasonable extent upon the personal affairs of the individual concerned.

Those collecting the information will ensure:

- individuals and parents/caregivers are made aware of how their information will be used as required under Rule 3
- health information is collected in a professional, considerate and respectful manner, sensitive to cultural differences.

Taking care of the information (housekeeping provisions)

Rule 5 – Storage and security

Rule 5 requires a health agency holding health information to ensure the information is protected, by security safeguards as it is reasonable in the circumstances to take, against loss; unauthorised access, use, modification or disclosure; and other misuse.

The Ministry of Health (via NZHIS) will ensure that appropriate storage and security safeguards are implemented to prevent unauthorised access to and use of the information contained on the NIR.

The NIR security policy will be developed prior to the implementation of the NIR. The security policy will be developed in conjunction with the Standards New Zealand 17799:2001 document *Information Technology: Code of Practice for Information Security Management*.

All DHBs will implement the NIR in accordance with the NIR security policy, and the NIR use and disclosure policy under their contractual obligations to the Ministry of Health.

The security safeguards will entail organisational and technical measures, including:

1. Privacy and security awareness training

All Ministry of Health and DHB employees who will have access to the NIR will receive privacy and security awareness training to ensure they understand all privacy requirements.

2. NIR Authorised User Agreement

A NIR Authorised User Agreement will be entered into between the Ministry of Health and providers (organisations, practices or clinics) on behalf of their staff and contractors prior to them being granted access to the information held on the NIR. The NIR Authorised User Agreements will be managed by each DHB. The NIR Authorised User Agreement will set out the rights and obligations of providers for the use and disclosure of NIR information. It will require all providers and their relevant staff and contractors to abide by the NIR security policy and the NIR privacy policy (see Appendix for the NIR Authorised User Agreement).

The levels of access for each NIR authorised user will be based on their role and purpose for using and disclosing the information held on the NIR (see Table 2 in the Appendix). Table 3 in the Appendix identifies what each authorised user will be able to

do on the NIR based on their role. Note Table 3 does not relate to how an authorised user will access the NIR.

3. User identification and passwords

There will be three ways to access the NIR:

- a) Practice management systems (PMS) – electronic access to the NIR will be via specific fixed messages sent to the NIR from the PMS. PMS access to the NIR will be via HealthLink (which is password and user ID protected).
- b) Health Intranet – electronic access to the NIR will be via a formal and secure Health Intranet browser, which is password and user ID protected.
- c) Telephone/paper – access to the NIR will be via the DHB NIR administrator. Business processes have been established to ensure information collected is correct and the administrator verifies the caller before disclosing information from the NIR.

The Ministry will ensure mechanisms are put in place for DHBs to identify, audit and monitor users of the information system to ensure adherence to NIR policies and so that misuse can be detected. This will involve regular security reviews.

User ID and passwords will individually identify authorised providers and system users.

Participating providers seeking access to the information on the NIR via the DHB NIR administrator will need to satisfy the administrator as to their identity and authority to access the information. An individual/parent/caregiver will be advised to seek information held on the NIR via their primary care provider. If this is not possible the DHB NIR administrator will need to be satisfied as to the individual/parent's/caregiver's identity and authority to access information.

Authorised providers will be responsible for ensuring that only authorised health professionals or employees working at their premises have direct access to the NIR. This will be managed via the NIR Authorised User Agreement.

4. Audit trails

Audit trails will be enabled within the NIR so that it is possible to identify each user who has accessed the NIR. There will be regular and random checking of audit trails.

5. Obligations of health agencies

Authorised providers will be required, via the NIR Authorised User Agreement, to ensure reasonable policies and procedures are in place to safeguard this identifiable information. These will include procedures to ensure that:

- a) passwords and all access for all authorised users leaving an agency are cancelled or made invalid
- b) non-authorised persons do not access or view information from the NIR at the provider's premises or using the provider's facilities and equipment

- c) authorised users access the NIR responsibly
- d) any information gained from the NIR is used and disclosed in accordance with the terms set out in the NIR Privacy Policy
- e) procedures are adopted to ensure information cannot be transferred between computers or discrete systems within the same computer without authorisation
- f) password-protected screen saver programmes are used by those providers with direct electronic access to the NIR
- g) any computers the provider wishes to dispose of are checked by IT technical staff to confirm all confidential information has been removed or destroyed from storage media.

6. Technical security

Appropriate technical and information security standards and procedures will be adopted for the storage, protection and access and transmission of health information held on the NIR and documented in the NIR security policy. These will include measures such as:

- a) stringent user identification and password access controls
- b) comprehensive facilities to restrict users, including all NIR system and database maintenance staff, to those functions and data they are authorised to access
- c) DHB monitoring, detection, prevention and reporting of unauthorised attempts to access the system
- d) implementation of a robust system and data back-up regime
- e) monitoring and logging of changes to the NIR, including the change originator, date and nature of the change.

The standards used will be the Standards New Zealand 17799:2001 document *Information Technology: Code of Practice for Information Security Management*, the *Security in Government Sector (SIGS) Manual* and the Ministry of Health Security Policy: Information and Physical Security.

7. Physical security

The NIR software and hardware will be stored within a secure environment, accessible only by authorised personnel.

All electronic copies and printed material containing identifiable information intended for or from the NIR will be securely stored (eg, locked rooms or cabinets) and/or disposed of by secure methods (eg, shredding) to protect against unauthorised access or disclosure.

Rule 8 – Ensure accuracy of information before use

Rule 8 requires that any agency that holds health information must not use that information without taking reasonable steps to ensure that, having regard to the

purposes for which the data is proposed to be used, the information is accurate, up to date, complete, relevant and not misleading.

Many different providers will be providing information to the NIR. The Ministry will require maternity, vaccination and Well Child providers to take all reasonable steps to provide accurate information to the NIR, and to check the accuracy of the information with the child and parent/caregiver prior to relaying the information. DHB NIR Administrators have the same responsibility of care when entering data provided manually. The NIR information system and information support systems will be sufficiently robust to ensure data is entered and maintained as provided, and is altered only in accordance with strict and well documented business processes.

The responsibility for ensuring the accuracy of the information held on the NIR prior to using it is that of the authorised user of that information. If the information is to be used for clinical purposes then the need for accuracy is much greater than if this information is to be used for statistical analysis. The Ministry will ensure there are processes in place to ensure the information held by the NIR is as accurate as possible. This is contingent, however, on the quality of the information collected by providers.

A business process manual and an IT user guide are being developed which will assist in maintaining an accurate record of an individual's personal information and their immunisation history. This is required to meet NIR objectives 1, 2, 3, 4, 5. Training on the manual and guide will be undertaken prior to implementation of the NIR.

NIR information technology and business processes are being developed to support:

- the verification and correction of an individual's information, including their demographic details, immunisation history and opt-off status, by the DHB NIR Administrator, vaccinators, primary care and Well Child providers, and maternity providers. This should be undertaken when an individual or their representative is registered and on receipt of the NIR registration confirmation letter, or when they request a change to their details and/or when they access an immunisation event
- maintaining the accuracy of the information held on the NIR by audit trails (eg, date stamp and editing user) recorded against changes made on the NIR. For example insertion of a date stamp when a change has been made to the individual's name, address and immunisation event.

The NIR will be updating the NHI database with amended names and contact details as a mechanism to ensure the future use of their health information is accurate. Individuals and their representatives will be informed of this process.

NIR information systems and business processes will include:

- LMCs and maternity staff will check with parents/caregivers of children born within the birth cohort to gather and confirm the completeness and accuracy of all required information for NIR
- individuals/parents/caregivers will receive a letter confirming NIR registration, stating the information held in relation to the individual and offering an opportunity for amendment, or addition to the information, or withdrawal from the NIR (opt off

immunisation data collection). This will not be the case for the Meningococcal B Immunisation Programme (refer to Rule 3)

- individual/parents/caregivers will be informed through this letter and other channels that they may access the information and request correction where necessary, at any time, and how to do so (refer to Rule 3)
- participating providers will be required, via the NIR Authorised User Agreement, to take all reasonable efforts to ensure the health information submitted to the NIR is complete, accurate and up to date (refer to Rule 5)
- participating providers will be required to provide updated information (including amended messages from PMSs) to the NIR at the next immunisation event where any of the information required for the NIR has been changed in their own patient records (unless the parent/guardian has opted off the NIR)
- where appropriate, data entry fields will incorporate basic checks and validations to ensure data is entered in the correct form and does not introduce obvious errors
- a series of basic system and data integrity checks will be performed electronically and manually to verify the validity of data before it is written to the database
- electronic information exchange will be continually pursued for the programme and providers, reducing the potential for basic data entry and transcription errors inherent in manual processes, and ensuring that information is updated regularly
- authorised providers will be encouraged to adopt electronic messaging using secure links
- updated immunisation information on an individual received from one provider will be sent to their nominated provider, and (for preschoolers only) to other providers who have delivered immunisation services to that child.

Collectively, these measures should ensure that information held on the NIR is reasonably accurate, up to date and complete.

Aggregate information on the birth cohort will be validated by data matching with the NHI index to ensure the birth cohort denominator held on the NIR is an accurate record of the New Zealand births. The Ministry of Health does not intend to identify individuals who are not registered on the NIR from the NHI index. However, for individuals registered on the NIR who have died data matching with the NIR will ensure their deaths are accurately verified and collected on the NIR.

Rule 9 – Retention of information¹¹

Rule 9 states that a health agency that holds health information must not keep that information for longer than is required for the purposes for which the information may lawfully be used.

The NIR Steering Group has approved that health information and data will be retained on NIR for the whole of life of an individual plus a period of ten years after the death of that individual. The purpose of retaining this information for the life of an individual is to provide an accurate record of the immunisation events received by that individual and to monitor vaccine safety and efficacy. Security safeguards will protect the privacy and confidentiality of information about an identifiable deceased person. This retention period meets the purpose and objectives of the NIR fully.

New Zealand is required to have the NIR in place prior to the delivery of the Meningococcal B Immunisation Programme. This requirement is essential to identify vaccine recipients for the purpose of monitoring vaccine safety and effectiveness. The retention of information for the life of an individual plus an additional 10 years following death for those receiving the MeNZB™ vaccine would enable investigation of any adverse events attributed to the vaccination any number of years later.

Information received from manual health providers should be retained for three months (for checking and auditing) once the information has been entered on the NIR. The paper record of the information can then be destroyed, as providers will have recorded the information on their patient records. All correspondence received from parents/caregivers (eg, opt off forms) should be retained for a minimum of 10 years once the information has been entered onto the NIR, as there will not necessarily be another copy of this information held elsewhere.

The HIPC imposes an obligation on the Ministry and its agents as holders of health information to ensure that where information is not to be kept or is no longer required, either by the individual concerned or the agency, that the information is disposed of in a manner, which ensures the privacy and confidentiality of the individual concerned remains intact.

At the conclusion of the retention period, the identifiable health information will be deleted and/or made unidentifiable.

Any decisions about the treatment of any information about identifiable individuals will be made in accordance with the relevant legal and professional standards prevailing at the time.

Aggregate and non-identifiable information will be retained for an indefinite period to assist and improve population-based analysis, research, planning and development around the funding and delivery of immunisation services.

¹¹ The *Retention of Health Information on the NIR* policy paper provides detailed analysis of the retention of information. Note this policy paper was approved by the NIR Steering Group on 4 December 2003.

Note that an individual or a child's parents/caregivers can choose not to have any further immunisation information collected by the NIR at any time (opt off). The NIR can record future immunisation information if an individual chooses to reverse an opt-off decision (ie, if they wish to have their future immunisation information collected).

Using and disclosing the information¹²

Rules 10 and 11 – Limits on use and disclosure of information

Rules 10 and 11 establish that, generally, a health agency has the discretion to use or disclose health information if it was obtained for that purpose, or directly related to that purpose. A health agency obtaining information for one purpose must obtain the individual's authorisation before using the information for another purpose, unless one of the exceptions apply.

Only authorised users will have access to the information held on the NIR. An 'authorised user' means an individual (or the organisation the individual works for where a responsible person has signed on behalf of the organisation) who will have signed the NIR Authorised User Agreement. Such a person will be authorised to use and disclose NIR data and information in accordance with their function (see Table 2 in the Appendix for a list of NIR authorised users). In addition, it may be appropriate for other parties to use some of the information held on the NIR (eg, researchers accessing data with the approval of the NIR national governance body or with the individual's consent). Use will be based on the purpose for which the information is needed and the authorised use of that person/function (refer to Table 2 in the Appendix).

The intended purposes of collecting the information have been established and are set out earlier in this document (refer to Rule 1).

Providers will be made aware of these purposes when agreement to participate in the NIR is sought. In the case of childhood immunisation, parents/caregivers will be made aware of these purposes and how the information is to be used, in their interaction with their LMC, their maternity facilities, and the NIR registration confirmation letter. Their primary care and Well Child providers can also confirm these purposes and uses.

¹² The *Use and Disclosure of Information Held on the NIR* policy paper provides detailed analysis of the use and disclosure of health information. Note this policy paper was approved by the NIR Steering Group on 4 December 2003.

Levels of access to information will depend on the purpose for which such access is required. If information is required for statistical analysis or planning purposes, then there will be no need to make information available which identifies the individual. However, providers of immunisation services will need information about their patients available at the point of care. CARM may require identifiable information held within the NIR for the purpose of monitoring vaccine safety and sending an individual's immunisation history to the NIR following an AEFI. The Child and Youth Mortality Review Committee has statutory powers to require the National Immunisation Programme to disclose identifiable information to the Committee for the purpose of investigating a child's/youth's death. The Ministry of Health Meningococcal Vaccine Strategy Data Management Group will also require access to identifiable information for the purpose of MeNZB™ vaccine hospital-based safety monitoring.

Use and disclosure of the information held on the NIR will only occur in accordance with those stated purposes, and in the manner as outlined in this document, unless one of the exceptions set out in Rule 10 or 11 of the HIPC applies. Another exception may be where information requests are made under a different piece of legislation (eg, Official Information Act 1982, Health Act 1956).

The security provisions will limit access of authorised providers to information about identifiable individuals on an individual enquiry basis.

Providers may disclose information to administration and reception staff they employ, provided that such access is connected with one of the clinician's duties (eg, a clinician has requested the DHB NIR administrator to access the NIR to carry out an administrative function).

Primary care providers may disclose identifiable information about an individual to an outreach immunisation service to assist in the recall and follow-up of individuals who have missed or are late for immunisation events.

Information may be disclosed to authorised technical support staff for the purposes of providing technical support and they will be bound by existing confidentiality arrangements applying to the Ministry and DHB staff and contractors.

An authorised provider will be able to obtain aggregate information about their specific provision of immunisation services, or for the individuals for whom the provider gives care. Providers and provider groupings (eg, PHOs) will be able to access aggregate information about their registered populations in standard NIR reports, through the application, or from their DHB NIR Administrator or another secure report distribution path (such as the Health and Disability Information Exchange (HADIE)).

A similar process will be used for other requests for aggregate information that clearly fall within the parameters of the stated NIR purpose and objectives. The NIR national governance body will decide the policy regarding the release of non-routine requests, both for aggregated and identifiable data (eg, for research purposes).

From time to time, there may be non-anticipated requests for information held on the NIR. These requests will be managed via the NIR national governance body.

DHBs will be able to use the information held within the NIR to improve service delivery and better target immunisation resources. It is not the role or the intention of the Ministry to undertake provider monitoring and management.

The Ministry and DHBs may publish reports that include data relevant to the NIR (eg, coverage rates for immunisation, opt-off rates, outreach referrals rates for those children who have missed an event or are not responding to recall). The Ministry and DHBs may also publish the results of NIR audits and surveillance undertaken, identifying any breaches of the security policies or processes. Such reports will make recommendations about the future management and use of the NIR.

Assignment of the NHI

Rule 12 – Unique identifiers

Rule 12 establishes that a health agency must not assign a unique identifier to an individual unless the assignment of that identifier is necessary to enable the agency to carry out one or more of its functions effectively.

An individual will only be able to register on the NIR if they have an assigned NHI number. The NIR will use the NHI number assigned to each individual as an identifier, but will not assign NHI to individuals.

Requests by the individual

Rule 6 – Access to information

Rule 6 sets out that when health information is collected, individuals have a right to know which agencies will hold their information and also have a right of access to that information.

An individual will be able to access their information on the NIR via their nominated provider or another provider involved in their care relating to immunisation (or in some instances through the DHB NIR Administrator). This includes all information on the NIR sent to the DHB NIR Administrator for the purpose of amending information collected by the NIR from a non-computerised provider. Individuals or their representative will be able to access the NIR information to correct or update demographic data and to determine immunisation status.

Requests from a child's representative should be considered under Rule 11, Rule 6, and section 22F of the Health Act 1956. In the case of very young children there would seldom be reason to withhold the information from a parent as a representative of the child, unless it was considered not to be in the best interests of the child. NIR business processes will ensure that when the nominated representative (parent/caregiver) wishes to access their child's information they know how to proceed, who to contact and who has the ultimate responsibility for managing the information on the NIR.

NIR business processes will ensure compliance with the Privacy Act section 27(1)(d) and section 29, which enables some information to be withheld in specific circumstances. However, taking into account the nature of the information on the NIR it is unlikely that requests by the individual or their representative will be refused.

NIR information (including brochures) for individuals/parents/caregivers will clearly set out:

- that any individual or his or her representative may request access to information on the NIR concerning himself or herself and
- how to access the information, through their provider(s) or, if that is not possible, the DHB NIR Administrator
- the NIR national governance body is responsible for holding and managing the information within the NIR.

In the first instance, any individual or representative requesting information about a child will need to satisfy the health professional or DHB NIR Administrator of their right of access. If this is not clearly established, such a request must be made in writing. NIR business processes will ensure there is a defined protocol to deal with such requests within a reasonable timeframe.

The development of the NIR business processes will also ensure compliance where applicable to Part V of the Privacy Act, which relates to the procedural provisions relating to access to and correction of personal information.

If the DHB NIR Administrator (and consequently the NIR national governance body) believes there are reasonable grounds for withholding this information, in accordance with the provisions set out in the Privacy Act 1993, this will be worked through in an appropriate manner with the individual making the request.

Rule 7 – Correction of information

Rule 7 states that an individual may request correction of their health information. If the health agency is not willing to correct the information, it must attach a statement of correction in such a manner that the statement of correction can be read with the information.

Individuals or their representatives will be able to correct their individual details including the decision to opt-off the NIR.

Individuals and their representatives will be provided with the opportunity to correct their information:

1. When they receive confirmation that their details have been entered onto the NIR. The individual or their representative will be asked to contact their local DHB NIR Administrator to amend the information, if it is not correct.
2. When an individual accesses a primary care provider, they will be given the opportunity to correct any details before the immunisation event message is sent to the NIR.

Primary care and Well Child providers, vaccinators and maternity providers will be able to correct information about a registered individual prior to the message being sent to the NIR. For example, if the details of a vaccine such as batch number or site are entered incorrectly, the vaccinator will be able to amend this information. If the message is sent prior to any amendments the vaccinator must send a specific amendment message to correct the information either electronically or manually via the NIR DHB Administrator.

For preschool children, participating immunisation providers associated with their care will be notified of information corrected on the NIR. This will assist them to accurately maintain their own clinical records for that child.

Providers at each immunisation event will be requested to submit updated corrected information on their patient or themselves to the NIR.

Primary care and Well Child providers, vaccinators and maternity providers will only be able to correct their own personal details by a formal request to amend the information via the DHB NIR Administrator.

Where NIR business processes prevent correction of information held on the NIR, this will be worked through with the person who made the request, in accordance with Rule 7 and related provisions of the Privacy Act 1993, and a statement to this effect will be attached to the individual's information on the NIR.

12. Complaints and breaches of privacy

In accordance with section 23 of the Privacy Act, the Ministry of Health and DHBs will at all times have at least one employee who will carry out the following functions:

- Encourage participants in the NIR to comply with the HIPC.
- Deal with requests made under the HIPC or Privacy Act 1993.
- Work with the Privacy Commissioner in relation to any investigations that might take place.
- In conjunction with the Chair of the relevant governance group, be responsible for dealing with any complaints relating to the NIR, an alleged breach of the HIPC or breaches of the privacy policies set out in this document.

The general procedure for dealing with a complaint or alleged breach will be as follows:

Acknowledgement: In conjunction with the Chair of the relevant governance group, the privacy officer will on hearing of a breach or complaint:

- contact the person making the complaint or breach in writing within 10 working days of learning about the complaint or breach – unless it has already been resolved
- inform the complainant of any relevant internal and external complaint procedures and the action that will be taken by the relevant officer or governance group within 10 working days.

Investigation: As soon as practicable after the Ministry of Health or DHB privacy officer accepts a complaint, he or she will inform the complainant of the steps the relevant officer or governance group proposes to take to resolve the breach or complaint. The person will also be informed that he or she can contact the Privacy Commissioner.

No investigation: If the Ministry of Health or DHB privacy officer decides not to accept a complaint or a breach that has occurred – on the basis that none of the terms of the HIPC, Privacy Policy, or NIR Authorised User Agreement have been reasonably breached, then he or she will as soon as reasonably practicable inform the complainant of the reasons for the decision, the right to contact the relevant officer or governance group regarding the decision and the right to complain to the Privacy Commissioner.

13. Penalties for unauthorised disclosure of information

Existing Ministry of Health and DHB penalties for the unauthorised use or disclosure of health information will cover information held on the NIR and will be enforced. These penalties could include the revocation of authorised user privileges, professional sanctions and disciplinary action, up to and including termination of employment.

Appendix: National Immunisation Schedule 2002

Patient's age	DTaP-IPV	Hib-Hepatitis B	Hepatitis B	IPV	MMR	DTaP/Hib	Td	Influenza
6 weeks	■	■						
3 months	■	■						
5 months	■		■					
15 months					■	■		
4 years	■				■			
11 years				■ *			■	
45 years							■	
65 years							■	■

Key: D-Diphtheria, T-Tetanus, aP-acellular Pertussis, IPV-Inactivated Polio Vaccine, Hib-*Haemophilus influenzae* type b, MMR-Measles-Mumps-Rubella, Td-Adult Tetanus-diphtheria.

* IPV is scheduled at 11 years of age for children who have not previously received four doses.

Babies of HBsAg positive mothers need hepatitis B immune globulin (HBIG) and vaccine at birth.

Neonatal BCG should be offered to infants at increased risk of tuberculosis.

Definitions

Health information – The HIPC under subclause 4(1) applies to the following information or classes of information about an identifiable individual:

- a) information about the health of that individual, including his or her medical history
- b) information about any disabilities that individual has, or has had
- c) information about any health services or disability services that are being provided, or have been provided, to that individual
- d) information provided by that individual in connection with the donation, by that individual or derived from the testing or examination of any body part, or any bodily substance of that individual or
- e) information about that individual which is collected before or in the course of, and incidental to, the provision of any health service or disability service to that individual.

Migration of Kidslink information on to the NIR

In addition to the immunisation events collected by the NIR following national rollout (ie, routine immunisation schedule events plus MeNZB™), the NIR national server will hold, and collect Well Child and immunisation information on identifiable individuals who:

1. are part of the Kidslink cohort registered between January 2002 and the Counties Manukau District Health Board (CMDHB) 'go live' date, who receive Well Child and immunisation events as residents of CMDHB.
2. are part of the Westkids cohort registered between 4 February 2002 and the 'go live' date of NIR, who receive Well Child and immunisation events as residents within WestKids area.

Note: Information will only be collected for the Well Child Schedule up to five years of age.

The NIR will also collect and hold Well Child data on the CMDHB 'NIR birth cohort' (ie, for CMDHB children born after the NIR 'go live' date), on behalf of CMDHB.

The NIR project is responsible for the management of immunisation information only. Governance of the immunisation information held on the NIR following national rollout will be the responsibility of the NIR national governance body. Future immunisation events collected for the historic Kidslink CMDHB and Westkids cohorts will be managed under NIR policy and business rules, with the exception of reporting and retention period rules. It should be noted that reporting from the historic Kidslink CMDHB and Westkids cohorts will need to be supported directly by CMDHB or managed via the Ministry of Health through an additional arrangement to that of the NIR project.

Table 1: Identifiable and non-identifiable information held on NIR

	Category	Identifiable	Non-identifiable	Ministry of Health NIR	DHB District Registers
1	Unique NHI identifier	NHI number	–	All	All
2	Demographics of the individual	Full name Full address Contact numbers Alias names	Domicile code Ethnicity Date of birth Date of death Gender DHB code Place of birth (health facility code) Domicile code Geo code	All	All
3	Demographics of the parent/ caregiver	NHI of mother Full name Full address Contact details Second contact name and details	Relationship to individual Domicile code	All	All
4	Entrance to Programme and notes made by DHB NIR Administrator	Updated by nominated provider Notes recorded by	Name of programme Date entered Status on programme	All except notes	All
5	Provider details including lead maternity carers, primary care and Well Child providers and vaccinators	Name Title Identifier Provider code Provider clinic Provider contact details Registration code	–	All	All
6	Immunisation event	Provider responsible Vaccinator Clinic where immunisation given	Vaccine (type, dose number, batch number, expiry date) Date due Date completed/declined Event status code Body injection site	All	All

Note: This table corresponds to column 3 of Table 2.

Table 2: Use and disclosure of information held within the NIR by authorised NIR users

User	NIR objectives	Type of information	Use of information on NIR*	Disclosure of information from the NIR*
Vaccinators (including practice nurses, GPs, independent vaccinators, Medical Officers of Health, public health nurses, LMCs, Well Child and outreach vaccinators, paediatricians, hospital paediatric and outpatient clinic nursing staff)	1 2 3 4 5 6 7 8 9 10	Identifiable categories 1, 2, 3, 4, 5, 6 and associated non-identifiable information	<ul style="list-style-type: none"> To provide information on an associated** individual, their parents/caregivers and providers to register an individual on the NIR and correct information as necessary. To check/record/update the immunisations given to an individual, including opportunistic vaccinations and school based vaccinations. To recall an individual if they have missed or are late for an immunisation episode. To refer an individual to an outreach immunisation service if recall has failed. To advise the DHB NIR administrator of a change in status of an individual (eg, opt off immunisation data collection or opt back onto the NIR). To audit/evaluate their own service delivery. 	<p>Vaccinators will need to disclose identifiable information about the individual/parent/caregiver and provider for the purpose of:</p> <ul style="list-style-type: none"> providing individuals/parents/caregivers with the immunisation information held by the NIR providing the DHB NIR administrator and/or outreach immunisation services with information to assist in locating an individual for a late or missed immunisation episode.
Non-vaccinating health professionals (primary care, Well Child and outreach providers)	2 3 4 5	Identifiable categories 1, 2, 3, 4, 5, 6 and associated non-identifiable information	<ul style="list-style-type: none"> To provide information on an associated individual, their parents/caregivers and provider details on the NIR to update to update an individual's demographic details. To check the immunisation status of individuals who have been identified as having missed or being late for an immunisation. 	<p>Non-vaccinating health professionals will need to disclose identifiable information for the purpose of:</p> <ul style="list-style-type: none"> locating an individual who has been referred to the outreach immunisation service for a late/missed immunisation episode referring the individual to another health professional to receive an immunisation episode eg, primary care provider or Medical Officer of Health.
IPAs	6 7 8 9 10 12	Non-identifiable categories 2, 4, 6 Identifiable 5	<ul style="list-style-type: none"> To determine the immunisation coverage of their population. To identify the specific areas/populations with low coverage so resources can be made available eg, outreach. To audit the provision of their immunisation services. 	<p>Only non-identifiable information will be disclosed for the purpose of calculating immunisation coverage, planning services and reporting on immunisation services and coverage to their providers and their populations.</p>

User	NIR objectives	Type of information	Use of information on NIR*	Disclosure of information from the NIR*
Primary Health Organisations (PHOs)	6 7 8 9 10 12	Non-identifiable categories 2, 4, 6 Identifiable 1, 2, 3, 4, 5, 6	<ul style="list-style-type: none"> To determine the immunisation coverage of their enrolled population. To identify the specific areas/ populations with low coverage so resources can be made available eg, outreach. To audit the provision of their immunisation services. 	<p>A PHO may disclose identifiable information to:</p> <ul style="list-style-type: none"> monitor their provider behaviour refer an individual to an outreach immunisation service manage their immunisation coverage rates. <p>Only non-identifiable information will be disclosed for the purpose of calculating immunisation coverage, planning services and reporting on immunisation services and coverage to their providers and their populations.</p>
DHB NIR Administrators and associated staff eg, data entry	1 2 3 4 5	Identifiable categories 1, 2, 3, 4, 5, 6 and associated non-identifiable information	<ul style="list-style-type: none"> To manage an individual's data and recall processes, including referral to outreach services. To update and correct details for individuals on the NIR. Create a new record for every individual who is not entered via transfer of maternity discharge data. To set up and modify access levels for each authorised user. To generate DHB reports for their DHB population. 	<p>DHB NIR administrators will disclose identifiable information for the purpose of:</p> <ul style="list-style-type: none"> co-ordinating the management of an individual's demographic and immunisation information with vaccinators, primary care and outreach providers, Medical Officers of Health. <p>DHB NIR administrators will disclose non-identifiable information for:</p> <ul style="list-style-type: none"> planning services reporting on immunisations services and coverage to their providers and their populations.
Data entry personnel employed for the Meningococcal B Immunisation Programme	2 3 4 5 6 9 10	Identifiable categories 1, 2, 3, 5, 6 and associated non-identifiable information	<ul style="list-style-type: none"> To only enter MeNZB™ vaccine and any concurrent immunisation events information collected as part of the Meningococcal B Immunisation Programme 	<p>Data entry personnel will disclose identifiable information to only the Meningococcal B NIR Administrator or the National NIR Administrator for the purpose of:</p> <ul style="list-style-type: none"> Clarifying an omission or error on the Meningococcal B Immunisation Programme event form.

User	NIR objectives	Type of information	Use of information on NIR*	Disclosure of information from the NIR*
DHB funding and planning staff (including managers and analysts)	6 7 8 9 10 11 12	Non-identifiable 2, 4, 6 Identifiable 5	<ul style="list-style-type: none"> To determine the immunisation coverage of their population. To identify the specific areas/populations with low coverage so resources can be made available eg, outreach. To audit and improve service delivery of their immunisation services. 	<p>Only non-identifiable patient information will be disclosed for the purpose of calculating immunisation coverage, planning services and reporting on immunisation services and coverage.</p> <p>DHB funding and planning staff may be required to disclose identifiable provider information for the purpose of service delivery.</p>
Ministry of Health National Immunisation Programme including general NIR management, policy analysis and NIR national governance body, and Meningococcal Vaccine Strategy Team	5 6 7 8 9 10 11 12	Identifiable 1, 2, 3, 4 (excluding notes), 5, 6 for specific circumstances only and associated non-identifiable information	<ul style="list-style-type: none"> To determine local, district and national immunisation coverage rates. To identify the specific areas/populations with low coverage so resources can be made available eg, outreach. To improve immunisation programme policy and delivery of services based on the information collected by the NIR. To evaluate the delivery of new vaccines eg, MeNZB™ vaccine. To evaluate MeNZB™ vaccine safety and effectiveness. To assist in managing vaccine preventable diseases (VPDs). To research and evaluate vaccines and immunisation programmes. To monitor, audit and evaluate the effectiveness of the NIR. To provide information requested under legislation eg, Child and Youth Mortality Committee. To assist in the provision of NIR information for research purposes once clearance has been approved by the NIR national governance body. 	<p>Non-identifiable information will be disclosed for the purpose of calculating immunisation coverage, planning services, policy analysis, reporting, audit/evaluating the NIR and research.</p> <p>The National Immunisation Programme may be required to disclose identifiable information for the purpose of:</p> <ul style="list-style-type: none"> clarifying an issue in regard to NIR governance eg, abuse of confidentiality clause responding to a request from the Child and Youth Mortality review Committee – this is required by law responding to a request for information from CARM or ESR research, only if approved by the NIR national governance body. <p>The National Immunisation Programme may disclose identifiable information for individuals to ESR for the purpose of monitoring vaccine preventable disease outbreaks.</p>
Ministry of Health Meningococcal Vaccine Strategy Team Data Management Group	5 10	Identifiable 1, 2, 3, 5, 6 Non-identifiable 2, 4, 6	<ul style="list-style-type: none"> To monitor the vaccine safety for the new MeNZB™ vaccine. 	<p>The MVS Data Management Group will disclose identifiable information to nurse monitors in hospitals where hospital based monitoring of the MeNZB™ vaccine occurs.</p>

User	NIR objectives	Type of information	Use of information on NIR*	Disclosure of information from the NIR*
National NIR Administrator and associated National NIR staff eg, data entry	1 2 3 4 5 6	Identifiable categories 1, 2, 3, 4, 5, 6 and associated non-identifiable information	<ul style="list-style-type: none"> To manage an individual's data and recall processes, including referral to outreach services. To update and correct details for individuals on the NIR. Create a new record for every individual who is not entered via transfer of maternity discharge data. To set up and modify access levels for each authorised user. To generate NIR reports and extracts. To monitor, audit and evaluate the effectiveness of the NIR. To calculate local, district and national immunisation coverage rates. To set up and modify access levels for each authorised user as backup to DHB NIR administrators. Ensure the NIR assists in the national management of individual data and recall processes, including opportunistic immunisations. Ensure the NIR assists in the management of participating providers data on the NIR. Provide information for the NIP when requested by the ESR. Provide information for the NIP when requested by the CARM. Provide information for the NIP when requested by the CYMRC. Provide information for the NIP when requested by researchers. Provide information for the NIP as requested for NIR audit and evaluation purposes. To delete information on the NIR. 	<p>National NIR administrators will disclose identifiable information for the purpose of:</p> <ul style="list-style-type: none"> co-ordinating the management of an individual's demographic and immunisation information with vaccinators, primary care and outreach providers, Medical Officers of Health. <p>National NIR administrators will disclose non-identifiable information for:</p> <ul style="list-style-type: none"> planning services reporting on immunisations services and coverage to their providers and their populations. <p>Under specific circumstances the National NIR Administrator or National Immunisation Programme Manager may need to disclose identifiable NIR information for the purpose of audit and evaluation of the NIR.</p>

User	NIR objectives	Type of information	Use of information on NIR*	Disclosure of information from the NIR*
Ministry of Health NZHIS (NIR IT management)	1 2 3 4 5 6 7 8 9 10 11 12	Identifiable 1, 2, 3, 4 (except notes), 5, 6 and associated non- identifiable information	<ul style="list-style-type: none"> To monitor, audit and evaluate the effectiveness of the NIR. Ensure the NIR assists in the management of participating providers data on the NIR. Resolve IT system problems. 	<p>The NIR IT management team will disclose identifiable information for the purpose of:</p> <ul style="list-style-type: none"> assisting in the transfer of an individual information to all authorised users nationally to assist in completing an immunisation record, facilitating outreach and opportunistic immunisation ensuring that nationally identifiable information regarding the nominated provider/clinic is available to assist in the safe administration of immunisations. <p>Only non-identifiable information will be disclosed for the purpose of calculating immunisation coverage and planning services.</p>
IT technical support staff at the national NIR server	1 2 3 4 5 6 8 9	Identifiable 1, 2, 3, 4, 5, 6 and associated non- identifiable information	<ul style="list-style-type: none"> Resolve IT system problems. 	NIR IT technical support staff will not be authorised to disclose an individual's identifiable information.
Ministry of Health other directorates (eg, child health, primary health care, DHB Funding and Performance)	7 9	Non- identifiable 2, 4, 6	<ul style="list-style-type: none"> To improve immunisation programme policy and delivery of services, integrating with other health services. 	Only non-identifiable information will be disclosed for the purpose of calculating immunisation coverage, planning services and reporting.

User	NIR objectives	Type of information	Use of information on NIR*	Disclosure of information from the NIR*
Medical Officers of Health	1 2 3 4 5 6 9 10 11	Identifiable 1, 2, 3, 4, 5, 6 and associated non- identifiable information	<ul style="list-style-type: none"> To provide follow-up of individuals requiring hepatitis B and BCG immunisations. To check the immunisation status of individual's in their care. To respond effectively to vaccine preventable disease outbreaks in their regions. To monitor disease surveillance for their regions. 	<p>The Medical Officer of Health will disclose identifiable information for the purpose of:</p> <ul style="list-style-type: none"> assisting in the follow-up of an individual's immunisation status, which included notifying their nominated provider that an immunisation has been given alert parents/caregivers to a vaccine preventable disease outbreak. <p>Only non-identifiable information will be disclosed for the purpose of calculating regional immunisation coverage and planning services for outbreak control.</p>
District Immunisation Facilitators and coordinators	6 7 9	Non-identifiable 2, 4, 6	<ul style="list-style-type: none"> To identify specific areas/ populations with low coverage so resources can be made available to improve coverage. 	Only non-identifiable information will be disclosed for the purpose of calculating immunisation coverage, planning services and reporting.
Research	12	Non-identifiable 2, 4 (excluding notes), 6 In some instances identifiable information may be required	<ul style="list-style-type: none"> To research and evaluate vaccines, coverage and immunisation programmes. 	After due consideration, the NIR national governance body may disclose identifiable NIR information for research purposes. This will be done via the NIP. For example, following up the consequences of cold chain or batch failures.
Institute of Environmental Science and Research (ESR)	11 12	Identifiable 1, 2, 3, 5, 6 Non-identifiable 2, 4, 6	<ul style="list-style-type: none"> To assist in research and the provision of VPD surveillance reports. 	Only non-identifiable information will be disclosed for the purpose of calculating immunisation coverage and research.

User	NIR objectives	Type of information	Use of information on NIR*	Disclosure of information from the NIR*
CARM	5 9 12	Identifiable 1, 2, 3, 5, 6 Non-identifiable 2, 4, 6	<ul style="list-style-type: none"> To assist in the safe administration of vaccines and the reporting of AEFIs To correct an individual's immunisation history following an AEFI. 	<p>CARM will disclose identifiable information to the NIR and the individual's provider for the purpose of correcting or following up an individual's immunisation history following an AEFI.</p> <p>Note: CARM disclosure to the NIR will be via manual processes only.</p> <p>Only non-identifiable information will be disclosed for the purpose of reporting the incidence of AEFIs.</p> <p>Note: Non-identifiable information will also be provided to CARM for planning and policy purposes.</p>
Child and Youth Mortality Review Committee	3 4 5	Identifiable 1, 2, 3, 4, 5, 6	<ul style="list-style-type: none"> To collect information following the death of an individual between four weeks and 24 years of age 	<p>The National Immunisation Programme is required under Statute to disclose identifiable information to the Child and Youth Mortality Review Committee for the purpose of:</p> <ul style="list-style-type: none"> an investigation by the Child and Youth Mortality Review Committee of the death of an individual between four weeks and 24 years of age.
NIR auditors/ evaluators	12	Non-identifiable 2, 4 (except notes), 6	<ul style="list-style-type: none"> To audit and evaluate the NIR 	<p>The National Immunisation Programme will disclose non-identifiable information for the purposes of:</p> <ul style="list-style-type: none"> NIR audit and evaluation.

Notes:

New categories of users will be referred to the NIR national governance body.

* Any reference to NIR in this paper refers to the dataset held on the NIR.

** A provider can become associated to an individual by being included in the maternity information system as the LMC, nominated primary care or Well Child provider; by completing an immunisation event; by being added to an individual's record as their provider.

	Status query on an individual	Provide information to register an individual on NIR	Add immunisation event	Modify demographic changes	Send corrected immunisation event information	Send corrected provider details to DHB NIR administrator	Modify NIR data based on changes received	NHI merge	Modify status of individual eg, opt-off/on, death and database status	Delete information on NIR (eg, 20 years after death)	Generate standard reports non-identifiable	Generate extracts identifiable and non-identifiable (under strict business rules)	Receive operational reports on own patients identifiable	Receive standard reports non-identifiable	Receive extracts (identifiable and non-identifiable) (under strict business rules)
Ministry of Health NZHIS NIR IT system and analysts											✓	✓		✓	✓ Identifiable and non-identifiable
Ministry of Health directorates														✓	
District Immunisation Facilitators														✓	
Research														✓	✓ Identifiable and non-identifiable via NIP
Institute of Environmental Science and Research (ESR)														✓	✓ Identifiable and non-identifiable via NIP
CARM	✓** Individual and event				✓									✓	✓ Identifiable and non-identifiable
Child & Youth Mortality Review Committee															✓ Identifiable and non-identifiable via NIP
NIR auditors and evaluators														✓	✓ Identifiable and non-identifiable via NIP

Notes:

This is not related to how an authorised user will access the NIR eg, PMS, Health Intranet browser or paper based.

IT system support staff at the National server may need to view identifiable information for the purpose of resolving technical issues.

* A provider can become associated to an individual by being included in the maternity information system as the LMC, nominated primary care or Well Child provider; by completing an immunisation event; or by being added to an individual's record as their provider.

** Read access only

NIR Authorised User Agreement for a Provider, Organisation or Practice

The NIR is designed as a tool for health providers to keep an accurate record of an individual's immunisation history and to help achieve 95 percent national immunisation coverage rates.

The NIR will succeed only if individuals, parents and guardians have full confidence that their information is secure and that there is no invasion of their privacy or infringement of their rights. The NIR system has been designed to meet all Health Information Privacy Code requirements. To further protect and safeguard individuals, you are required to read, understand and agree to comply fully with this agreement and continue to meet your professional obligations before you can be granted a user access code.

NIR obligations and accountabilities

I will fulfil my NIR user obligations and accountabilities by ensuring appropriate data quality and operational security and privacy conditions exist as per the procedures in the NIR Operations Manual and, in particular, by focusing on high-quality management of confidential data by:

- checking the demographic and immunisation related data thoroughly and ensuring the data I, or the staff covered by this agreement, provide, enter and use is accurate, valid and complete
- using and disclosing NIR information only for the purpose for which it was collected
- keeping all identifiable information and reports containing identifiable information secure at all times
- ensuring only staff of this organisation or practice, including myself, use the authorised user access code and do not release it to anyone else or allow anyone to alter data under someone else's identity
- ensuring all staff, including myself, use the relevant authorised user access code at all times and do not obtain or use anyone else's authorised user code
- participating in any NIR data quality reviews.

I understand and agree that if I, or any of the staff covered by this Agreement, breach this NIR Authorised User Agreement, this organisation or the individuals may be subject to the usual penalties and disciplinary action, associated with my organisation or professional processes.

NIR user agreement compliance and accountability statement

I have read and fully understand the NIR Authorised User Agreement obligations and accountabilities, and certify that I take full responsibility and accountability for all the NIR users in the organisation and state that I will, in good faith, comply with all these NIR Agreement requirements and meet the obligations under the Health Information Privacy Code.

I understand that this NIR Agreement is to protect the security of information and the privacy of the patients served by this organisation and understand that I, and all staff covered by this Agreement, have obligations under law to protect such information and the privacy of patients.

Name of person signing the agreement:.....

Position in organisation:.....

On behalf of:

Organisation:

Signature:

Date:.....

Organisation details

For organisations that nominate one person (the director, owner, office manager etc) to be responsible for managing the practice's security and privacy procedures and ensuring that all staff understand the security and privacy policies and comply with them as per the NIR Operations Manual.

Practice or clinic name:

PHO or IPA:.....

DHB:.....

Street number and name:.....

Town, city or district:.....

Postal address (if different to street address):

Town, city or district:.....

Phone number:

Fax number:

Email address:.....

Key contact person's name:

Access to NIR will be:

- PMS: Practice or clinic mail box ID:
PMS type and version:
- Browser: The NIR Administrator will contact you to assign a User ID
- Manual: The NIR Administrator will contact you to assign a User ID

Authorised users of NIR

Surname or family name:.....

First or given name(s):.....

Title:.....

Professional registration type: NZMC /NCNZ/APC

Registration number:

Vaccinator? Yes/No

To receive immunisation event messages? Yes/No

To receive overdue task messages? Yes/No

Surname or family name:.....

First or given name(s):.....

Title:.....

Professional registration type: NZMC/NCNZ/APC

Registration number:

Vaccinator? Yes/No

To receive immunisation event messages? Yes/No

To receive overdue task messages? Yes/No

Surname or family name:.....

First or given name(s):.....

Title:.....

Professional registration type: NZMC/NCNZ/APC

Registration number:

Vaccinator? Yes/No

To receive immunisation task updates? Yes/No

To receive overdue task messages? Yes/No

NIR Authorised User Agreement for an Individual Provider or User

The National Immunisation Register (NIR) is designed as a tool for health providers to keep an accurate record of an individual's immunisation history and to help achieve 95 percent national immunisation coverage rates.

The NIR will succeed only if individuals, parents and guardians have full confidence that their information is secure and that there is no invasion of their privacy or infringement of their rights. The NIR system has been designed to meet all Health Information Privacy Code requirements. To further protect and safeguard individuals you are required to read, understand and agree to comply fully with this agreement and continue to meet your professional obligations before you can be granted a user access code.

NIR obligations and accountabilities

I will fulfil my NIR user obligations and accountabilities by ensuring appropriate data quality and operational security and privacy conditions exist as per the procedures in the NIR Operations Manual and, in particular, by focusing on the high quality management of confidential data by:

- checking the demographic and immunisation related data thoroughly and ensuring the data I provide, enter and use is accurate, valid and complete
- using and disclosing NIR information only for the purpose for which it was collected
- keeping all identifiable information and reports containing identifiable information secure at all times
- being the only person to use my authorised user access code and not releasing it to anyone else or allowing anyone to alter data using my identity
- using my authorised user access code at all times and not obtaining or using anyone else's authorised user code
- participating in any NIR data quality reviews.

I understand and agree that, if I breach this NIR Authorised User Agreement, I may be subject to the usual penalties and disciplinary action, associated with my organisation or professional processes.

NIR user agreement compliance and accountability statement

I have read and fully understand the NIR Authorised User Agreement obligations and accountabilities, and state that I will, in good faith, comply with all these NIR Agreement requirements and meet their obligations under the Health Information Privacy Code.

I understand that this NIR Agreement is to protect the security of information and the privacy of patients and understand that I have obligations under law to protect such information and the privacy of patients.

Name:

Practice or clinic:

Signature:

Date:

Your details

Surname or family name:

First or given name(s):

Title:

Role:

Professional registration type: NZMC /NCNZ/APC

Registration number:

Practice or clinic name:

PHO or IPA:

DHB:

Street number and name:

Town, city or district:

Postal address (if different to street address):

Town, city or district:

Phone number:

Fax number:

Email address:

NIR user: Vaccinator / Non-vaccinator

Access to NIR will be:

- PMS: Practice or clinic mail box ID:
PMS type and version:
- Browser: The NIR Administrator will contact you to assign a User ID
- Manual: The NIR Administrator will contact you to assign a User ID

I want to receive immunisation task updates Yes/No

I want to receive overdue task messages Yes/No

Office use only

Date person or practice registered: / /

Date security codes issued (manual and browser users): / /

Date practice connection with NIR tested: / /

NIR Administrator's name:

NIR Administrator's signature: