

1. Background

Everyone has the right to know how their personal information is being used (Health Information Privacy Code 1994). Health agencies¹, administering public health programmes need to be open about how information is being collected and managed so that people can have confidence that their personal information is only used for the intended purpose.

2. What would the Ministry like to achieve?

The Ministry of Health wants people to have confidence in how personal information is being collected and managed in the HPV Immunisation Programme.

3. What information systems are involved in the HPV Immunisation Programme?

The HPV Immunisation Programme requires interface between:

- practice management systems
- the School Based Vaccination System
- the National Health Index
- the National Immunisation Register.

In primary care, practice management systems held by individual general practices record information about immunisation events. For immunisations that take place in schools, the School Based Vaccination System or another system, held by the local district health board, is used to collect information. Both of these systems submit information to the National Immunisation Register. All of these systems may record information for the HPV Immunisation Programme.

Practice Management Systems

Practice management systems are a category of computer-based programmes that deal with the day-to-day operations of a medical practice. Such computer-based programmes frequently allow users to hold patient demographics, medical records, schedule appointments and generate reports.

School-Based Vaccination System

The School Based Vaccination System is a computer-based programme designed to assist public health nurses/school based immunisation providers to manage, deliver and record information about immunisation programmes delivered in schools. It is held locally by the student's district health board. The information collected following HPV immunisation is entered into the School Based Vaccination System and also

¹ A health agency is any organisation involved in the provision of health services and may include (but is not limited to) a general practice, public health unit, school-based immunisation service or district health board.

sent to the National Immunisation Register. The National Immunisation Register cannot access the School Based Vaccination System.

Students' details from the school roll (specific details are listed on the next page) are loaded into the School Based Vaccination System and data can be checked to confirm the correct name, gender, date of birth, address and phone number. Consent form information is entered into the School Based Vaccination System prior to immunisation, and the immunisation event data is entered after the immunisation.

HPV immunisation event information should be entered in the School Based Vaccination System as soon as practicably possible after the immunisation has been administered. Information should ideally be entered no longer than 5 working days after HPV vaccine has been administered in a school-based programme.

The School Based Vaccination System sends HPV immunisation event data to the National Immunisation Register, including non-consents/declines. After receiving immunisation through a school based programme, should a student receive further immunisations in a primary care setting, the authorised administrator can look at the National Immunisation Register to confirm what immunisations are due.

Reports from the School Based Vaccination System can be generated by the district health board to measure the progress of the school-based programme and to assist in follow-ups. Public health nurses use the information on the School Based Vaccination System and the National Immunisation Register to manage the immunisation programme by identifying students who have missed an immunisation or are due for one.

National Health Index

The National Health Index (NHI) is a database that generates and stores National Health Index numbers.

A unique National Health Index number is assigned to each person who accesses publicly funded health services in New Zealand. The National Health Index holds information on names and addresses, ethnicity, date of birth, date of death, gender and New Zealand residency status, but does not hold clinical information.

The National Health Index number is used to ensure that health information is attributed to the right person. Only health agencies that are involved in providing health services can read and use the National Health Index. The Ministry of Health manages and maintains the National Health Index under the guidance of the Health Information Privacy Code 1994.

National Immunisation Register

The National Immunisation Register (NIR) is a computerised information system, managed by the Ministry of Health that holds the immunisation details of New Zealand children/students. The National Immunisation Register records information

from both primary care and school-based programmes about HPV immunisations delivered as part of the national HPV Immunisation Programme.

The National Immunisation Register holds the child's name, address, date of birth, gender, ethnicity, National Health Index number, the child's general practitioner, caregiver details for children under 16 (may include name, contact phone number, address and National Health Index number) and the HPV immunisations given or declined (batch number and date of vaccine given).

It is not compulsory to be enrolled on the National Immunisation Register to receive HPV immunisation. Parents have the option to 'opt off' if they do not want their children's immunisation information recorded on the National Immunisation Register. Children aged 16 and over can also exercise this option. If an immunisation is received at school, a tick-box on the consent form is used to indicate the choice to 'opt off' the National Immunisation Register. If an immunisation is received outside of school, an 'opt off' form must be completed and signed if a child's information is not to be recorded on the National Immunisation Register.

Where the choice is to 'opt off' the National Immunisation Register, information on the child is still recorded on the district health board's School Based Vaccination System or the Practice Management System. The child's National Health Index number, date of birth, district health board and earlier immunisation events (immunisations that were recorded prior to opting off the National Immunisation Register) are still recorded on the National Immunisation Register. All other information is removed.

4. School roll information

Why do district health boards request specific school roll information?

Specific information from school rolls facilitates the delivery of immunisations to all students who wish to receive them.

The information from school rolls allows vaccinators to:

- ensure that all students and parents/caregivers have the opportunity to receive information to make an informed decision about immunisation
- ensure that the correct students are immunised
- follow-up with students who do not return consent forms or were absent for school-based immunisation clinics
- assist with checking that accurate details are recorded.

What specific information do district health boards request from school rolls?

District health board vaccinators request the following specific school roll information:

- female student's full name
- Date of birth

- ethnicity²
- contact address and phone number(s)
- school room number.

What has the Privacy Commissioner advised about disclosing specific school roll information to district health boards for HPV immunisation purposes?

The Privacy Commissioner has advised that, given the importance of the public health goals at issue, school boards of trustees may decide to disclose personal information about their students for immunisation purposes as long as they first notify the students, parents/guardians that they intend to do so.

The Privacy Commissioner has also advised that school roll information should not be stored on the School Based Vaccination System for longer than required to administer the programme.

Copies of advice that the Ministries of Education and Health have provided to schools and education sector groups about disclosing specific school roll information to district health boards for HPV immunisation purposes are available at www.minedu.govt.nz and www.moh.govt.nz

The Privacy Commissioner has published a guide to the Privacy Act for principals, teachers and boards of trustees entitled *Privacy in Schools*. This is a book designed to help New Zealand primary and secondary schools and their associated units find solutions to issues involving privacy. This guide can be downloaded from <http://www.privacy.org.nz/privacy-in-schools-a-guide-to-the-privacy-act-for-principals-teachers-and-boards-of-trustees/>

What happens to specific school roll information after it is provided to district health boards by school boards of trustees?

The district health board authorised users take the specific school roll information and match, from the National Health Index database, National Health Index numbers to students. The school roll details and NHI numbers are then entered on to the School Based Vaccination System.

Prior to immunisation, a consent form is given to each student or to their parents/guardians. The returned consent form information is entered onto the School Based Vaccination System and matched to that already obtained through school rolls. Vaccinators use the updated information from the consent forms to confirm the National Health Index number, if a number is present, and obtain a National Health Index number for those students where school roll information did not previously give a match. If the student does not have a National Health Index number, then a new National Health Index number will be allocated.

² Ethnicity data is collected to provide total population numbers for different ethnic groups. Coverage rates by ethnicity can then be ascertained.

5. How is the privacy of personal information collected for the HPV Immunisation Programme maintained?

The management of health information, including collecting, holding, use and disclosure and the individual's right to access or amend it is governed by the Health Information Privacy Code 1994 and Privacy Act 1993.

Public Health Nurses administering immunisations in a school setting need to retain accurate immunisation records as health professionals, in the same way healthcare workers in clinics, general practice and hospitals are required to.

The National Immunisation Register Privacy Policy provides guidance for the management of health information held on the National Immunisation Register. The SBVS is a sub-project of the National Immunisation Register and therefore operates under the same privacy and governance frameworks. District health boards also have privacy policies for all information and these are adhered to alongside the National Immunisation Register Privacy Policy in their local area.

Only those authorised as National Immunisation Register and School Based Vaccination System (or alternative) users can access the information held on the National Immunisation Register. There are varying levels of access for authorised users, depending on the requirements associated with their position, which are determined by the Ministry of Health or district health board (refer to the National Immunisation Register Privacy Policy for more information on authorised users).

Parents/guardians and individuals must be well informed about the National Immunisation Register and its purpose and benefits, and what data will be collected, how it will be used and who will have access to it. Information about the National Immunisation Register has been included within the HPV school-based programme consent form to inform students, parents and guardians about the National Immunisation Register.

How can an individual access their own information on the National Immunisation Register?

Citizens and residents of New Zealand have a right to access their own health information under rule 6 of the Health Information Privacy Code. Parents also have a limited right to access health information about their children who are aged less than 16 years.

To access an individual's information from the National Immunisation Register, the first point of contact for that individual (or his or her parent, in the case of children under 16) should be through their general practitioner.

For more information on the Use and Disclosure of Information held on the National Immunisation Register see [http://www.moh.govt.nz/moh.nsf/pagesmh/6692/\\$File/use-disclosure-info-held-on-nir-v2.doc](http://www.moh.govt.nz/moh.nsf/pagesmh/6692/$File/use-disclosure-info-held-on-nir-v2.doc)

How can an individual access their own information on the School Based Vaccination System?

To access an individual's information from the School Based Vaccination System, the individual should contact their local district health board.

6. How long will information be retained on the National Immunisation Register and the School Based Vaccination System?

National Immunisation Register

Health information and data will be retained on the National Immunisation Register for the whole of life of an individual plus a period of ten years after the death of that individual, unless they opt off. The purpose of this retention period is to provide an accurate record of the immunisation events received by that individual and to assist with the monitoring of vaccine safety and efficacy.

School-based Vaccination System

Under the Public Records Act 2005, district health boards have to retain patient file information about an individual for a minimum of ten years after the most recent contact with that individual.

School roll information is not required to be retained on the School Based Vaccination System after completion of the HPV Immunisation Programme. District Health Board's should delete school roll information once the school based immunisation programme is completed.

7. How does the Health Information Privacy Code 1994 and the Privacy Act 1993 apply to School Based Immunisation Programmes?

The Health Information Privacy Code gives people rights of access and correction in relation to their own health information. It also:

- requires agencies collecting health information to be open about why they are collecting it and how it is to be held
- restricts how the collected health information can be used and disclosed
- requires health agencies to keep the information they hold secure.

Information collected for a particular purpose can generally be used or disclosed for that purpose or for directly related purposes.

Parents and guardians of children under 16 do have a limited right of access to information about their children under section 22F of the Health Act 1956. However, section 22F access requests may be refused where the person holding the information believes that the child does not or would not want the information disclosed, or that the disclosure is not in the interests of the child.

8. What can district health boards do to provide assurance that personal information collected for the HPV Immunisation Programme remains private?

Make privacy policies available

- Be prepared to share privacy policies and processes with the public – these may include policies around:
 - the safe management and privacy of personal health information
 - retention and destruction of personal health information
 - security of information on computer equipment
 - authorised provider information – authorised user agreements
 - transportation of client data
- Seek comment from the district health board legal team which gives assurance and explanation of policy and processes around the management of personal information.

Manage relationships

- Relationship with schools
 - Discuss the purpose and process of requesting specific school roll information with boards of trustees and principals and explain how this information will be used – aim to provide assurance by also outlining the Privacy Commissioner's view and local DHB policies and procedures for ensuring privacy of this information.
- Relationships with parents/guardians and students
 - Inform parents of the purpose and process of specific information collection and management for the HPV Immunisation Programme – aim to provide assurance by outlining the flow of data ie, what is collected and where it goes, who is involved in collecting the data and what policies and procedures are in place to maintain privacy.

9. Useful links

- The Privacy Commissioner
<http://www.privacy.org.nz/>
- The National Immunisation Register Privacy Policy
<http://www.moh.govt.nz/moh.nsf/indexmh/privacy-policy-nir-may04>
- Use and Disclosure of Information held on the National Immunisation Register
[http://www.moh.govt.nz/moh.nsf/pagesmh/6692/\\$File/use-disclosure-info-held-on-nir-v2.doc](http://www.moh.govt.nz/moh.nsf/pagesmh/6692/$File/use-disclosure-info-held-on-nir-v2.doc)
- The Code of Health and Disability Services Consumers' Rights
<http://www.hdc.org.nz/theact/theact-thecode>