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New Zealand Health Information Service

Current Data Access Policy

October 2002

1 Purpose of this document

The purpose of this document is to provide an overview of the current data access policy used by Analytical Services. These general guidelines are followed in response to requests for data held by the New Zealand Health Information Service (NZHIS).

2 Introduction/Background

NZHIS is a group within the Ministry of Health (MOH) responsible for the collection and dissemination of health-related data. NZHIS has as its foundation the goal of making accurate information readily available and accessible in a timely manner throughout the health sector. The vision of NZHIS is to support the health sector's ongoing effort to improve the health status of New Zealanders. Effective and timely use of information is crucial to achieving this vision.

NZHIS must ensure that the Privacy Act (1993) and Health Information Privacy Code (1994) are followed when considering data requests.

All requests for non-identifiable data held by NZHIS are processed by the information analysts in the Analytical Services Team, which is part of the Information Delivery Section of NZHIS. Requests for identifiable data held by NZHIS are handled by the information analysts in consultation with the Chief Analyst and Privacy Officer. For details on releasing identifiable data please see the NZHIS Information Release Policy, September 2001 (refer to Appendix 1).

3 Data access

Data held by NZHIS is available to a number of agencies through the information analysts in Analytical Services. The methods by which data can be obtained are outlined below.

Staff from MOH (external to NZHIS), District Health Boards (DHBs), Shared Support Agencies (SSAs), Independent Practitioner Associations (IPAs) and Pharmac can access summarised data through publications, the NZHIS website, from the information analysts, or directly through Business Objects if access is approved. Unit record data with encrypted NHI numbers can also be obtained from the information analysts if appropriate (refer to Section 4). Unit record data is usually provided to DHBs with unencrypted NHI numbers for clients seen by the DHB and encrypted NHI numbers for clients seen by other DHBs.

Other groups (eg, universities, research groups, other government organisations and the general public) can access summarised data through publications, the NZHIS website and via the information analysts. Unit record data with encrypted NHI numbers can be accessed via the information analysts if appropriate (refer to Section 4).

3.1 Adhoc information requests

The information analysts respond to adhoc requests for statistical information. Data typically comes from published or previously produced material and is provided in a summarised form where available. Requests are usually responded to within 3 working days and are completed at no cost to the client.

3.2 Customised information requests

Analytical Services respond to customised requests for statistical information. Customised requests include any information requests that cannot be completed using readily available reports and summary spreadsheets, and require specific additional effort (such as querying databases). An information analyst will work with the client to understand their information requirements and prepare a detailed specification that is signed off by the client. A program is then written to extract the data required. Any requests for unit record data with unique identifiers (encrypted NHI numbers) must be obtained directly from the information analysts as customised requests.

Customised requests are usually completed within 2 to 3 weeks of the job specification being signed off. Delivery timeframes may change if high-priority urgent requests are received, such as data requests from the Minister of Health. Customised data requests usually incur a charge (refer to Section 5).

3.3 Standing orders

Analytical Services produce standard reports or data extracts for clients if required. An information analyst will work with the client to understand their information requirements and prepare a detailed specification that is signed off by the client. A program is then written to extract the data required. The data specification agreed to is then extracted on a regular basis as agreed with the client, and only minor changes may occur eg, time periods. Most standing orders incur a charge (refer to Section 5).

3.4 Business Objects

NZHIS has developed Business Objects universes for some data warehouses, and these data warehouses can be accessed directly through Business Objects if access approval is given. The data warehouses and specific approval processes are outlined in Section 4. Business Objects access is at different levels, and some objects are only visible to specific users. Business Objects does not contain encrypted NHI numbers, so if unit record data is required with unique identifiers this must be obtained directly from the information analysts as a customised request.

3.5 Publications

NZHIS produces regular publications and pamphlets containing statistical data. Publications can be purchased through the Publication Officer at NZHIS by email nzhis-pub@nzhis.govt.nz and electronic copies are available free of charge on the NZHIS website at www.nzhis.govt.nz/publications/.

3.6 NZHIS website

Selected data is also available on the NZHIS website. The tables given there are summaries of aggregated data. Many of them contain more recent information than currently available in print at www.nzhis.govt.nz/stats.

4 Data available

Data from the databases and warehouses listed below can be accessed through the information analysts, or directly through Business Objects if access is approved. Appendix 2 of this document details the current on-line reporting access levels available for the warehouses, and specific details of the process for gaining access to a warehouse. For more information about these databases, please see the NZHIS website (www.nzhis.govt.nz) or contact one of the information analysts on (04) 922 1800, or inquiries@nzhis.co.nz.

4.1 National Minimum Dataset (NMDS)

Adhoc or customised data requests can be made through the information analysts. Standard casemix reports are made available to DHB staff via the Health Information Network (HIN) (<https://hinnt1.moh.govt.nz>). An annual publication of public hospital morbidity data is produced. Users who are granted permission by NZHIS can access data directly through Business Objects.

4.2 Mortality

Adhoc or customised data requests can be made through the information analysts. An annual mortality publication is produced. Note that no direct reporting access is currently available to this system.

4.3 Cancer

Adhoc or customised data requests can be made through the information analysts. An annual cancer publication is produced. Note that no direct reporting access is currently available to this system.

4.4 Workforce

Data requests can be made through the information analysts. Annual workforce publications are produced. Note that no direct reporting access is currently available to this system.

4.5 Mental Health Data Warehouse (MHDW)

Adhoc or customised data requests can be made through the information analysts. Standard reports are sent to the Provider and Funder arms of the DHB by email and are posted on the HIN (<https://hinnt1.moh.govt.nz>). Users who are granted permission by the MHINC Steering Group can access data directly through Business Objects.

4.6 Pharmhouse Warehouse

Adhoc or customised data requests can be made through the information analysts. All data requests must be approved by Pharmac, and the information analysts will forward the request by email to Pharmac. NZHIS have been advised by Pharmac that no data should be provided to anyone making requests for information for or on behalf of pharmaceutical companies, and these groups should approach Pharmac directly.

Pharmac email the standard Drug Expenditure reports to DHB and SSA staff on a monthly basis. Pharmac also produce occasional reviews and reports that are available for downloading from their website (<http://www.pharmac.govt.nz>).

Users who are granted permission can access data directly through Business Objects. Access requests are made as for other warehouses, but NZHIS will confer with Pharmac before granting access.

If identifiable healthcare provider information (eg, regarding GPs, nurses) is requested, NZHIS requires a written response from the client regarding the purpose, the intended use of the information, and their authority to have identifiable provider data.

4.7 Laboratory Testing Warehouse

Adhoc or customised data requests can be made through the information analysts. Laboratory Tests Expenditure Standard reports are made available via the HIN (<https://hinnt1.moh.govt.nz>) to DHB staff, and are updated monthly. Users who are granted permission by NZHIS can access data directly through Business Objects. If identifiable healthcare provider information (eg, regarding GPs, nurses) is requested, NZHIS requires a written response from the client regarding the purpose, the intended use of the information, and their authority to have identifiable provider data.

4.8 National Booking Reporting System (NBRS)

Adhoc or customised data requests can be made through the information analysts. All data requests must be approved by MOH Elective Services. Elective Services publish data in their quarterly report. Note that no direct reporting access is currently available to this system.

4.9 Maternity and Newborn Information System (MNIS)

Adhoc or customised data requests can be made through the information analysts. All data requests must be approved by the MNIS Advisory Board. An annual maternity report is produced. Note that no direct reporting access is currently available to this system.

4.11 National Health Index & Medical Warnings System

For details on releasing identifiable data, please see the NZHIS Data Release Policy, September 2001 (Appendix 1). As these databases refer to individual clients' details, privacy considerations are paramount. Note that no direct reporting access is currently available to this system.

5 Costs

Most adhoc requests are provided at no cost to the client, but if a significant amount of collation is involved there may be a charge.

Customised data requests are usually provided at no cost to MOH staff, and to DHBs requesting their own data with no added value from NZHIS. DHB requests that require other data or large amounts of programming work may incur a charge. All other data requests originating from outside MOH and DHBs may incur a charge. The information analysts discuss cost details of data requests with each client. The charge may be waived at the discretion of the NZHIS Management Team. There is a standard charge per hour for analyst, programmer and system time involved in producing the information required. Rates are charged in line with the Official Information Act.

6 Conclusion

NZHIS s goal is to make timely and accurate data readily available throughout the health sector. This document outlines the policies followed by Analytical Services when responding to data requests. NZHIS will be consulting with the sector from time to time to ensure our access policies are meeting their requirements. If you have any queries regarding access to data please contact the Analytical Services Team Leader on (04) 922 1800.

Appendix 1: NZHS Information Release Policy, September 2001

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New Zealand Health Information Service

Information Release Policy

Issued: February 2001
Version 3

1 PURPOSE

The purpose of this Information Release Policy is to set out the considerations that NZHIS takes into account when evaluating requests to release information held on national collections by NZHIS, including the NMDS, NHI, MHINC, Cancer and Mortality collections.

2 INTRODUCTION

NZHIS holds collections of identifiable health data that Government departments, private organisations, researchers and other individuals wish to access.

POLICY

NZHIS must ensure that release of information complies with the Official Information Act 1982, Privacy Act 1993, Health Information Privacy Code 1994, and any NZHIS stipulated conditions. This Policy clarifies the application of that legislation.

THE RELEVANT LEGISLATION

A request for information held by NZHIS, from someone who is not the subject of the information, or their personal agent, is a request under Part II of the Official Information Act 1982 (even where the requester does not cite the Official Information Act in their request). Such information is subject to a principle of availability (s 5) and should be made available unless good reason for withholding exists.

Information may be withheld if it falls within the scope of section 9 of the Act provided that the reasons for withholding it are not outweighed by other considerations that render it desirable, in the public interest, that the information be released. Section 9 includes reasons relating to the protection of individual privacy. Therefore a balancing of private and public interests is required.

Relevant to this balancing exercise is the fact that NZHIS, as part of the Ministry of Health, is subject to the Privacy Act. Therefore, the Privacy Act and the Health Information Privacy Code 1994 may be taken into account under section 9(2)(a) of the Official Information Act, which provides that good reason for withholding official information exists if the withholding of the information is necessary to protect the privacy of natural persons, including that of deceased natural persons.

PROCEDURE

STEP 1 – RECEIPT OF REQUEST

NZHIS receives a request for health information.

NZHIS checks the request to ascertain whether the data requested is information about an identifiable individual (and that the requesting individual is not the subject of the information or a agent of that person). The Chief Analyst of NZHIS is consulted in this process.

STEP 2 – DOES THE INFORMATION REQUESTED CONTAIN PERSONALLY IDENTIFIABLE INFORMATION?

This question relates to section 9(2)(a) of the Official Information Act. Section 9(2)(a) allows information to be withheld where it is "*necessary to protect the privacy of natural persons, including that of deceased natural persons*". Therefore, it is necessary to ask whether the information requested contains personally identifiable information.

If no, go to Step 4.

If yes, the following will apply.

Before accepting in a particular case that there is good reason for refusing a request pursuant to section 9(2)(a), NZHIS must be satisfied that:

- (a) The withholding of the information requested is "*necessary to protect the privacy of natural persons, including that of deceased natural persons*", and
- (b) This interest is not "*outweighed by other considerations which render it desirable, in the public interest, to make that information available*" (the requirement to consider the public interest comes from section 9(1) of the Act).

In every case, an objective assessment of the facts and circumstances must be made, including the Privacy Act and the Health Information Privacy Code, before deciding whether or not section 9(2)(a) has been satisfied. However, the Privacy Act and the Health Information Privacy Code are not the only relevant privacy considerations that make up section 9(2)(a) of the Act. There could be others, depending on the facts of each case.

Rule 11 of the Health Information Privacy Code places limits on the disclosure of information. The Code is a set of principles that those who make their information available to Health Agencies can expect those agencies to apply. Therefore the limits expressed in the Code are relevant to the balancing exercise. Set out below, is the method that NZHIS uses to determine whether any of the limits apply to the request.

A Disclosure is authorised

1. *Disclosure is authorised by the individual concerned – Rule 11(1)(a) & (b) of the HIPC*

The requester must advise whether he or she intends to seek authorisation by the individual concerned¹ to the release of the particular information requested.

- *If the requester does intend to seek the individual's authorisation*, then the requester should reasonably seek this before he or she is given the information. Proof of authorisation must be given to NZHIS before it will release the information. Then, go to Step 4.
- *If the requester does not intend to seek consent of the persons who are the subject of the information*, then if the NZHIS considers the individual(s) should be contacted and their views on disclosure to the requestor obtained, that obligation falls on the NZHIS (under the Official Information Act). However, this may not be possible/practical in some circumstances. Other grounds below may then apply.

2. *Disclosure is specifically authorised by Statute*

Some statutes or regulations authorise or require personal information to be made available, e.g. the Health Act. In these cases, the Privacy Act (and, consequently, the Code) defers to the legislation, and the restrictions on disclosure do not affect the operation of the statute or regulations authorising or requiring the personal information to be made available.

If no statute or regulations authorise or require the personal information to be made available, one of the grounds listed below may apply.

B Permitted disclosures for particular reasons – Rule 11(1)(c) – (g) of the HIPC

NZHIS may release the information if it believes on reasonable grounds that one of the grounds listed below applies, or if it believes that there are stronger countervailing public interest considerations in releasing the information than personal privacy considerations²:

- The disclosure of the information is one of the purposes in connection with which the information was obtained³ (this may include reference to the legislation that sets up the relevant register e.g. the Cancer Registry Act 1993)
- The source of the information is a publicly available publication⁴

Where the disclosure is 'authorised' under Rule 11(1) there is no need to go on to consider whether Rule 11(2) applies. The balancing exercise will almost certainly favour release of the information. However, where disclosure is not authorised under Rule 11(1), Rule 11(2) lists provisions that may provide for the release of the information.

C Permitted disclosures where it is not desirable or practicable to obtain authorisation from the individual concerned – Rule 11(2)

¹ Rule 11(1)(b) of the Code refers. Note we are not talking about requests where the requester cannot identify the individuals involved without the information requested, or at least their names and contact information.

² Rule 11(1)(c) and (d) of the Code and section 9(1) of the Official Information Act refer. Rule 11(1)(e), (f) and (g) are not referred to as they are not likely to be relevant to requests made of NZHIS. However, if a requester believes they are relevant, then inform NZHIS before it considers your request for information.

³ Rule 11(1)(c) of the Code refers.

⁴ Rule 11(1)(d) of the Code refers.

Where the request does not come within any of the above permitted disclosures, disclosure may still be permitted in certain situations where it is not desirable or practicable to obtain authorisation from the individual concerned.

If, after considering the requester's views, NZHIS believes on reasonable grounds that it is not desirable or practicable to obtain authorisation from the individual(s) concerned, then NZHIS may release the information if it believes on reasonable grounds that one of the grounds listed below applies, or if its believes that there are public interest considerations in releasing the information which outweigh individual privacy considerations reflected in the Code ⁶:

Grounds on which disclosure may be made

- That the disclosure of the information is directly related to one of the purposes in connection with which the information was obtained (this will include peer review and quality audit)⁷
- That the information is to be used in a form in which the individual concerned is not identified^{8A}
- That the information is to be used for statistical purposes and will not be published in a form that could reasonably be expected to identify the individual concerned^{8B}
- That the information is to be used for research purposes (for which approval by an ethics committee (one approved by the Health Research Council or the Director-General of Health), if required, has been given) and will not be published in a form which could reasonably be expected to identify the individual concerned^{8C}
- That the disclosure of the information is required for the purposes of a professionally recognised accreditation of a health or disability service and the publication of the information will not identify the individual(s) concerned⁹
- That the disclosure of the information is required for a professionally recognised external quality assurance programme and the publication of the information will not identify the individual(s) concerned.¹⁰

What about information required for research?

As noted above, most of the requests for information that NZHIS receives are for information required for research. Unless Rule 11(1) applies, and consistent with Rule 11(2)(c)(iii) NZHIS will generally need to be satisfied that all of the following pre-conditions exist before it can release the information to the researchers:

- it is not practicable or desirable to obtain consent
- the information is to be used for research purposes
- an ethics committee has approved the research, if required
- the information will not be published in a form which could reasonably be expected to identify the individual concerned.

⁶ Rule 11(2) of the Code and section 9(1) of the Official Information Act refer. Rule 11(2)(b), (d), (e), (f) (g), (h)(iii), (i), (j), or (k) are not referred to as they are not likely to be relevant in requests made of NZHIS. However, if a requester believes they are relevant, then inform NZHIS before it considers your request for information.

⁷ Rule 11(2)(a) of the Code refers.

^{8A} Rule 11(2)(c)(i) of the Code refers.

^{8B} Rule 11(2)(c)(Ii) of the Code refers.

^{8C} Rule 11(2)(c)(iii) of the Code refers.

⁹ Rule 11(2)(h)(i) of the Code refers.

¹⁰ Rule 11(2)(h)(Ii) of the Code refers.

These factors represent a balancing within the Code itself of the particular privacy interests of the individual and the public interest in legitimate research. There may, nevertheless, be some cases where the balancing of the legitimate public and private interests by NZHIS may warrant disclosure notwithstanding that the above points are not satisfied. The NZHIS retains discretion under the Official Information Act and will consider each case on its merits: see D below.

D Public interest grounds

Even where none of the grounds in the Code apply to the information requested, in some limited situations, the information might still be released by virtue of section 9(1) of the Official Information Act. This section contemplates that the reasons for withholding the information are not outweighed by other considerations that render it desirable, in the public interest, that the information be released.

However, please note that, given the sort of information that NZHIS holds, these sorts of situations will be limited.

STEP 3 – RECIPIENT UNDERTAKING

The customer must then also sign the Recipient Undertaking (see below), which sets out the terms and conditions of using the data.

STEP 4 – ARE THERE ANY OTHER GROUNDS IN THE OFFICIAL INFORMATION ACT THAT MAY BE RELEVANT TO WHETHER THE INFORMATION IS DISCLOSED?

NZHIS considers whether there are any other grounds in the Official Information Act that may apply to the information, and whether the public interest test outweighs the consideration of those grounds.

NZHIS provides to the customer a detailed specification and an estimated cost to extract the data. Costs must be estimated in accordance with the Official Information Act (section 15 refers).

RECIPIENT UNDERTAKING

(To be completed by recipients of information about identifiable individuals)

Declaration to be made by the Recipient

I, _____

(Full Name of Recipient)

of _____

(Address)

undertake to:

1. Use the information provided by the NZHIS only for the purposes set out in the proposal/documentation provided to NZHIS
2. Provide a secure storage environment and restrict access to personal information supplied by the NZHIS.
3. Limit access to such information to members of the project team (the personal information must not be provided, sold or otherwise transferred to any third party in any shape, manner or form).
4. Provide the NZHIS with an advance copy of any article, documents, analyses, compilations, or any form of material produced from the personal information released by the NZHIS, intended for publication (it is the responsibility of the author(s) of any publications to ensure that information is not published in a manner which could reasonably be expected to identify any individual concerned).
5. Acknowledge the NZHIS as a source of information.
6. Destroy all personal information on completion of the project and notify - The Manager, Information Delivery, P O Box 5013, Wellington, when this has been done.
7. Comply in all respects with the relevant requirements of the Privacy Act 1993 and the Health Information Privacy Code 1994.

(Recipient Signature)

(Date)

Appendix 2: NZHIS Data Warehouse Direct Access Settings & Procedures (Oct 2002)

The details below provide a snap-shot of the access levels available to the current data warehouse Business Objects universes.

Note that unless specifically stated, no encrypted or unencrypted NHI/HCU is available in these environments, i.e.: no data is uniquely identifiable.

Mental Health Data Warehouse

Access Level: PUBLIC
Key Fields Unavailable: Number of Discharges (aggregated)
Current Users: MOH Mental Health Directorate
MOH NZHIS Quality Analysts

Access Level: CONTROLLED
Key Fields Unavailable: None
Current Users: MOH NZHIS Information Analysts

Process for Obtaining PUBLIC Access Authorisation:

- Request form from NZHIS or download from Webi Server
- Complete form, attain necessary authorization, and forward completed form to NZHIS
- Request implemented
- Users accessing MH data reviewed by Mental Health Steering Group at monthly meeting

Laboratory Claims Data Warehouse

Access Level: PUBLIC
Key Fields Unavailable: None
Current Users: DHB s, IPA s,
MOH Directorates, MOH NZHIS,
Pharmac, Premec

Process for Obtaining PUBLIC Access Authorisation:

- Request form from NZHIS or download from Webi Server
- Complete form, attain necessary authorization, and forward completed form to NZHIS
- Request reviewed & implemented

Pharmacy Claims Data Warehouse

Access Level: PUBLIC
Key Fields Unavailable: Pharmacode detail / Claim date / Approved date / Prescription details / Provider details (due to data quality) / Claimant addresses / Some regional

groupings / fields of reduced data quality / fields unavailable in controlled or restricted access.
 Current Users: IPA s
 MOH Public Health Directorate

Note: Public access is intended to give a cut down view for new users. Once users are familiar with the objects available controlled access should be requested.

Access Level: CONTROLLED
 Key Fields Unavailable: Medicode details / Daily dose data / PHARMAC subsidy data / Prescription identifiers / Special authority numbers / fields unavailable in restricted access.
 Current Users: DHB s and SSA s
 MOH HealthPAC South
 MOH NZHIS Information Analysts
 MOH NZHIS Data Quality

Access Level: RESTRICTED
 Key Fields Unavailable: NHI reference data.
 Current Users: Premec

Access Level: CONFIDENTIAL
 Key Fields Unavailable: None
 Current Users: Pharmac
 MOH DHB Funding & Performance Directorate
 MOH NZHIS Information Analysts

Process for Obtaining Access Authorisation:

- Request form from NZHIS or download from Webi Server
- Complete form, attain necessary authorization, and forward completed form to NZHIS
- Request authorised by Pharmac
- Implemented if confirmed by Pharmac

NMDS Data Warehouse

Access Level: PUBLIC
 Key Fields Unavailable: None
 Current Users: DHB s, SSA s, IPA s
 MOH Directorates, MOH NZHIS,
 Pharmac, Premec

Process for Obtaining PUBLIC Access Authorisation:

- Request form from NZHIS or download from Webi Server
- Complete form, attain necessary authorization, and forward completed form to NZHIS
- Request reviewed & implemented