

REVIEW OF THE NATIONAL HEALTH
INDEX NUMBER

PRIVACY CONSIDERATIONS

for

New Zealand Health Information Service

Elisabeth Harding
April 1999

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

TABLE OF CONTENTS

1. Executive Summary	1
2. Introduction	6
3. Role of NZHIS	8
4. Unique health identifiers from a privacy perspective	8
5. Background to the NHI database - perceptions and realities	11
6. Legislative framework	15
7. Health Act 1956	15
8. Health and Disability Services Act 1993	19
9. Privacy Act 1993	21
10. Health Information Privacy Code 1994	22
11. Health Information Strategy for the Year 2000	27
12. Ethical standards	30
13. Current use of NHI	31
13.1 NZHIS	31
13.2 Individuals	33
13.3 Providers	33
13.4 Funders	35
14. Future use of NHI	38
15. Frequently asked questions	39
16. Conclusions	41
17. Recommendations (not in order of priority)	42
Bibliography	45
Appendix 1 Health Act 1956	47
Appendix 2 Health and Disability Services Act 1993	49
Appendix 3 Health Information Privacy Rules	51

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

REVIEW OF THE NATIONAL HEALTH INDEX NUMBER PRIVACY CONSIDERATIONS

1. Executive Summary

- 1.1 Up until now different health services providers have had differing numbering systems for administrative purposes associated with the delivery of care. This has enabled providers to identify patients and link patient information internally.
- 1.2 The delivery of health services¹ has changed dramatically over recent years. Patients, now sometimes referred to as clients or consumers, in many circumstances exercise a choice about from whom they seek health services. However, the delivery of health services is dependent (and always has been) on those providing care having access to relevant information to enable them to make the best decisions. As the New Zealand health sector moves towards integrated health care models the complexity of information flows may increase, but the basic idea remains the same, those delivering and funding health services require information on a need to know basis. Regardless of the model, the ultimate objective regarding the use and disclosure of health information remains the same, improving and optimising of the delivery of health services to individuals.
- 1.3 The review of the privacy issues and risks covered in this report includes consideration of:
- role of NZHIS;
 - privacy issues associated with the use of unique health identifiers;
 - background to the NHI database;
 - legislative framework;
 - current use of NHI number;
 - future use of NHI number;
 - frequently asked questions;
 - conclusions;
 - recommendations.
- 1.4 Ultimately it is for the providers, funders and the Ministry of Health to ascertain how they each intend to use the NHI number. Although illustrations are provided throughout this review, it is not intended that the review covers all existing and potential uses of the NHI number by agencies. Such issues are beyond the scope of this review. However, it is

¹ In this review the term health services includes the term disability services

hoped that this review will stimulate debate and discussion about the use of the NHI number and will consequently increase awareness of the privacy issues.

1.5 Conclusions

1.5.1 Conclusion 1: The policy framework set out in Health Information Strategy for the Year 2000 and the legislative framework discussed above, provide useful direction for agencies to safely manage identifiable health information. However, there is little evidence of the implementation of those frameworks. The management of health information seems to remain fragmented.

1.5.2 Conclusion 2: The Strategy identified that its success would depend on the willingness of individuals and organisations to subscribe to its general aims, and implement its specifics. To date this has not occurred on any large scale.

1.5.3 Conclusion 3: It is not sufficient to say that information must be provided with an NHI number attached say, for example, for statistical purposes or monitoring purposes. Those supplying the information, either individuals or health care providers, must be made aware of the purposes for which information about identifiable individuals is needed.

1.5.4 Conclusion 4: This review has raised concerns about the use of the NHI number to monitor the service agreements. The scope of the information suggested as being the basis for reporting statistical information by the HFA to the Ministry also raises cause for concern.

1.5.5 Conclusion 5: Overall, there seems to be a lack of clarity and understanding about the purposes for which agencies collect information with the NHI number attached and what they may be doing with that information. It is this sort of uncertainty which will hinder any co-ordinated and co-operative approach to the appropriate disclosure and use of information with NHI numbers attached. It will also impact on the accuracy of the information obtained by health agencies.

1.5.6 Conclusion 6: Administrative convenience must be balanced against potential privacy risks and health agencies need to find a balance at which point they can operate efficiently but not at the risk of unnecessary intrusion into individual privacy.

1.6 Recommendations (not in order of priority)

- 1.6.1 **Recommendation 1:** NZHIS should undertake a publicity campaign to improve individual awareness of the existence of the NHI, its purpose and the protections in place to prevent its misuse, including the unauthorised linkages of health information.
- 1.6.2 **Recommendation 2:** NZHIS needs to build trust in the NHI database and the NHIS by being open about their purposes. Increased trust will help to improve the quality of data supplied for the databases.
- 1.6.3 **Recommendation 3:** NZHIS should consider including in any agreement providing access to the NHIS a clause specifying the purposes for which the NHI number will be used by the health agency and what information will be linked by NHI number by that agency. The use of the NHI number will be limited to those purposes specified in the agreement.
- 1.6.4 **Recommendation 4:** NZHIS should consider the way the NHI database may be searched. It should consider whether it is necessary to enable those with access to the database to search on any field or whether searches should be restricted to searching on a name to get a number and not allowing searches on a number to obtain a name.
- 1.6.5 **Recommendation 5:** NZHIS should develop guidelines for health agencies which have access to the NHIS about the NHI and how it is used by NZHIS. Such guidelines should include the requirement that information obtained from different sources may only be linked by NHI number if that use is specified in the NHI access agreement.
- 1.6.6 **Recommendation 6:** The Ministry of Health should address the priority area identified in the Health Information Strategy for the Year 2000 relating to the *review and adjustment of core information requirements needed to enable the monitoring of purchase and service delivery policies and to meet local, regional and international reporting obligations.*
- 1.6.7 **Recommendation 7:** NZHIS and the HFA should do a stocktake of their current collection and collation of information where that information is sought with an NHI number attached.
- 1.6.8 **Recommendation 8:** Health agencies should develop information management policies to identify the purposes for which they obtain information with an NHI number attached. Such a policy should anticipate and document:

- legal justification/authority for obtaining information including whether the health agency's powers, duties and functions is consistent its use of the information;
- how the information is to be collected, including how individuals will be made aware of the purpose for the collection of the information;
- storage and security safeguards implemented by the health agency, including details of on-going staff training programmes;
- how long the information needs to be retained, with reference to any statutory requirements to retain information;
- procedures for ensuring information is accurate before it is used or disclosed;
- purposes for which the information may be used and disclosed, including how the agency will deal with requests for information made under the Official Information Act;
- mechanism for enabling individuals to access and request correction of their information;
- the identity and role of the privacy officer.

Policies should also identify:

- who may use the unique identifier;
- the purposes for which the unique identifier may be used;
- what information will be attached to the unique identifier;
- all information obtained from different sources which is linked by NHI number;
- controls preventing the unauthorised linkages of information by unique identifier.

1.6.9 Recommendation 9: NZHIS should set up a procedure to enable people to find out what their NHI number is and how they may access personal information held on the NHIS. A mechanism also needs to be set up for correcting information held on the NHIS.

1.6.10 Recommendation 10: The accuracy of the information on the NHI database needs to be improved.

1.6.11 Recommendation 11: A governance body, comprising of representatives from the Ministry, funder, providers and consumers should be set up to monitor the use of the NHI and in particular the linking of information by NHI number.

1.6.12 Recommendation 12: The funding agreement between the Minister of Health and the Health Funding Authority should be

reviewed with respect to the information flows to ensure they comply with the law.

- 1.6.13 Recommendation 13:** Statistical information about the delivery of primary health services needs to be improved. The statistics need to address the information requirements of the Ministry, HFA and providers.

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

2. Introduction

2.1 The review of National Health Index ("NHI") privacy considerations forms part of the NHI Review currently being undertaken by New Zealand Health Information Service. There are to be three other associated reports:

- NHI Data Quality Assessments;
- Update to the Greene Hanson Report;
- Stakeholder Perspectives.

2.2 The purpose of this part of the review is to consider the privacy risks associated with the existing and potential use of the NHI number as a unique national health identifier.

2.3 A critical question to answer is "What does privacy mean?". The term 'privacy' is often equated to 'secrecy', even though their meanings are quite distinct. Secrecy results from the intentional concealment or withholding of information.² In contrast, the *Oxford English Reference Dictionary* defines privacy as "*1 (a) state of being private and undisturbed. (b) a person's right to this. (2) freedom from intrusion or public attention. 3 avoidance of publicity*". However, privacy is gaining a new definition when considered in the context of information privacy. Information privacy is concerned about giving individuals the means to control information about themselves, and making agencies holding identifiable information about individuals accountable for the way in which such information is managed.

2.4 People 'trade' their personal information for goods and services every day. In a health context, people supply information to providers of health services in order to obtain care and treatment. Consequently, the term privacy in this review, and the legislation discussed within the review, is concerned with fair management of health information about identifiable individuals, it is not just about security and confidentiality. The theme throughout this review is that individuals should be aware of the purposes for which their health information is obtained. This requires openness on the part of any provider, funder or the Ministry about the purposes for which they require health information about identifiable individuals to be supplied. Thus secrecy is not the objective of protection of privacy but one facet of fair information management.

2.5 The existence of a unique identifier is not in itself a risk to information privacy, for instance, a unique identifier may be used by a health agency as an administrative tool in its delivery of health services.³ In addition, a common unique identifier may be used to aid the communication of information between different providers of health services, funding

² *Health Information Privacy, Confidentiality and Medical Ethics* Address by the Privacy Commissioner at the Wellington School of Medicine, February 9, 1994, Office of the Privacy Commissioner, Auckland.

³ The term health services is used to include health services and disability services.

agencies and the Ministry of Health. The use of a unique identifier aids the identification and authentication of individuals and enables information about an identifiable individual to be more easily linked to that person.

- 2.6 In this review, the term information is used to mean health information about identifiable individuals. Information that does not contain a name but does contain a unique identifier is still information about an identifiable individual. Any person who has the key to link the number to an individual will be able to identify the individual. Only information with an encrypted unique identifier (and no other identifiable features) may be considered anonymous. This is providing the agency holding the information does not have the key to decrypt the information.⁴
- 2.7 There is some ill-ease amongst health care providers about the use of the NHI number.⁵ Concerns were articulated in the report commissioned by the Privacy Commissioner, released April 1998, including privacy issues associated with the increased use of the NHI number.⁶
- 2.8 Much of this concern arises out of uncertainties about the use of the NHI number rather than the existence of the number. The current trend in the health sector is a move towards health care providers supplying information with an NHI number attached. However, no-one seems entirely sure about how different health agencies are using information identified by an NHI number. Furthermore, there is a lack of understanding about what, if any, information is being linked using the NHI number.
- 2.9 Failure to address the privacy concerns associated with the use of the NHI number may reflect on its credibility as a unique identifier. Health agencies unsatisfied about its use may be more inclined to provide inaccurate or incorrect information, at best compromising and at worst sabotaging the integrity of the NHI number. Conversely, the proper use of a unique identifier will facilitate delivery of health services by ensuring providers, funders and the Ministry have appropriate health information for each to be able to perform its functions.

3. Role of NZHIS

⁴ Encryption is a way of converting information about identifiable individuals into a code, enabling an end-user to access information without being able to identify individuals. The aim of encrypting information is to prevent unauthorised or unnecessary access to information about identifiable individuals. However, the information may be made identifiable again by running a programme to unencrypt the information. Only information which has no identifiers, encrypted or otherwise is truly unidentifiable. The advantage of encrypting information rather than removing all identifiers is that information may be added to a record in the future, enabling trends to be analysed.

⁵ New Zealand Doctor 2 September 1998 *Big berg threatens NHI maiden.*

⁶ *Medical Records databases: Just what you need?* Report prepared for the Privacy Commissioner by Robert Stevens, paragraph 11.

- 3.1 New Zealand Health Information Service ("NZHIS") is a group within the Ministry of Health responsible for the collection and dissemination of health related information in statistical form.
- 3.2 Its foundation goal is to make accurate information readily available and accessible, in a timely manner, throughout the health sector.
- 3.3 As administrator of the NHI database together with the other National Health Information Systems ("NHIS"),⁷ NZHIS has the responsibility for maintaining the NHI database and authorising health agencies entitled to assign the NHI number to access the NHI database.⁸
- 3.4 NZHIS uses the NHI number as an administrative tool. The use of the number facilitates the addition of information provided by public sector hospitals to the NHIS for statistical purposes. The efficacy of the NHI and the NHIS is reliant on the co-operation of those providing the information. In some circumstances, the flow of information to NZHIS for addition to the NHIS is facilitated through the Health Funding Authority ("HFA")⁹ provider service agreements.
- 3.5 For NZHIS to successfully operate the NHI database and NHIS, it needs to ensure information quality and accuracy. This requires building trusting relationships with health agencies providing and using information on the NHI and the NHIS.

4. Unique health identifiers from a privacy perspective

- 4.1 Unique identifiers provide individual authentication and identification.
- 4.2 Currently, the most common form of unique identifier is a code, made up of a series of numbers or combination of numbers and characters which, unlike a name, identifies only one person. For the purpose of convenience the unique identifier will be referred to as a number (even though it contains characters). It is desirable that this number be random or sequential, but should not contain any embedded logic which may enable the number to identify an individual. Examples of unique identifiers include tax file numbers, client account number, bank account numbers, mobile telephone numbers.¹⁰
- 4.3 However, a number on its own is meaningless and therefore must be combined with common information obtained from all individuals assigned a number. For instance, a tax file number is associated with a name and address. Accuracy of this information is essential. In addition, any unique identifier system must have safeguards to ensure that:

⁷ National Health Index (NHI), Medical Warning System (MWS), National Minimum Dataset (NMDS).

⁸ Paragraph 5.7.

⁹ Paragraph 8.2.

¹⁰ A telephone number may be considered a unique identifier if associated with one person only.

- the same number is not assigned to another person; and
- each individual has only one number.

4.4 Another way of assigning a unique health identifier is to use biometric technology.

4.5 Biometric technology measures a unique physical trait, such as the ridges of the fingerprint or the retina of the eye. A biometric scan creates and stores a digitised description of this feature. A computer programme converts the scanned image into a unique identification number for the individual.¹¹ This information could be stored on a smart card. Discussion of this type of identification is outside the scope of this review, but such a system also raises significant privacy issues.

4.6 Privacy concerns about the use of unique identifiers have been articulated by the Privacy Commissioner in his review of the Privacy Act 1993.¹² Principle 12 of the Privacy Act and rule 12 of the Health Information Privacy Code restrict the way in which unique identifiers may be assigned and used. This is discussed in more detail below. However, the rationale behind those protections found in principle/rule 12 is useful to consider at this stage:

- *Principle 12 is in response to concerns about the accuracy and use of personal information where a unique identifier is assigned. In particular, the risk is that if one unique identifier is used for a wide variety of authentication and identification purposes in both the public and private sectors this would amount to a universal identifier. De facto universal identifiers have been viewed as unsatisfactory because they are unreliable and a threat to privacy.*
- *Because a de facto universal identifier is not designed to be a true universal identifier it can be technically unreliable and vulnerable to falsification or error.*
- *Any unique identifier that facilitates the exchange and matching of personal information held by different agencies and within different record systems is perceived to be a threat to privacy. This may also lead to the socially undesirable practice of compiling composite profiles of individuals which may lead to any and every aspect of their lives being open to potential scrutiny by governments or private enterprise.*
- *The fear is that a de facto universal identifier emerging could ease the way towards the requirement of a national identity card or document. This brings with it a variety of concerns about inaccuracies and such like and the constraint on liberties. For some the idea of a national identity card is equated with the mechanisms of a Police State where*

¹¹ Unique Identifiers for the Health Care Industry Technical Advisory Group White Paper, October 1993, <http://www.wedi.org/htdocs/resource/report/file17.htm>

¹² *Necessary and Desirable - Privacy Act 1993 Review* Report of the Privacy Commissioner on the First Periodic Review of the Operation of the Privacy Act, Office of the Privacy Commissioner, November 1998, 88. In this part of the review the Privacy Commissioner draws on *Privacy Law and Practice* Dr Paul Roth, Butterworths, 1006.65.

*identification can only be authenticated and entitlements made upon presentation of the card. Loss, lack or confiscation of such a card makes the individual a "non-person".*¹³

4.7 Despite the privacy risks, a national unique health identifier has administrative, clinical and personal benefits justifying controlled use:

- information may be communicated without attaching a name;
- simplification of administrative tasks;
- standardisation of unique identification numbers within the health sector;
- facilitation of the collection of information for national statistical purposes;
- easier detection of fraud;
- improved accuracy of information;
- easier transfer of information;
- improved linkages of information.

4.8 Relying solely on a name for identification may cause difficulties:

- some people have several names or different way of spelling their name;
- some people have the same name as others.

4.9 A unique identifier can help an agency identify an individual and consequently reduce the risk of one person's information being included on the wrong record. Obviously, these authentication and identification benefits are dependent on using the correct unique identifier and accurate data entry is essential.

4.10 There are already many unique health identifiers in existence administered by health agencies for internal use. On admission, say, a public hospital assigns a unique identifier to an individual. The hospital uses this number in the delivery of services to that person. However, when communicating information to another health agency, the use of the hospital assigned number will not help the identification of that individual. Using a national unique health identifier when communicating health information to third parties facilitates the identification of an individual, ensuring that the correct information is associated with the right person.

4.11 From a privacy perspective, an effective unique health identification system must balance the administrative, clinical and personal benefits with a policy specifying:

- who may use the unique identifier;
- the purposes for which the unique identifier may be used;

¹³ Ibid.

- controls preventing the unauthorised linkages of information by unique identifier.

4.12 Unless restrictions are placed on who may assign a unique identifier, there is a risk that it may become a de facto national identifier across many sectors. This has been the case in the in the United States where the use of the Social Security Number as a unique identifier has enabled wide scale linking of personal information. Widespread access to unique identifiers, even without a name attached, may offer little or no privacy if many people are able to link a number to an identity.

4.13 It is not sufficient for an agency administering or using the unique identifier to develop internal controls and protections only, it must also convey to individuals who are assigned unique identifiers the existence of the unique identifier and its proposed uses. Agencies must be open about what information is attached to the unique identifier and who will receive any such information.

5. Background to the NHI database - perceptions and realities

5.1 The NHI was established in 1978. It provides a mechanism for uniquely identifying health care users. Initially, the NHI only identified health care users receiving hospital treatment. The NHI number is the identifier used when adding information to the NHIS such as the Medical Warning System and the National Minimum Dataset.¹⁴

5.2 The Health Information Privacy Code places restrictions on which agencies may assign the NHI number and protects individuals against the wider use of the NHI number by non-health sector agencies. However, the use of the NHI number within the health sector has gradually extended and now has become a de facto mechanism used to identify every individual who accesses the health care system and receives health and disability services.

5.3 The terms of reference for the NHI review states:¹⁵

The main benefit of the NHI number is to improve health care for New Zealanders by:

- *Linking laboratory results, GP records and hospital records to avoid loss or duplication.*
- *Improving best practice through tracing both primary and secondary health care for each New Zealander.*
- *Assisting health outcome research that will be used to improve quality of care.*

¹⁴ Paragraph 13.1.

¹⁵ Terms of reference for National Health Index Review, Prepared by Peter Aagaard, February 1998, revised October 1998.

- *Protection of individual privacy by eliminating the need for personal details such as name and address on health documents. The NHI number is encrypted on the National Minimum Data Set to ensure health events can not be traced back to identifiable individuals.*

5.4 The NHI database provides the link between NHI numbers and individual identities. The NHI number is a seven character string in the format of ABC1234. This number is assigned randomly. No part of it has any meaning or significance. Since 1991 hospitals have been required to assign and report NHI numbers to babies born under their care. Many hospitals did not however fully comply with this requirement until well into 1992. Lead carers have been required to assign and report NHI numbers for babies born under their care since 1995. It should be noted that babies born at home where there is no midwife attending would not be assigned NHI numbers.

5.5 Only agencies specified in the Health Information Privacy Code 1994 may assign an NHI number to an individual. These include:

- any agency authorised expressly by statute or regulation;
- any agency or class of agencies listed in Schedule 3 of the Code:
 - ⇒ Ministry of Health;
 - ⇒ Licensed hospitals;
 - ⇒ Registered Medical Practitioners;
 - ⇒ Royal NZ Plunket Society;
 - ⇒ Blood Transfusion Service;
 - ⇒ Accident Rehabilitation and Compensation Insurance Corporation;
 - ⇒ Registered Midwives;
 - ⇒ Health Benefits Limited;
 - ⇒ Health Funding Authority;
 - ⇒ Registered physiotherapists.

5.6 Previously, the Director General of Health could approve assignment of the NHI number by an agency or registered medical health professional. The Privacy Commissioner was notified of any such assignment. Following a recent amendment to the Health Information Privacy Code, the Director General of Health may no longer approve such assignment. Now, any agency wishing to assign the NHI number, and which is not covered by the Code, would need to seek an amendment to Schedule 3.

5.7 Before an eligible agency may access the NHI database, it must enter an access agreement, specifying terms and conditions, with NZHIS. The agreement does not contain any provision specifying or restricting how an agency may use the NHI number. It only refers to the agency's obligations

under the Health Act, the Cancer Registry Act, the Privacy Act and Health Information Privacy Code.

5.8 Approximately 90% of New Zealanders have an NHI number. Currently, there are approximately 5.5 million NHI registrations.¹⁶ This includes approximately 0.5 million deceased persons and 0.5 million identified duplicate entries. These registrations also include foreign visitors, pre-1979 deaths and records identified by “baby of”. NZHIS currently estimates that there are between 3-5% of unidentified duplicates. NZHIS also acknowledges that there will always be a percentage of unidentified duplicate records on the NHI database.

5.9 The NHI database contains the following fields:

- family name;
- first given name;
- second given name;
- third given name;
- preferred given name;
- date of birth;
- date of death;
- residential address, street, suburb, city/town, country;
- domicile code;
- sex;
- ethnicity;
- residence status

There is provision for the NHI database to hold a person's aliases.

5.10 In some circumstances the NHI may protect health information, particularly information held on computer systems. Using the NHI enables easily recognisable identifying details such as name and address to be removed before transferring health information to other health agencies.

5.11 The extension of the use of the NHI beyond the hospitals to a wider range of health agencies enables more people access to the NHI database. Consequently, linking an NHI number to an individual becomes easier, reducing some of the privacy protections.¹⁷

5.12 Although some individuals hold religious concerns about the process of numbering individuals,¹⁸ public concerns and perceptions about the NHI number relate not so much to the existence of the NHI and the information

¹⁶ Terms of reference for National Health Index Review, Prepared by Peter Aagaard, February 1998, revised October 1998.

¹⁷ *Medical Records databases: Just what you need?* Report prepared for the Privacy Commissioner by Robert Stevens, paragraph 4.7.

¹⁸ *Necessary and Desirable - Privacy Act 1993 Review* Report of the Privacy Commissioner on the First Periodic Review of the Operation of the Privacy Act, Office of the Privacy Commissioner, November 1998, 89.

contained on the database, but to the way in which health agencies may use the NHI number to link information about identifiable individuals.¹⁹

- 5.13** These perceptions are important as they affect the quality of the data on the NHI database. For example, the report commissioned by the Privacy Commissioner provides anecdotal evidence that some doctors used a different name for transactions involving their own health care.²⁰ This was due to the lack of trust in the security of records held by hospitals, laboratories and other health care agencies. Such perceptions put at risk the integrity and accuracy of the information contained on the NHI database.
- 5.14** Provider concerns also relate to the integration of health information. A New Zealand Doctor article reports a survey which indicates that there is a general lack of awareness about practitioners' responsibilities regarding how they use the NHI number.²¹ New Zealand Doctor reports that *doctors say the need for open and public debate on the purpose and use of the NHI number is not only warranted but urgent.*
- 5.15** Supplying information to the HFA with the NHI number attached enables the HFA to compile a record about the health services provided to one particular identifiable individual. By linking information received from different providers, say, a pharmacy, diagnostic laboratory and a GP, the HFA or, any other organisation in receipt of this information, could build a comprehensive health profile about an identifiable individual.
- 5.16** If it is the intention of any health agency to build this sort of profile about individuals, it is essential that individuals are made aware of such an intention. If it is not the intention of the health agency to build such a profile, even though it may be capable of doing so, this should also be conveyed to those supplying the information.
- 5.17** Health agencies collecting information have an obligation to ensure that individuals are aware of the purposes of that collection, including to whom that information may be disclosed and for what purposes. Consequently, a health agency collecting information for the purpose of disclosure to a third party agency needs to be aware of the purposes for which the other health agency requires the information.
- 5.18** In summary, the concerns about the NHI number relate to the use of the NHI for unknown purposes rather than the actual existence of a national unique health identifier. These concerns suggest that health agencies need to be far more open about their use of the NHI number. Before any health agency requests information with an NHI number attached, it needs to take a step back and clearly determine the purposes for collecting that

¹⁹ For example, New Zealand Doctor, 11 November 1998, Editorial "Going to the highest bidder".

²⁰ *Medical Records databases: Just what you need?* Report prepared for the Privacy Commissioner by Robert Stevens, paragraph 10.4.

²¹ 11 November 1998.

information. It must also have specified whether that information will be linked to other information obtained from different sources.

6. Legislative framework

6.1 There are no enactments that require individuals to have an NHI number. The only references to the NHI number are found in the:

- Cancer Registry Regulations 1994 regulation 4 which requires the reporting of cancer to the Director-General to include either the person's NHI identifier or their full name, maiden name (if any) and any known aliases;
- Health Information Privacy Code 1994 rule 12 which concerns the assignment of unique identifiers and in particular which agencies may assign the NHI number.

6.2 In order to understand the privacy risks associated with the use of the NHI it is important to consider the statutory framework controlling the use of unique identifiers and the circumstances concerning the use and disclosure of information.

6.3 Where no specific statutory provision applies, the health agency's information management policy determines information flows. The Health Information Privacy Code 1994 ("HIPC") provides the framework for developing such a policy.

7. Health Act 1956

7.1 Section 22C relates to the disclosure of identifiable health information by specified persons for specific purposes. Under this section, health agencies, providing health services and funding such services, have a discretion when deciding whether to provide the requested information.

7.2 Section 22C(2)(g) enables NZHIS to collect information from health agencies. It provides that NZHIS, as part of the Ministry of Health, may collect information from any health agency, including providers and funders of health services, for the purposes of:

- administering the Health Act or the Hospitals Act 1957, or
- compiling statistics for health purposes.

7.3 NZHIS obtains information for compiling the NHI database and other databases which are part of the NHIS under section 22C(2)(g). Information provided to NZHIS for the NHIS would be identifiable, often by NHI number.

- 7.4 Another provision of section 22C applies to requests for information by a funding agency. Section 22C(2)(j) enables a health agency to provide any employee of a funder with information which is *essential* for the purposes of exercising or performing any of the funder's powers, duties, or functions under the Health and Disability Services Act 1993.
- 7.5 Consequently, before a funder may request information, it must first be clear about its powers duties and functions,²² and then consider whether the request for information about identifiable individuals is essential for it to exercise or perform any of those powers, duties, or functions.
- 7.6 The legislation does not define the term *essential*. Consequently, it is necessary to look at a dictionary definition. The Oxford English Reference Dictionary (1996) defines essential as meaning "(1) *absolutely necessary; indispensable. (2) fundamental, basic. (3) of or constituting the essence of a person or thing.*" The dictionary defines essence as "(1) *the indispensable quality of element identifying a thing or determining its character; fundamental nature or inherent characteristics.*"
- 7.7 These definitions indicate that a funder would only be able to request information about identifiable individuals from a health agency if it could show that without that information the funder would not be able to exercise or perform any of its powers, duties, or functions.
- 7.8 If the HFA had a service agreement which related to tonsillectomy operations and the HFA requested the NHI numbers of those having such operations, before supplying the information the provider would need to know the purpose of collecting the information and be satisfied that it was essential for the HFA to know the identity of people having tonsillectomies. The obligation would be on the HFA to show that this was the case. There is also an onus on the provider to ask these questions to satisfy itself that it is legally entitled to disclose the information.
- 7.9 There will always be tension between what a funding agency considers essential information requirements and what information providers are prepared to supply.
- 7.10 It follows that if the disclosure of information to a funder forms part of the terms and conditions of a service agreement, the funder needs to make the provider aware of the purposes for which it is being obtained and be satisfied that without the information the funder would not be able to exercise or perform any of its powers, duties, or functions.
- 7.11 The provider also needs to be aware of the purposes for which the funder is requesting the information in order to exercise its discretion and also to

²² Health and Disability Services Act 1993, see paragraph 8, Appendix 1.

ensure that individuals are aware of the purposes for which the information is being collected, to whom it may be disclosed and for what purposes.²³

- 7.12** A provider might decide (in its discretion) that certain types of information are essential for the purposes of carrying out a funder's duties. It could have a policy providing all such information and could contract to do so. In other words the discretion is being exercised, but not on a case-by case basis. However, the provider should not agree to provide the information without any thought being given to the discretion to provide the requested information to the funder.
- 7.13** Health information held by NZHIS is not subject to requests made under section 22C because NZHIS is not an agency providing health or disability services. Nor is it a funding agency. The provisions of section 22C, therefore, do not apply to any requests made to NZHIS for information about identifiable individuals (including information with the NHI number attached). Such a request would have to be considered under the Official Information Act 1982.
- 7.14** However, NZHIS could possibly act as the agent of the HFA and collect information on its behalf. If this were the case, NZHIS, as agent of the HFA, would be collecting the information under section 22C(2)(j) rather than section 22C(2)(g). Consequently, information could be collected if it was essential to the HFA for the purpose of carrying out its powers, duties, or functions. The obligation would lie with the HFA to convince the provider that supplying the information was essential.
- 7.15** Likewise, where the HFA makes provision in the service agreement for the supply of information by providers to NZHIS for addition to the NHIS, the HFA appears to be acting as an agent for the NZHIS (Ministry of Health) and the request would be considered under section 22C(2)(g).
- 7.16** Section 22D enables the Minister of Health to require any funder or hospital and health service to provide specified returns or other information concerning the condition or treatment of, or the health and disability services provided to, any individual in order to obtain statistics for:
- health purposes; or
 - the purposes of advancing:
 - ⇒ health knowledge;
 - ⇒ health education; or
 - ⇒ health research;
- 7.17** No information that would enable the identification of individuals must be provided unless the individual has consented to the provision of the

²³ Both of these issues are developed below under the consideration the Health Information Privacy Code 1994 below.

information or the identifying information is essential for the purpose for which the information is sought.

- 7.18** Section 22F provides that every person who holds health information of any kind shall, at the request of the person that is providing or is to provide health care services to an individual, disclose the information. This is an important provision as it provides statutory authority for the disclosure of information between health care providers. Information disclosed is limited to the extent necessary for delivering the care.
- 7.19** There are limited grounds for refusing to provide the requested information. The most significant for this review is where the holder of the information has reasonable grounds to believe that the individual does not want their information disclosed. However, even though that may be the case the person holding the information may still comply with the request. In other words, the holder of the information has a discretion when deciding whether to refuse to provide the information.
- 7.20** Section 22G specifically enables the HFA to inspect the records of providers who have made a claim for payment relating to services provided. The meaning of "records" was considered by the Court of Appeal.²⁴ The Court held that records include health information.
- 7.21** Section 22G enables the HFA to verify a claim for payment. It also gives the HFA extensive powers enabling it to investigate providers where there may be a suspicion of fraudulent claims.
- 7.22** Under section 22G, individuals do not have the right to veto the inspection of their health information. However, they should be made aware of the possibility that inspection may take place.
- 7.23** Section 22H provides that any person may supply to any other person health information that does not enable the identification of the individual to whom the information relates.
- 7.24** Overall, this part of the Health Act makes a distinction between the information requirements of different health agencies. Only providers of health services and the Minister of Health are given the right to request information and for that information to be supplied. In other cases the health agency holding the information has a discretion when deciding whether to disclose the information.

8. Health and Disability Services Act 1993

- 8.1** In 1993, the Health and Disability Services Act reformed the public funding and provision of health and disability services in order to:

²⁴ *Hobson v Harding* CA 50-95, 12 December 1996.

- (a) *Secure for the people of New Zealand—*
- (i) *The best health; and*
 - (ii) *The best care or support for those in need of those services; and*
 - (iii) *The greatest independence for people with disabilities— that is reasonably achievable within the amount of funding provided; and*
- (aa) *Improve, promote, and protect public health; and*
- (b) *Facilitate access to personal health services and to disability services; and*
- (c) *Achieve appropriate standards of health services and disability services.*

8.2 The Act establishes:

- The National Advisory Committee of Health and Disability (also known as the National Health Committee "NHC") to advise the Minister of Health on priorities for public funding of public and personal health and disability services;
- The Health Funding Authority, an amalgamation of the original four regional health authorities, having the responsibility for purchasing public and personal health and disability services;
- Hospital and health services ("HHS"), formally known as Crown Health Enterprises ("CHEs") with the responsibility for providing a range of health and disability services.

8.3 The Act sets out the objectives of the Crown, HFA and HHS.²⁵ It is relevant when considering the disclosure of information to note that a hospital and health service must uphold the ethical and quality standards generally expected of providers of health services and/or disability services. A funder may only fund services provided by persons who maintain standards (including ethical standards) that the funder considers appropriate for those services.²⁶

8.4 Agreements control the relationships between the Crown and the HFA and the HHS and other providers of health and disability services:

8.4.1 Under the funding agreement (also referred to as the Evergreen agreement) the Crown agrees to provide money to a funder in return for the funder funding, or arranging the funding of, health or disability services, for the people specified in the agreement;²⁷

²⁵ Health and Disability Services Act 1993, sections 8, 10 and 11 are set out in full in Appendix 1.

²⁶ Ibid. section 19.

²⁷ Ibid. section 21.

8.4.2 Under the service agreement a funder agrees to provide money to a person in return for the person providing, or arranging provision of health and/or disability services. These agreements may include terms and conditions. The funder is also able to monitor the performance of each service agreement.

8.5 Section 33 of the Act gives the HFA specific functions:

- (a) *To monitor the need for public health services, personal health services, and disability services of the people of New Zealand:*
- (b) *To fund public health services, personal health services, and disability services, for the people of New Zealand, by means of service agreements or otherwise:*
- (c) *To monitor the performance of service agreements and other arrangements by persons with whom it has entered into such agreements or arrangements:*
- (d) *Any other functions it is for the time being—*
 - (i) *Given by or under any enactment, or*
 - (ii) *Authorised to perform by the Minister, by written notice to the Authority after consultation with it.*

8.6 Under section 51 of the Act, the HFA may give notice of the terms and conditions on which it will make payment to any person. Following the notice, acceptance of payment constitutes acceptance of the terms and conditions. The HFA may enforce compliance with the terms and conditions as if the person had signed a deed under which the person agreed to the terms and conditions.

8.7 *Hobson v Harding* considers the relationship between section 51 and section 22G of the Health Act. In that case the Court stated that "*even if there were some contradiction between the notice under section 51 and the power conferred by section 22G [of the Health Act], the statutory provision must, of course, prevail.*"²⁸ As the Health and Disability Services Act does not specify information requirements, guidance for the content of the terms and conditions relating to the provision of information must be consistent with the requirement specified in the Health Act.

8.8 Presumably, the same applies to the relationship between conditions requiring information to be supplied under section 51 (or as part of a service agreement) and section 22C of the Health Act which provides a discretion to disclose requested information.

8.9 Unilaterally imposing terms requiring the provider to supply information under section 51 is not consistent with the provider exercising its discretion under section 22C. Before requiring information to be provided either under a service agreement or under section 51, the provider must be given the opportunity to exercise its discretion in deciding whether to supply the information.

²⁸ *Hobson v Harding* CA 50-95, 12 December 1996, page 14.

8.10 Section 129 provides protection of persons acting under authority of Act. A person disclosing information under the above provisions is protected against civil and criminal actions unless that person has acted in bad faith or without reasonable care.

9. Privacy Act 1993

9.1 The Privacy Act came into force on 1 July 1993. It aims to protect personal information about identifiable individuals in accordance with international guidelines. Underlying the Act is the idea that individuals should be able to exercise some control over the management of their personal information by others. This requires agencies holding personal information to be open about their information management policies.

9.2 In particular, the Act:

9.2.1 Establishes information privacy principles which:

- control the collection, storage and security, retention, use and disclosure of personal information by public and private sector agencies;
- provide the right for an individual to access her or his personal information held by public and private sector agencies and the right to request to have that information corrected;
- control the management of unique identifiers.

9.2.2 Enables the appointment of a Privacy Commissioner to:

- investigate complaints about interference with individual privacy;
- carry out other functions including:
 - ⇒ education and publicity;
 - ⇒ auditing personal information maintained by an agency;
 - ⇒ monitoring compliance with public register privacy principles;
 - ⇒ reporting to the Prime Minister;
 - ⇒ advising a Minister or any agency on any matter relevant to the operation of the Act.

9.3 At the heart of the Act are 12 information privacy principles. These principles promote and protect an individual's personal information. Nearly everything else in the Act flows from them. Rather than providing a set of prescriptive rules, the principles provide a framework for agencies to develop their own personal information management policy taking into account the particular nature of their industry.

- 9.4 The principles encompass the collection, storage and security, accuracy, retention, use and disclosure, and access and correction of personal information and the use of unique identifiers.
- 9.5 Section 7 of the Privacy Act is a savings provision. In summary, it provides that if another enactment authorises or requires personal information to be made available or authorises or requires an action that would otherwise be a breach of one of the information privacy principles, then the provision of the other enactment applies rather than the provisions of the information privacy principles.

10. Health Information Privacy Code 1994

- 10.1 Under the Privacy Act the Privacy Commissioner may issue a code of practice which modifies the application of one or more of the information privacy principles. Such a code takes into account the particular nature of the information involved.
- 10.2 Within a month of the Privacy Act coming into force the Privacy Commissioner issued the Health Information Privacy Code 1993 (Temporary). A permanent Health Information Privacy Code, issued in June 1994, replaced the temporary Code.
- 10.3 The Health Information Privacy Code 1994 ("HIPC") modified all of the information privacy principles taking into account the sensitive nature of health information.²⁹
- 10.4 The HIPC works in conjunction with the Privacy Act so that where there is no specific provision within the HIPC, the relevant provision of the Privacy Act applies. The HIPC is applicable to the way in which health agencies manage health information about identifiable individuals.
- 10.5 The Ministry of Health, including NZHIS, funders and providers of health and disability services and health agencies are subject to the provisions of the HIPC.
- 10.6 The HIPC applies to information about a person's health and/or disabilities, services which have been or are to be provided, and information incidental to the provision of health and/or disability services. The definition of health information includes administrative details.
- 10.7 The principles in the HIPC are referred to as Health Information Privacy Rules ("rules"). The numbering of the rules follows the numbering of the information privacy principles.³⁰

²⁹ There have been three amendments to the Health Information Privacy Code 1994, the most recent in September 1998.
³⁰ Health Information Privacy Rules are set out in the Appendix 1.

- Rule 1: Purpose of collection of health information
- Rule 2: Source of health information
- Rule 3: Collection of health information from individual
- Rule 4: Manner of collection of health information
- Rule 5: Storage and security of health information
- Rule 6: Access to personal health information
- Rule 7: Correction of health information
- Rule 8: Accuracy, etc, of health information to be checked before use
- Rule 9: Retention of health information
- Rule 10: Limits on use of health information
- Rule 11: Limits on disclosure of health information
- Rule 12: Unique identifiers

10.8 The rules of the HIPC should not be considered in isolation. The HIPC works as a whole so that while an issue may appear to fall within the disclosure rule (rule 11) it has to be considered in the context of the collection rules (rules 1-4) to ascertain the purpose for which information was collected and whether the individual was made aware of that purpose.

10.9 For instance, under rule 3 the health agency collecting information directly from the individual, must take reasonable steps to ensure that the individual is aware of:

- the fact information is being collected;
- the purpose for which it is being collected;
- the intended recipients of the information;
- name and address of the health agency collecting the information and the agency that will hold the information;
- whether the supply of information is mandatory;
- consequences of not supplying the information;
- rights to access and correction of health information

10.10 While immediate liability might fall with a provider for breach of rule 3, responsibility also lies with the ultimate receiver of the information to ensure that the provider is able to fulfil its obligation to ensure the individual is aware of the purposes of disclosing information.

10.11 Before disclosing information about an identifiable individual a provider needs to be satisfied that the individual was made aware that the information collected could be disclosed for the proposed purpose.

10.12 Alternatively, if the disclosure was not contemplated at the time the information was collected, before the provider decides to disclose any information it must be satisfied that:

- it is not desirable or practicable to obtain the individual's authorisation:
and
 - one of the exceptions to rule 11 applies.
- 10.13** In such cases the information disclosed should be limited to that necessary to achieve the purposes of disclosure, and the information should only be disclosed to a person who is in a position to affect that purpose.
- 10.14** There are several exceptions to rule 11 which may be relevant regarding the disclosure of information with an NHI number attached. For example:
- 10.14.1** Rule 11(2)(c)(ii) enables the use of information for statistical purposes where it will not be published in a form that could reasonably be expected to identify the individual concerned:
- 10.14.2** Rule 11(2)(i)(i) enables disclosure of information to avoid prejudice to the maintenance of the law by any public sector agency, including the prevention, detection, investigation, prosecution and punishment of offences.
- 10.15** Rule 11 provides a discretion for the health agency to disclose information in certain circumstances. In other words, even if one of the exceptions applies, the provider may still exercise its discretion not to disclose the information.
- 10.16** Once an agency holds information it must ensure that the information is protected, by such storage and security safeguards (rule 5) as it is reasonable in the circumstances to take against:
- loss;
 - access, use, modification, or disclosure, except with the authority of the agency; and
 - other misuse.
- 10.17** The importance of staff training cannot be over-emphasised as an integral part of storage and security safeguards. Other considerations include:³¹
- physical security;
 - operational security;
 - technical security;
 - security of transmission;
 - disposal or destruction of health information.
- 10.18** Health agencies must not use information without taking such steps as are reasonable in the circumstances to ensure that the information is accurate, up to date, complete, relevant and not misleading (rule 8). Accuracy of

³¹ Health Information Privacy Code 1994, commentary to Rule 5, page 16.

information may be prejudiced by the wrong entry of the NHI number. In addition, mechanisms must be implemented to enable records to be updated to ensure accuracy.

- 10.19** Rule 12 relates to the assignment of unique identifiers. A health agency must not assign a unique identifier unless it is necessary for the health agency to carry out one or more of its functions more efficiently. The rule also prevents the assignment of a unique identifier that another agency has assigned. However, rule 12 contains an exception with respect to assignment of the NHI number and enables specified agencies to assign the NHI number.
- 10.20** There is no definition of the term assign in the HIPC or the Privacy Act. Therefore, it is useful to refer to the dictionary definition for its meaning. The Oxford English Reference Dictionary (1996) defines assign as *(1)(a) allot as a share or responsibility. (2) fix (a time, place, etc.) for a specific purpose.*
- 10.21** Before assigning a unique identifier the health agency must have taken all reasonable steps to ensure that the identity of the individual is clearly established.
- 10.22** If a health agency wishes to assign the NHI number, and the agency is not specified in the schedule, an amendment to the HIPC by the Privacy Commissioner would be required.
- 10.23** There is a distinction between assigning a unique identifier and using one. For example, if a provider uses the NHI number on a requisition order for carpentry services from another agency, and that other agency does not use the number for the purposes of identifying an individual, then it is not a unique identifier in relation to that agency and not assigned.³²
- 10.24** In some cases batches of numbers may be provided by the administrator of a unique identifier database to other agencies. In such cases, assignment of numbers does not occur until actually allocated to an identifiable individual by the second agency.
- 10.25** A health agency cannot require an individual to disclose any unique identifier unless it is for one of the purposes, or directly related to those purposes, in connection with which the unique identifier was assigned. Currently, few people are aware of their NHI number. However, this is likely to change with the increased use of the number, at which time this provision of rule 12 will become more relevant.

³² "Information privacy principle 12 and the Superannuation Schemes Unique Identifier Code 1995" Notes for an address to the IIR 5th Annual Super Fund and Funds Management Conference, Auckland, 27 November 1995 Blair Stewart, Manger Codes and Legislation (now Assistant Commissioner).

10.26 Although the HIPC sets a framework for the management of personal health information, the Privacy Commissioner still has the power to vary the HIPC or issue a new code to cover a specific activity if he considers it necessary.

10.27 The savings provision of the Privacy Act (section 7) applies to the rules as it does to the information privacy principles. In other words, if another enactment contains provision about personal health information management then that provision will prevail over the HIPC. However, if there is a requirement to disclose information it will still be necessary, unless there is a contrary provision in the other enactment, to inform the individual of the information flow even though she or he may not be able to veto the action.

11. Health Information Strategy for the Year 2000

11.1 The Health Information Strategy for the Year 2000 was the culmination of work undertaken by a project team within the Ministry of Health. The report, published in 1996, created an action plan for the following five years with respect to the management of health information. One of the aims of the project, due to the fragmented nature of existing health information systems and the increasing use of technology, was to bring co-ordinated management of health information to the sector.

11.2 Any strategy needed to be applicable to all users of health information, big and small, public, private or voluntary including funders (now referred to as the Ministry), purchasers (now known as funders), providers, consumers, researchers and others. It recognised the use of personally identifying health and disability information needed to be administered within the context of strong protection of privacy and confidentiality. Leadership for the area of information management was to come from the Health Information Council.

11.3 The strategic vision proposed for information management in the year 2000 was:³³

Timely, accurate and robust information appropriate to their roles and needs will be available to all individuals and agencies involved in the provision of health and disability support services, and to consumers, with the knowledge, agreement and confidence of everyone, which will facilitate the ongoing, continuous improvement in the health and disability status of all New Zealand people.

11.4 The building blocks envisaged by the strategy include:³⁴

³³ Health Information Strategy for the Year 2000, page 6; also available <http://www.health.govt.nz/>
³⁴ Ibid. page 7.

- *use of appropriate standards, guidelines and measures creating a relatively stable information infrastructure;*
- *agreement on who can access what information, and under what conditions;*
- *involvement of health and disability professionals in the development and implementation of appropriate systems;*
- *health and disability information systems that are seen as enabling, and build trust and confidence.*

11.5 One of the priority areas to be addressed over the first twelve months of the implementation of the Strategy was the:³⁵

- *review and adjustment of core information requirements needed to enable the monitoring of purchase and service delivery policies and to meet local, regional and international reporting obligations.*

11.6 To date this review has not been performed.

11.7 The Ministry of Health's role was central to the implementation of the strategy and it was to take a leadership role regarding developments of the health information strategy. In particular it was to retain a significant role both directly and indirectly in identifying the range of information which should be nationally available to:

- *promote the development of health and disability support services options;*
- *contribute to international bench-marking of the performance of the sector.*³⁶

11.8 The information needs of consumers, providers and funders were sought and documented in an earlier report released in April 1997, *Gaps, Overlaps and Issues*.³⁷ Each group presented a different set of information needs. In parallel, working groups were established, providing input on the features of an information strategy.

11.9 Naturally, different groups had different information needs, however, issues identified and relevant to the use of the NHI included:

- *the need to establish a set of mechanisms and procedures designed to provide, at the national level, information required for policy development, planning, management and evaluation of health and disability support services, that is readily available to consumers, policy makers, purchasers and providers. (Education and Research Working Group);*

³⁵ Ibid. page 8.

³⁶ Ibid. page 8.

³⁷ <http://www.health.govt.nz/HIS2000/gaps/GOR-contents.html>

- *the importance of the concept of a national minimum dataset (including demographic information on the population as well as health status, resource and service utilisation, and outcomes). (Education and Research Working Group);*
- *the integration of information from a variety of sources (both routine and non-routine) in order to provide ready access to comprehensive information for consumers, providers, purchasers, and policy makers. (Education and Research Working Group);*
- *promote the wide use of the National Health Index (NHI) as a national resource, vital for the aggregation of information from various sources with the health and disability sector. (Education and Research Working Group);*
- *use of the NHI as the common unique identifier, and the use of the NHI instead of personally identifying information such as name and address when recording or exchanging health information. (Purchaser Working Group);*
- *inclusion of Community Service Card (CSC) information as part of the NHI. (Purchaser Working Group).*

11.10 In discussing the implementation of the vision, the report refers to a 'meta-system' providing the infrastructure for a health information network. One suggestion was for an interoperable framework referred to as an intranet which enables "*health care organisations to transcend the limitations and redundancies created by islands of information centred around function or geography the result being a more co-ordinated service to their patients.*"³⁸

11.11 In considering the design of such a meta system the report states:

*...the meta-system will link existing networks, and avoid the need to create central repositories of information attempting to service the needs of the entire sector. That is not to say that centralised systems and repositories may not be required for specific purposes for individual organisations or groups of organisations, but it does imply that these systems will also have specific roles and responsibilities and there should be no attempt to build a system which is all things to all people. All organisations would retain control of their own data and share it on a need to know basis to ensure patient care or where specific agreements apply. The "network of networks" approach and the resulting architecture enables information exchange only when warranted, authorised and agreed to.*³⁹

11.12 The Health Information Strategy for the Year 2000 report identifies that there will need to be agreement about access to records by different groups.

³⁸ Ibid. page 44.

³⁹ Ibid. page 53.

This agreement will need to be developed in the context of the HIPC. The report also acknowledges that there is a lack of agreement about access to records and a lack of clarity about the purposes for which information obtained in the context of providing health and disability services will be used. It states:⁴⁰

Explicit default agreement will be necessary in order to at least provide a starting point, and this will be vital to the development of a collaborative, integrated environment.

- 11.13** To date, agreement about access to records by different agencies does not seem to have been reached nor the purposes for such access properly identified. This lack of agreement and understanding is hindering a collaborative approach to the flow of information within the health sector. Consequently, the management of information remains fragmented.

12. Ethical standards

- 12.1** Ethics provide influences to the formulation of laws and the interpretation of those laws. Ethical standards governing the conduct between health professionals and their clients provide a guide to standards expected of a competent practitioner. Professional codes of ethics set out ethical standards. Professional bodies such as the Medical and Nursing Councils administer these codes through a disciplinary process.

- 12.2** Such codes of ethics concern the confidential nature of the relationship between health professional and client. For example, the New Zealand Medical Association's *Code of Ethics* states that all physicians must "*protect the patient's secrets even after his or her death.*" It explains the doctor must:

[K]eep in confidence information derived from the patient, or from a colleague regarding a patient and divulge it only with the permission of the patient except when the law required otherwise.

- 12.3** Principle Three of the *Code of Conduct for Nurses and Midwives*, issued by the Nursing Council of New Zealand, requires the nurse or midwife to respect the rights of patients/clients. In the criteria for this principle it states the nurse or midwife:

3.4 safeguards confidentiality and privacy of information obtained within the professional relationship.

Principle one, requires that the nurse or midwife "*complies with the legislated requirements*".

⁴⁰ Ibid. page 32.

- 12.4 The inter-relationship between ethics and the law is complicated. However, ethical standards provide an important means for interpreting legal discretions enabling disclosure of information. The lawful disclosure of information must have ethical justification.
- 12.5 Where enactments provide a discretion to disclose information, ethical standards provide guidance for the exercise of that discretion. Tension rises between any requester of information and providers of health services when ethical obligations indicate that the information should not be provided.

13. Current use of NHI

13.1 NZHIS

- 13.1.1 NZHIS uses the NHI number as a mechanism for creating and updating records on the Medical Warning System ("MWS") database and the National Minimum Dataset ("NMDS") database.
- 13.1.2 The MWS is closely aligned to the NHI. The MWS warns health care providers of the presence of any known risk factors that may be important in making clinical decisions about individual patient care.
- 13.1.3 The responsibility for maintaining the content of the MWS rests primarily with health care providers. Clinicians at hospitals provide updates to the MWS. General Practitioners ("GPs") GPs advise warnings to the Centre for Adverse Reactions Monitoring (CARM) located in the National Toxicology Group at Otago University Medical School in Dunedin. CARM enter these details on to the MWS for the GPs. If appropriate, CARM also raise the warnings advised to them to a 'danger' status.
- 13.1.4 Generally the use of the MWS to date has been poor and redevelopment is likely.
- 13.1.5 The MWS comprises of:
- *Medical warnings* - incorporating adverse medical reactions and significant medical conditions;
 - *Event summaries* - incorporating identification of the facility where a patient's medical record is located;
 - *Donor information* - incorporating donor summaries and details of the nominated contact provided by the health care user.

13.1.6 Information held on the MWS is identifiable through the NHI and subject to the provisions of the Health Information Privacy Code 1994.

13.1.7 The NMDS is a single integrated collection of secondary and tertiary health data developed in consultation with health sector representatives. The information is required at a national level for:

- policy formation;
- monitoring and evaluation of policy implementation;
- performance monitoring and evaluation;
- health status measurement;
- meeting international requirements.

13.1.8 Each record is identified with the health care user's NHI number in encrypted form. This ensures that health-event data provided to, and held on, the NMDS is anonymous. In approved cases only a special utility is run, which decrypts the NHI number and enables the information to be identifiable. In most cases, any organisation requiring access to information about identifiable individuals from the NMDS (typically for research purposes) requires the approval of an ethics committee.

13.1.9 The various types of data available from the NMDS includes:

- Inpatients and day-patients discharged from publicly funded hospitals;
- Inpatients and day-patients discharged from private hospitals;
- Events summaries;
- NZ Cancer Registry;
- Mental health data;
- Mortality data (cause of death).

13.1.10 Provided the information is not about an identifiable individual it will not be subject to the Health Information Privacy Code.

13.1.11 However, summary health event information is 'passed through' to the MWS where there has been a significant health event unless the patient has indicated that the information is to remain confidential. Although information is collected primarily for the purposes of providing statistical information it is also used for other purposes, such as updating the MWS and Cancer Registry when appropriate.

13.1.12 Any information used or disclosed which contains the person's NHI number in a format not encrypted would be identifiable and subject to the HIPC.

13.1.13 NZHIS uses the NHI number as the unique identifier for the Cancer Registry.

13.1.14 The NHI number will be the unique identifier in the Mental Health Information Project for the purpose of adding and updating records to the database. However, once updated, the NHI number will be encrypted so that the information is not identifiable. The data contained in the record will not however be encrypted.

13.2 Individuals

13.2.1 Generally, it is safe to say that most people are unaware of the existence of the NHI number, the fact that they have such a number and the purposes for which it is being used.

13.2.2 There is no specific mechanism currently in place which enables individuals to find out whether they have an NHI number and what that number is. However, it may be easily ascertained if, say, a GP uses the number on a form requesting a blood test. Alternatively, someone could find out their NHI number by making an access request to either their health care provider or to NZHIS.

13.2.3 There is no requirement for individuals to know or supply their NHI number when seeking health and/or disability services. Under rule 12 of the HIPC a health agency must not require an individual to disclose a unique identifier assigned to them unless disclosure is one of the purposes in connection with which it was assigned, or the disclosure is directly related to those purposes.⁴¹

13.3 Providers

13.3.1 To date, many providers have assigned a unique identifier to individuals for internal administrative purposes. In the past this has been the health agencies own unique identifier system and not the NHI number.

13.3.2 Hospitals and health services and private hospitals, supply information to NZHIS with an NHI number attached for entry on the NMDS database. NZHIS may request this information under section 22C of the Health Act and under section 139A of the Hospitals Act. In practice, the HFA requires providers to supply such information to the NZHIS under the service agreements. As the information is provided for statistical purposes, it appears that

⁴¹ Paragraph 10.19-25.

the HFA is acting as the agent of the Ministry, facilitating the collection of information. Acting as the Ministry's agent the request by the HFA would be considered under section 22C(2)(g) rather than section 22C(2)(j) of the Health Act.

- 13.3.3** Increasingly, the HFA is requiring providers to supply information to either itself or NZHIS with an NHI number attached.⁴² Although some providers are supplying the information, others are resisting the supply of information about identifiable individuals to the HFA until an awareness campaign has been run.⁴³
- 13.3.4** Information about identifiable individuals flows between different providers as part of the ongoing provision of care. Frequently, disclosure of certain information to another provider will be one of the purposes for obtaining the information. However, information may be requested by another provider of health care under section 22F of the Health Act. The information must be provided unless there is reason to believe that the individual does not want the information disclosed. Generally, this information does not have an NHI number attached. However, the provision of information with an NHI number attached is becoming more commonplace.
- 13.3.5** Some providers, mainly hospital and health services, have direct access to the NHI database held by NZHIS and are able to check an individual's NHI number, or assign a number to the person if necessary. Searches based on names and NHI numbers are possible.
- 13.3.6** In those cases where providers, for example medical practitioners, do not have direct access to the NHI they are able to obtain and verify NHI numbers via a telephone and facsimile 0800 number operated by HBL (Health Benefits Limited, a company owned by the HFA). Other practitioners use hospital access to NHI. Such use is normally covered by an agency agreement as part of the NHIS access agreement.
- 13.3.7** In some cases, providers obtain batches of unique identifier numbers from NZHIS so that the provider may assign a number to individuals who do not already have an NHI number. For example, for future allocation of numbers to new-born babies. The number is assigned once a live delivery occurs. Once the agency has assigned one of the numbers in the batch to an

⁴² GP Weekly, 16 December 1998 *NHI number deadline extended again*.

⁴³ New Zealand Doctor, 11 November 1998, *Public debate on NHI numbers needed now*. "In October, pharmacists signed a contract to supply NHIs on all claims after a national NHI awareness campaign had been run."

individual, the agency provides those details to NZHIS for updating the NHI database.

13.3.8 In some instances, providers supply information to NZHIS directly as part of the access agreement. In such cases NZHIS requires the agency to follow NZHIS procedures, including ensuring the information is accurate and complete. Reference is made to the agency providing information in accordance with the HIPC.

13.3.9 The agreement enables access to the NHIS for purposes contemplated by the agreement. However, those purposes are not explicitly stated. Consequently, it is not clear how the access agreement can restrict, say, the linkage of information using the NHI number.

13.3.10 Information flows involving providers can be summarised as:

- provider to individual: no use of NHI;
- provider to provider: NHI number not generally used, but there is an increasing trend toward the use of NHI numbers when transmitting information;
- provider to funder: funder requires information to be provided with NHI number attached. In some cases information is to be supplied to NZHIS, in other cases to the HFA;
- provider to NZHIS: use of NHI number encourage wherever possible when providing information for NHIS.

13.4 Funders

13.4.1 The HFA has access to the NHI database and is able to assign NHI numbers. It also has access to information on the NMDS. It does not have access to the MWS.

13.4.2 The funding agreement between the Ministry of Health and the HFA specifies information requirements:

- HFA under its service agreements will require providers to provide appropriate medical warnings to the MWS;
- HFA under its service agreements will require that NMDS data relating to purchased services are made available to NZHIS;
- All NMDS data is to be supplied to NZHIS using the health care users NHI number;
- All NMDS data provided to NZHIS from a provider under service agreement will be provided to the HFA in an agreed electronic format.

13.4.3 The Evergreen funding agreement between the Ministry of Health and the HFA specifies the information requirements in Appendix A. There is no reference to whether that information is obtained from providers under section 22C(2)(g) or section 22C(2)(j). Consequently, it is unclear how that information may be used. If it is collected under section 22C(2)(g) then NZHIS obtains information for entry on the NMDS database for statistical purposes. By including a condition in the service agreement requiring the provision of this information for this purpose, the HFA appears to be acting as the agent of NZHIS.

13.4.4 However, if this information were requested under section 22C(2)(j), NZHIS becomes the agent of the HFA and information about identifiable individuals may only be requested if it is essential for the HFA to exercise or perform any of its powers, duties, or functions.

13.4.5 In either situation, the provider supplying the information needs to be made aware of the purpose of supplying the information so that it can exercise its discretion when considering the request. If it decides to supply the information it has an obligation under rule 3 to ensure that individuals are aware of the disclosure and the purpose of that disclosure.

13.4.6 The agreement also requires the HFA to supply the Ministry with statistical information about service delivery. In the context of primary care services it specifically states that information is to be provided to the Ministry with no personal identification possible. However, the Ministry and the HFA have agreed that the reports regarding primary care contracting arrangements are likely to be based on information collected (either currently or in the future) by the HFA on:

- ethnicity, age, sex, domicile etc (this information will result from the use of NHI numbers and electronic claiming);
- Community Service Card and High Users Health Card information;
- Health professional including doctor, nurse, other (from health professional code);
- Date of event;
- Reason for encounter/diagnosis (at a high level);
- Linking information to other services.

13.4.7 The primary care contracting arrangements reports to be provided to the Ministry relate to:

- number of primary care providers funded in part or whole by the HFA;

- number of primary care providers on capitated or block contracts;
- population enrolled with capitated or block primary practices;
- number of primary care providers on fee-for-service contracts/arrangements;
- number of Pharmacists on a fixed fee contract;
- number of Pharmacists on section 51⁴⁴ arrangements.

13.4.8 However, it is difficult to reconcile why it is necessary for the HFA to collect identifiable information for the specified reporting purposes.

13.4.9 As a consequence of the funding agreement, the HFA is moving toward including a condition in its service agreements with providers that providers must supply information to either NZHIS or the HFA with an NHI number attached.

13.4.10 The requirement to provide information must be considered alongside the HFA's functions. For example, section 33(c) of the Health and Disability Services Act enables the HFA to monitor the performance of service agreements and other arrangements by persons with whom it has entered into such agreements or arrangements.

13.4.11 This raises two issues:

- HFA needs to show providers that information about identifiable individuals, that is information with an NHI number attached, is *essential* for it to be able to monitor the performance of service agreements.
- If the HFA can show that information about identifiable individuals is essential, the HFA cannot require the provision of such information as part of a service agreement. It has to give the provider the opportunity to exercise its discretion under section 22C of the Health Act.

14. Future use of NHI

14.1 The Health Information Strategy for the Year 2000 concluded that health information systems and services need to expand to meet the information needs of consumers, providers, funders and the Ministry. That expansion will include the increased use of the NHI number in the communication of information about identifiable individuals between providers, funders and the Ministry.

⁴⁴ Health and Disability Services Act 1993.

- 14.2 The health sector is moving towards an integrated delivery of health and disability services. In a recent address to the NZIHM Conference, Phil Pryke, CEO, HFA stated:⁴⁵

Integrated care is seen as a holistic, comprehensive group of services. It aims to provide an optimal balance between prevention, early intervention, treatment, rehabilitation, and ongoing support. Its focus is on health gains and improved independence.

- 14.3 Implementing this model will mean an increased flow of information between different health agencies. However, the purpose of such information flows will need to be clearly determined beforehand.
- 14.4 In developing the Health Intranet project, NZHIS recognised the need for providers to communicate with each other by electronically transmitting health information. This will also facilitate information flows between providers, funders and NZHIS.
- 14.5 As more health providers utilise the Health Intranet, health information transmitted will have the NHI number attached. Although information will be encrypted during on-line transmission, health providers will be able to decrypt the information and link it to existing information about the individual to whom it relates.⁴⁶
- 14.6 It seems likely that the HFA will continue to require providers to supply information with an NHI number attached.

15. Frequently asked questions

- 15.1 An understanding of the statutory requirements and policy framework enables the following questions to be answered:

15.1.1 *What happens if an individual refuses to have an NHI number?*

A health agency may decide that in order for it to be able to function efficiently and communicate information with other health agencies it needs to assign an NHI number to each individual when it provides health services.

As an individual goes to a bank and opens accounts, the person is provided with a customer number and a suffix identifying each account. This is the basis for the transactions with the bank. Use

⁴⁵ "Partnership for Health Gain" NZIHM Conference, 29 & 30 October 1998, Auckland.

⁴⁶ Information transmitted by facsimile will not be encrypted.

of the unique identifier enables information to be associated with the customers accounts.

Although there is no statutory requirement for the allocation of a customer number, without such a number the bank will not be able to provide services to that person.

The same could be said of the NHI number. For example, in the communication of information between different health care providers, it is important that the information is associated with the correct file. The NHI number is a way of helping to ensure information is accurate, by helping to ensure that information is attached to the correct record.

There are very few people who do not now have an NHI number. NHI numbers are now allocated at birth in the vast majority of cases.⁴⁷ The individual is not given the opportunity to refuse to have the number assigned. Assignment is an administrative procedure.

In some circumstances, depending on the health agency, if a person refuses to allow the agency to use an NHI number, or any other unique identifier, the agency may decide not to provide the service to the individual, or alternatively, charge an extra fee if the information is required in order to claim a subsidy.

The answer to the question, therefore, is that it is most unlikely that a person could refuse to have an NHI number.

She or he could possibly request that a health agency not use the NHI number when disclosing information to other health agencies. However, this may result in higher costs for health services if the provision of information with an NHI number attached is a condition of funding. Individuals then have the choice of foregoing subsidies on, say, services or pharmaceuticals.

15.1.2 *Can a person opt out of the NHI database?*

Once assigned an NHI number, there is no provision for deleting that name and number. Under rule 6 of the HIPC, an individual may request access to personal information held on the NHI database. If it were not correct, under rule 7 she or he could request correction of the information.

The HIPC does not provide for deletion of information except by way of correction.

⁴⁷ Paragraph 5.4.

If not already assigned an NHI number, then the discussion under the previous question is relevant as to whether it is possible to opt out.

15.1.3 *Is the NHI number a link to access publicly funded health services?*

The Health Information Strategy for the Year 2000 report suggests that the NHI number could become a link to publicly funded health services if it should become a common unique identifier.

One of the justifications for this is that in order to monitor the delivery of health services throughout the health sector there is a need to obtain statistical information about trends in order to identify the priority of types of services to be funded.

Aggregate information about secondary health services is provided by NZHIS from its NMDS database. As individual records need to be updated from time to time, information supplied needs to be identifiable to ensure that the information is entered on the correct record. The most efficient way of identifying the record is by unique identifier.

In addition, if a health agency is required to provide an individual's NHI number in order to make a claim for payment, supplying the information is a link to publicly funded health services.

Current practice by NZHIS and the HFA indicates that there is an acceptance that the use of the NHI number is a link to accessing publicly funded services. Whether the use of the NHI number should be a link to the access to publicly funded health services is beyond the scope of this review. However, there is a need for health agencies to implement protections to prevent inappropriate use of the NHI and the unauthorised linking of information by NHI number. Health agencies must be open about and accountable for the way in which they use the NHI number and aware of patient sensitivities about such use.

15.2 Generally, these questions indicate the need for there to be a much greater awareness about the NHI, its purpose and its uses. People are more likely to accept the necessity of an NHI number if they know that there are protections in place to prevent the unauthorised use and in particular the unauthorised linking of health information.

- 15.3 The integrity of the NHI database will be improved by ensuring that there are safeguards in place to protect that information. Health agencies cannot focus on the uses of information before ensuring that safeguards exist to protect that information. The provision of quality data will follow the development of trust in the system - not the other way around.
- 15.4 One way of building trust is to ensure that health agencies know how the information will be protected. Openness and trust are essential.

16. Conclusions

- 16.1 The policy framework set out in Health Information Strategy for the Year 2000 and the legislative framework discussed above, provide useful direction for agencies to safely manage identifiable health information. However, there is little evidence of the implementation of those frameworks. The management of health information seems to remain fragmented.
- 16.2 The Strategy identified that its success would depend on the willingness of individuals and organisations to subscribe to its general aims, and implement its specifics. To date this has not occurred on a large scale.
- 16.3 It is not sufficient to say that information must be provided with an NHI number attached say, for example, for statistical purposes or monitoring purposes. Those supplying the information, either individuals or health care providers, must be made aware of the specific purposes for which information about identifiable individuals is needed.
- 16.4 This review has raised concerns about the use of the NHI number to collect information for the purpose of monitoring the service agreements and for reporting purposes. The scope of the information suggested as being the basis for reporting statistical information by the HFA to the Ministry also raises cause for concern.⁴⁸
- 16.5 Overall, there seems to be a lack of clarity and understanding about the purposes for which agencies collect information with the NHI number attached and what they may be doing with that information. It is this sort of uncertainty which will hinder any co-ordinated and co-operative approach to the appropriate disclosure and use of information with NHI numbers attached. It will also impact on the accuracy of the information obtained by health agencies.
- 16.6 Administrative convenience must be balanced against potential privacy risks and health agencies need to find a balance at which point they can operate efficiently but not at the risk of unnecessary intrusions into individual privacy.

⁴⁸ Paragraph 13.4.6.

17. **Recommendations (not in order of priority)**

- 17.1 **Recommendation 1:** NZHIS should undertake a publicity campaign to improve individual awareness of the existence of the NHI, its purpose and the protections in place to prevent its misuse, including the unauthorised linkages of health information.
- 17.2 **Recommendation 2:** NZHIS needs to build trust in the NHI database and the NHIS by being open about their purposes. Increased trust will help to improve the quality of data supplied for the databases.
- 17.3 **Recommendation 3:** NZHIS should consider including in any agreement providing access to the NHIS a clause specifying the purposes for which the NHI number will be used by the health agency and what information will be linked by NHI number by that agency. The use of the NHI number will be limited to those purposes specified in the agreement.
- 17.4 **Recommendation 4:** NZHIS should consider the way the NHI database may be searched. It should consider whether it is necessary to enable those with access to the database to search on any field or whether searches should be restricted to searching on a name to get a number and not allowing searches on a number to obtain a name.
- 17.5 **Recommendation 5:** NZHIS should develop guidelines for health agencies which have access to the NHIS about the NHI and how it is used by NZHIS. Such guidelines should include the requirement that information obtained from different sources may only be linked by NHI number if that use is specified in the NHI access agreement.
- 17.6 **Recommendation 6:** The Ministry of Health should address the priority area identified in the Health Information Strategy for the Year 2000 relating to the *review and adjustment of core information requirements needed to enable the monitoring of purchase and service delivery policies and to meet local, regional and international reporting obligations.*
- 17.7 **Recommendation 7:** NZHIS and the HFA should do a stocktake of their current collection and collation of information where that information is sought with an NHI number attached.
- 17.8 **Recommendation 8:** Health agencies should develop information management policies to identify the purposes for which they obtain information with an NHI number attached. Such a policy should anticipate and document:

- legal justification/authority for obtaining information including whether the health agency's powers, duties and functions is consistent its use of the information;
- how the information is to be collected, including how individuals will be made aware of the purpose for the collection of the information;
- storage and security safeguards implemented by the health agency, including details of on-going staff training programmes;
- how long the information needs to be retained, with reference to any statutory requirements to retain information;
- procedures for ensuring information is accurate before it is used or disclosed;
- purposes for which the information may be used and disclosed, including how the agency will deal with requests for information made under the Official Information Act;
- mechanism for enabling individuals to access and request correction of their information;
- the identity and role of the privacy officer.

Policies should also identify:

- who may use the unique identifier;
- the purposes for which the unique identifier may be used;
- what information will be attached to the unique identifier;
- all information obtained from different sources which is linked by NHI number;
- controls preventing the unauthorised linkages of information by unique identifier.

17.9 Recommendation 9: NZHIS should set up a procedure to enable people to find out what their NHI number is and how they may access personal information held on the NHIS. A mechanism also needs to be set up for correcting information held on the NHIS.

17.10 Recommendation 10: The accuracy of the information on the NHI database needs to be improved.

17.11 Recommendation 11: A governance body, comprising of representatives from the Ministry, funder, providers and consumers should be set up to monitor the use of the NHI and in particular the linking of information by NHI number.

17.12 Recommendation 12: The funding agreement between the Minister of Health and the Health Funding Authority should be reviewed with respect to the information flows to ensure they comply with the law.

- 17.13 Recommendation 13:** Statistical information about the delivery of primary health services needs to be improved. The statistics need to address the information requirements of the Ministry, HFA and providers.

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

Bibliography

Statutes

Cancer Registry Act 1993.
Health Act 1956.
Health and Disability Services Act 1993.
Privacy Act 1993.

Rules, Codes and Subordinate Legislation

Cancer Registry regulations 1994.
Health Information Privacy Code 1994.
Health Information Privacy Rules.

Cases

Hobson v Harding CA 50-95, 12 December 1996.

Secondary materials

Reports

Health Information Strategy for the Year 2000, also available http://www.health.govt.nz/Medical_Records_databases:_Just_what_you_need? Report prepared for the Privacy Commissioner by Robert Stevens.
Necessary and Desirable - Privacy Act 1993 Review. Report of the Privacy Commissioner on the First Periodic Review of the Operation of the Privacy Act, Office of the Privacy Commissioner, November 1998.

Books

Privacy Law and Practice Dr Paul Roth, Butterworths, 1006.65.
The Oxford English Reference Dictionary (2nd ed.), Oxford University Press, Oxford, 1996.

Periodicals

New Zealand Doctor, 2 September 1998, *Big berg threatens NHI maiden*.
New Zealand Doctor, 11 November 1998, Editorial "*Going to the highest bidder*".
New Zealand Doctor, 11 November 1998, *Public debate on NHI numbers needed now*.
GP Weekly, 16 December 1998, *NHI number deadline extended again*.

Conference notes

"*Information privacy principle 12 and the Superannuation Schemes Unique Identifier Code 1995*" Notes for an address to the IIR 5th Annual Super Fund and Funds Management Conference, Auckland, 27 November 1995 Blair Stewart, Manger Codes and Legislation (now Assistant Commissioner).

"Partnership for Health Gain" NZIHM Conference, Auckland, 29 & 30 October 1998 Phil Pryke, CEO - HFA.

Miscellaneous

<http://www.health.govt.nz/HIS2000/gaps/GOR-contents.html>

Terms of reference for National Health Index Review, Prepared by Peter Aagaard, February 1998, revised October 1998.

Unique Identifiers for the Health Care Industry Technical Advisory Group White Paper, October 1993, <http://www.wedi.org/htdocs/resource/report/file17.htm>

APPENDIX 1

Health Act 1956

22C. Disclosure of health information—

- (1) Any person (being an agency that provides health services, or disability services, or both, or being a funder) may disclose health information—
 - (a) If that information—
 - (i) Is required by any person specified in subsection (2) of this section; and
 - (ii) Is required (or, in the case of the purpose set out in paragraph (j) of that subsection, is essential) for the purpose set out in that subsection in relation to the person so specified; or
 - (b) If that disclosure is permitted—
 - (i) By or under a code of practice issued under section 46 of the Privacy Act 1993; or
 - (ii) If no such code of practice applies in relation to the information, by any of the information privacy principles set out in section 6 of that Act.
- (2) The persons and purposes referred to in subsection (1)(a) of this section are as follows:
 - (a) ...
 - (g) Any employee of the Ministry of Health, for the purposes of—
 - (i) Administering this Act or the Hospitals Act 1957; or
 - (ii) Compiling statistics for health purposes;
 - (j) Any employee of a funder, for the purposes of exercising or performing any of that funder's powers, duties, or functions under the Health and Disability Services Act 1993.

22D. Duty to provide health information—

- (1) The Minister may at any time, by notice in writing, require any funder or any hospital and health service to provide, in such manner as may from time to time be required, such returns or other information as is specified in the notice concerning the condition or treatment of, or the health services or disability services provided to, any individuals in order to obtain statistics for health purposes or for the purposes of advancing health knowledge, health education, or health research.
- (2) Subject to subsection (3), it is the duty of a funder or hospital and health service to provide the returns or other information specified in a notice given to it under subsection (1) within such time, and in such form, as is specified in the notice.
- (3) No information that would enable the identification of an individual may be provided under this section unless—
 - (a) The individual consents to the provision of such information; or
 - (b) The identifying information is essential for the purposes for which the information is sought.
- (4) For the purposes of subsection (3)(a) of this section, consent to the provision of information may be given—
 - (a) By the individual personally, if he or she has attained the age of 16 years; or
 - (b) By a representative of that individual.

22F. Communication of information for diagnostic and other purposes—

- (1) Every person who holds health information of any kind shall, at the request of the individual about whom the information is held, or a representative of that individual, or any other person that is providing, or is to provide, health services or disability services to that individual, disclose that information to that individual or, as the case requires, to that representative or to that other person.
- (2) A person that holds health information may refuse to disclose that information under this section if—
 - (a) That person has a lawful excuse for not disclosing that information; or

- (b) Where the information is requested by someone other than the individual about whom it is held (not being a representative of that individual), the holder of the information has reasonable grounds for believing that that individual does not wish the information to be disclosed; or
- (c) Refusal is authorised by a code of practice issued under section 46 of the Privacy Act 1993.
- (3) For the purposes of subsection (2)(a) of this section, neither—
- (a) The fact that any payment due to the holder of any information or to any other person has not been made; nor
- (b) The need to avoid prejudice to the commercial position of the holder of any information or of any other person; nor
- (c) The fact that disclosure is not permitted under any of the information privacy principles set out in section 6 of the Privacy Act 1993—
- shall constitute a lawful excuse for not disclosing information under this section.
- (4) Where any person refuses to disclose health information in response to a request made under this section, the person whose request is refused may make a complaint to the Privacy Commissioner under Part VIII of the Privacy Act 1993, and that Part of that Act, so far as applicable and with all necessary modifications, shall apply in relation to that complaint as if the refusal to which the complaint relates were a refusal to make information available in response to an information privacy request within the meaning of that Act.
- (5) Nothing in subsection (4) of this section limits any other remedy that is available to any person who is aggrieved by any refusal to disclose information under this section.

22G. Inspection of records—

- (1) Any person (in this section referred to as a "provider") who has claimed payment from the Health Funding Authority for services provided must forthwith after a request by the Authority, make available any records of the provider that relate to those services for inspection—
- (a) By a person authorised in writing by the Authority for this purpose, being a person who holds a professional qualification relevant to the services provided by the provider or such other person as the Authority considers appropriate; and
- (b) For the purposes of verifying the claim for payment.
- (2) Any person authorised in accordance with subsection (1) of this section to inspect the records of a provider may copy or take notes of those records for the purposes of the inspection.

22H. Anonymous health information—

Notwithstanding any enactment, rule of law, or other obligation, any person may supply to any other person health information that does not enable the identification of the individual to whom the information relates.

APPENDIX 2

Health and Disability Services Act 1993

8. Objectives of the Crown—
- (1) Before entering into a funding agreement with a funder (other than a funding agreement that relates solely to public health services), the Minister must give the funder written notice of the Crown's objectives in relation to the following matters:
 - (a) The health status of the communities served by the funder:
 - (b) The health outcomes sought to be attained for the communities served by the funder:
 - (c) The health services or disability services, or both, to be funded by the funder:
 - (d) The terms of access to those services; and the assessment and review procedures to be used in determining access to those services or such of those services as are specified in the notice:
 - (e) The standard of those services:
 - (f) The special needs of Maori and other particular communities or people for those services.
 - (2) Before entering into a funding agreement with a funder (being a funding agreement that relates to public health services), the Minister shall give to the funder written notice of the Crown's objectives in relation to public health.
 - (2A) Any objectives notified to a funder under subsection (2) of this section may be included in a notice given to that funder under subsection (1) of this section, or may be the subject of a separate notice to that funder.
 - (3) Every objective given to a funder under this section must be an objective that, if met, will, in the Minister's opinion, assist in securing for the people of New Zealand—
 - (a) The best health; and
 - (b) The best care or support for those in need of services; and
 - (c) The greatest independence for people with disabilities—that is reasonably achievable within the amount of funding provided.
 - (4) The Minister may at any time, by written notice to a funder, amend a notice given to that funder under this section.
 - (5) Where a notice is given to a funder under this section, the Minister shall, as soon as practicable after the giving of the notice, publish in the Gazette and lay before the House of Representatives a copy of the notice.
10. Objectives of Health Funding Authority—
- (1) The Health Funding Authority has the following objectives in carrying out its functions:
 - (a) To promote the personal health of people; and
 - (b) To promote care or support for those in need of personal health services or disability services; and
 - (c) To promote the independence of people with disabilities; and
 - (d) To improve, promote, and protect public health; and
 - (e) To meet the Crown's objectives notified to it under section 8.
 - (2) The Health Funding Authority must pursue its objectives in accordance with, and to the extent enabled by, its funding agreement.
11. Objectives of hospital and health services—
- (1) The principal objective of every hospital and health service is—
 - (a) To provide a range of health services or disability services, or both, to improve health outcomes and to enhance the health status of the people it serves; and
 - (b) To assist in meeting the Crown's objectives under section 8 by providing such services in accordance with its statement of intent and its service agreement with the Health Funding Authority and any other agreement for the provision of services.

- (2) Every hospital and health service must meet its principal objective while operating—
 - (a) In a businesslike and effective manner; and
 - (b) On a not-for-profit basis.
- (3) Without limiting subsection (1) or subsection (2), every hospital and health service has the following objectives:
 - (a) To exhibit a sense of social responsibility by having regard to the interests of the community in which it operates:
 - (b) To uphold the ethical and quality standards generally expected of providers of health services or disability services, or both, as the case may be:
 - (c) To be a good employer.
- (4) For the purposes of this section, a hospital and health service operates on a not-for-profit basis if its annual net income covers all its annual costs (including the cost of capital).
- (5) Subsection (2)(b) does not affect any obligation of a hospital and health service to pay—
 - (a) Income tax under the Income Tax Act 1994; or
 - (b) Specified health payments within the meaning of section OB1 of that Act.

RELEASED UNDER THE OFFICIAL INFORMATION ACT 1982

APPENDIX 3

HEALTH INFORMATION PRIVACY RULES

Rule 1

Purpose of Collection of Health Information

Health information must not be collected by any health agency unless:

- (a) the information is collected for a lawful purpose connected with a function or activity of the health agency; and
- (b) the collection of the information is necessary for that purpose.

Rule 2

Source of Health Information

- (1) Where a health agency collects health information, the health agency must collect the information directly from the individual concerned.
- (2) It is not necessary for a health agency to comply with subrule (1) if the agency believes on reasonable grounds:
 - (a) that the individual concerned authorises collection of the information from someone else having been made aware of the matters set out in subrule 3(1);
 - (b) that the individual is unable to give his or her authority and the health agency having made the individual's representative aware of the matters set out in subrule 3(1) collects the information from the representative or the representative authorises collection from someone else;
 - (c) that compliance would:
 - (i) prejudice the interests of the individual concerned;
 - (ii) prejudice the purposes of collection; or
 - (iii) prejudice the safety of any individual;
 - (d) that compliance is not reasonably practicable in the circumstances of the particular case;
 - (e) that the collection is for the purpose of assembling a family or genetic history of an individual and is collected directly from that individual;
 - (f) that the information is publicly available information;
 - (g) that the information:
 - (i) will not be used in a form in which the individual concerned is identified;
 - (ii) will be used for statistical purposes and will not be published in a form that could reasonably be expected to identify the individual concerned; or
 - (iii) will be used for research purposes (for which approval by an ethics committee, if required, has been given) and will not be published in a form that could reasonably be expected to identify the individual concerned;
 - (h) that non-compliance is necessary:
 - (i) to avoid prejudice to the maintenance of the law by any public sector agency, including the prevention, detection, investigation, prosecution, and punishment of offences;
 - (ii) for the protection of the public revenue; or
 - (iii) for the conduct of proceedings before any court or tribunal (being proceedings that have been commenced or are reasonably in contemplation); or
 - (i) that the collection is in accordance with an authority granted under section 54 of the Act.

Rule 3

Collection of Health Information from Individual

- (1) Where a health agency collects health information directly from the individual concerned, or from the individual's representative, the health agency must take such steps as are, in the circumstances, reasonable to ensure that the individual concerned (and the representative if collection is from the representative) is aware of:
 - (a) the fact that the information is being collected;
 - (b) the purpose for which the information is being collected;
 - (c) the intended recipients of the information;
 - (d) the name and address of:

- (i) the health agency that is collecting the information; and
 - (ii) the agency that will hold the information;
 - (e) whether or not the supply of the information is voluntary or mandatory and if mandatory the particular law under which it is required;
 - (f) the consequences (if any) for that individual if all or any part of the requested information is not provided; and
 - (g) the rights of access to, and correction of, health information provided by rules 6 and 7.
- (2) The steps referred to in subrule (1) must be taken before the information is collected or, if that is not practicable, as soon as practicable after it is collected.
- (3) A health agency is not required to take the steps referred to in subrule (1) in relation to the collection of information from an individual, or the individual's representative, if that agency has taken those steps in relation to the collection, from that individual or that representative, of the same information or information of the same kind for the same or a related purpose, on a recent previous occasion.
- (4) It is not necessary for a health agency to comply with subrule (1) if the agency believes on reasonable grounds:
- (a) that non-compliance is authorised by the individual concerned;
 - (b) that compliance would:
 - (i) prejudice the interests of the individual concerned; or
 - (ii) prejudice the purposes of collection;
 - (c) that compliance is not reasonably practicable in the circumstances of the particular case; or
 - (d) that non-compliance is necessary to avoid prejudice to the maintenance of the law by any public sector agency, including the prevention, detection, investigation, prosecution, and punishment of offences.

Rule 4 Manner of Collection of Health Information

Health information must not be collected by a health agency:

- (a) by unlawful means; or
- (b) by means that, in the circumstances of the case:
 - (i) are unfair; or
 - (ii) intrude to an unreasonable extent upon the personal affairs of the individual concerned.

Rule 5 Storage and Security of Health Information

- (1) A health agency that holds health information must ensure:
- (a) that the information is protected, by such security safeguards as it is reasonable in the circumstances to take, against:
 - (i) loss;
 - (ii) access, use, modification, or disclosure, except with the authority of the agency; and
 - (iii) other misuse;
 - (b) that if it is necessary for the information to be given to a person in connection with the provision of a service to the health agency, including any storing, processing, or destruction of the information, everything reasonably within the power of the health agency is done to prevent unauthorised use or unauthorised disclosure of the information; and
 - (c) that, where a document containing health information is not to be kept, the document is disposed of in a manner that preserves the privacy of the individual.
- (2) This rule applies to health information obtained before or after the commencement of this code.

Rule 6 Access to Personal Health Information

- (1) Where a health agency holds health information in such a way that it can readily be retrieved, the individual concerned is entitled:
- (a) to obtain from the agency confirmation of whether or not the agency holds such health information; and

- (b) to have access to that health information.
- (2) Where, in accordance with paragraph (1)(b), an individual is given access to health information, the individual must be advised that, under rule 7, the individual may request the correction of that information.
 - (3) The application of this rule is subject to:
 - (a) Part IV of the Act (which sets out reasons for withholding information);
 - (b) Part V of the Act (which sets out procedural provisions relating to access to information); and
 - (c) clause 6 (which concerns charges).
 - (4) This rule applies to health information obtained before or after the commencement of this code.

Rule 7
Correction of Health Information

- (1) Where a health agency holds health information, the individual concerned is entitled:
 - (a) to request correction of the information; and
 - (b) to request that there be attached to the information a statement of the correction sought but not made.
- (2) A health agency that holds health information must, if so requested or on its own initiative, take such steps (if any) to correct the information as are, in the circumstances, reasonable to ensure that, having regard to the purposes for which the information may lawfully be used, it is accurate, up to date, complete, and not misleading.
- (3) Where an agency that holds health information is not willing to correct the information in accordance with such a request, the agency must, if so requested, take such steps (if any) as are reasonable to attach to the information, in such a manner that it will always be read with the information, any statement provided by the individual of the correction sought.
- (4) Where the agency has taken steps under subrule (2) or (3), the agency must, if reasonably practicable, inform each person or body or agency to whom the health information has been disclosed of those steps.
- (5) Where an agency receives a request made under subrule (1), the agency must inform the individual concerned of the action taken as a result of the request.
- (6) The application of this rule is subject to the provisions of Part V of the Act (which sets out procedural provisions relating to correction of information).
- (7) This rule applies to health information obtained before or after the commencement of this code.

Rule 8
Accuracy etc of Health Information to be Checked Before Use

- (1) A health agency that holds health information must not use that information without taking such steps (if any) as are, in the circumstances, reasonable to ensure that, having regard to the purpose for which the information is proposed to be used, the information is accurate, up to date, complete, relevant, and not misleading.
- (2) This rule applies to health information obtained before or after the commencement of this code.

Rule 9
Retention of Health Information

- (1) 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.
- (2) Subrule (1) does not prohibit any agency from keeping any document that contains health information the retention of which is necessary or desirable for the purposes of providing health services or disability services to the individual concerned.
- (3) This rule applies to health information obtained before or after the commencement of this code.

Rule 10
Limits on Use of Health Information

- (1) A health agency that holds health information obtained in connection with one purpose must not use the information for any other purpose unless the health agency believes on reasonable grounds:
 - (a) that the use of the information for that other purpose is authorised by:

- (i) the individual concerned; or
 - (ii) the individual's representative where the individual is unable to give his or her authority under this rule;
 - (b) that the purpose for which the information is used is directly related to the purpose in connection with which the information was obtained;
 - (c) that the source of the information is a publicly available publication;
 - (d) that the use of the information for that other purpose is necessary to prevent or lessen a serious and imminent threat to:
 - (i) public health or public safety; or
 - (ii) the life or health of the individual concerned or another individual;
 - (e) that the information:
 - (i) is used in a form in which the individual concerned is not identified;
 - (ii) is used for statistical purposes and will not be published in a form that could reasonably be expected to identify the individual concerned; or
 - (iii) is used for research purposes (for which approval by an ethics committee, if required, has been given) and will not be published in a form that could reasonably be expected to identify the individual concerned;
 - (f) that non-compliance is necessary:
 - (i) to avoid prejudice to the maintenance of the law by any public sector agency, including the prevention, detection, investigation, prosecution, and punishment of offences; or
 - (ii) for the conduct of proceedings before any court or tribunal (being proceedings that have been commenced or are reasonably in contemplation);
 - (g) that the use of the information is in accordance with an authority granted under section 54 of the Act.
- (2) This rule does not apply to health information obtained before [1 July 1993].

Rule 11
Limits on Disclosure of Health Information

- (1) A health agency that holds health information must not disclose the information unless the agency believes, on reasonable grounds:
- (a) that the disclosure is to:
 - (i) the individual concerned; or
 - (ii) the individual's representative where the individual is dead or is unable to exercise his or her rights under these rules;
 - (b) that the disclosure is authorised by:
 - (i) the individual concerned; or
 - (ii) the individual's representative where the individual is dead or is unable to give his or her authority under this rule;
 - (c) that the disclosure of the information is one of the purposes in connection with which the information was obtained;
 - (d) that the source of the information is a publicly available publication;
 - (e) that the information is information in general terms concerning the presence, location, and condition and progress of the patient in a hospital, on the day on which the information is disclosed, and the disclosure is not contrary to the express request of the individual or his or her representative; or
 - (f) that the information to be disclosed concerns only the fact of death and the disclosure is by a registered health professional, or by a person authorised by a health agency, to a person nominated by the individual concerned, or the individual's representative, partner, spouse, principal caregiver, next of kin, whanau, close relative or other person whom it is reasonable in the circumstances to inform.
 - (g) the information to be disclosed concerns only the fact that an individual is to be, or has been, released from compulsory status under the Mental Health (Compulsory Assessment and Treatment) Act 1992 and the disclosure is to the individual's principal caregiver.
- (2) Compliance with paragraph (1)(b) is not necessary if the health agency believes on reasonable grounds that it is either not desirable or not practicable to obtain authorisation from the individual concerned and:
- (a) that the disclosure of the information is directly related to one of the purposes in connection with which the information was obtained;

- (b) that the information is disclosed by a registered health professional to a person nominated by the individual concerned or to the principal caregiver or a near relative of the individual concerned in accordance with recognised professional practice and the disclosure is not contrary to the express request of the individual or his or her representative;
- (c) that the information:
- (i) is to be used in a form in which the individual concerned is not identified;
 - (ii) 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; or
 - (iii) is to be used for research purposes (for which approval by an ethics committee, if required, has been given) and will not be published in a form which could reasonably be expected to identify the individual concerned;
- (d) that the disclosure of the information is necessary to prevent or lessen a serious and imminent threat to:
- (i) public health or public safety; or
 - (ii) the life or health of the individual concerned or another individual;
- (e) that the disclosure of the information is essential to facilitate the sale or other disposition of a business as a going concern;
- (f) that the information to be disclosed briefly describes only the nature of injuries of an individual sustained in an accident and that individual's identity and the disclosure is:
- (i) by a person authorised by the person in charge of a hospital;
 - (ii) to a person authorised by the person in charge of a news medium;
- for the purpose of publication or broadcast in connection with the news activities of that news medium and the disclosure is not contrary to the express request of the individual concerned or his or her representative;
- (g) that the disclosure of the information:
- (i) is required for the purposes of identifying whether an individual is suitable to be involved in health education and so that individuals so identified may be able to be contacted to seek their authority in accordance with paragraph (1)(b); and
 - (ii) is by a person authorised by the health agency to a person authorised by a health training institution;
- (h) that the disclosure of the information:
- (i) is required for the purpose of a professionally recognised accreditation of a health or disability service;
 - (ii) is required for a professionally recognised external quality assurance programme; or
 - (iii) is required for risk management assessment and the disclosure is solely to a person engaged by the agency for the purpose of assessing the agency's risk;
- and the information will not be published in a form which could reasonably be expected to identify any individual nor disclosed by the accreditation or quality assurance or risk management organisation to third parties except as required by law;
- (i) that non-compliance is necessary:
- (i) to avoid prejudice to the maintenance of the law by any public sector agency, including the prevention, detection, investigation, prosecution and punishment of offences; or
 - (ii) for the conduct of proceedings before any court or tribunal (being proceedings that have been commenced or are reasonably in contemplation);
- (j) that the individual concerned is or is likely to become dependent upon a controlled drug, prescription medicine or restricted medicine and the disclosure is by a registered health professional to a Medical Officer of Health for the purposes of section 20 of the Misuse of Drugs Act 1975 or section 49A of the Medicines Act 1981; or
- (k) that the disclosure of the information is in accordance with an authority granted under section 54 of the Act.
- (3) Disclosure under subrule (2) is permitted only to the extent necessary for the particular purpose.
- (4) Where under section 22F(1) of the Health Act 1956, the individual concerned or a representative of that individual requests the disclosure of health information to that individual or representative, a health agency:
- (a) must treat any request by that individual as if it were a health information privacy request made under rule 6; and
 - (b) may refuse to disclose information to the representative if:
 - (i) the disclosure of the information would be contrary to the individual's interests;

- (ii) the agency has reasonable grounds for believing that the individual does not or would not wish the information to be disclosed; or
 - (iii) there would be good grounds for withholding the information under Part IV of the Act if the request had been made by the individual concerned.
- (5) This rule applies to health information about living or deceased persons obtained before or after the commencement of this code.
- (6) Despite subrule (5), a health agency is exempted from compliance with this rule in respect of health information about an identifiable deceased person who has been dead for not less than 20 years.

Rule 12
Unique Identifiers

- (1) A health agency must not assign a unique identifier to an individual unless the assignment of that identifier is necessary to enable the health agency to carry out any one or more of its functions efficiently.
- (2) A health agency must not assign to an individual a unique identifier that, to that agency's knowledge, has been assigned to that individual by another agency, unless:
 - (a) those 2 agencies are associated persons within the meaning of section OD7 of the Income Tax Act 1994; or
 - (b) it is permitted by subrule (3) or (4).
- (3) The following agencies may assign the same National Health Index number to an individual:
 - (a) any agency authorised expressly by statute or regulation;
 - (b) any agency or class of agencies listed in Schedule 3; and
 - (c) [revoked]
- (4) Notwithstanding subrule (2) any health agency, having given written notice to the Commissioner of its intention to do so, may assign, to a registered health professional, as a unique identifier, the registration number assigned to that individual by the relevant statutory registration body.
- (5) A health agency that assigns unique identifiers to individuals must take all reasonable steps to ensure that unique identifiers are assigned only to individuals whose identity is clearly established.
- (6) A health agency must not require an individual to disclose any unique identifier assigned to that individual unless the disclosure is for one of the purposes in connection with which that unique identifier was assigned or for a purpose that is directly related to one of those purposes.
- (7) Subrules (1) to (5) do not apply in relation to the assignment of unique identifiers before the commencement of this code.
- (8) Subrule (6) applies to any unique identifier, whether assigned before or after the commencement of this code.