

Privacy Impact Assessment
and
Commentary
on the

Mental Health Information Project

for

New Zealand Health Information Service

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1. Executive Summary

1.1 In September 1997, the Minister of Health authorised the New Zealand Health Information Service (NZHIS) to develop a high level database containing information on the provision of secondary mental health and alcohol and drug services. The need to develop such a database flowed from the acknowledged need for national level information about the mental health sector.

1.2 In response to this requirement the Mental Health Information Project (MHIP) was established. The objective of the project is to provide complete, accurate and timely information on secondary mental health services.

1.3 This report focuses on privacy implications associated with the development of a database under the MHIP. It is split into two major parts:

- Part 1 provides a background to the MHIP.
- Part 2 provides a privacy impact assessment of the MHIP.

Part 1

1.4 Part 1 of the report provides a general overview of the MHIP in the context of:

- National mental health strategy;
- National mental health standards;
- NZHIS;
- The Mason Report;
- Mental Health Commission;
- Various legislative requirements; and
- Professional and ethical codes, Standards New Zealand requirements, and Health Research Council guidelines.

Further contextual background information is provided on:

- Database management;
- Databases and their relationship to privacy legislation;
- Current state of monitoring of mental health data; and
- Content of mental health information database.

1.5 **The following conclusions were reached in relation to Part 1 of this report:**

1.5.1 Conclusion 1: The Ministry of Health has made a commitment to ensure that mental health services are available to those who need them. In order to monitor the success of implementing this commitment, it has been considered necessary to measure the delivery of secondary mental health services by both the public sector and non-governmental organisations.

1.5.2 Conclusion 2: One of the objectives of the MHIP is to provide a mechanism for monitoring the implementation of the mental health strategy with respect to the delivery of secondary care services.

1.5.3 Conclusion 3: Although there is no statutory requirement for providers to supply this information, the funding agreement for 1998/99 includes, as part of the performance measures for the Health Funding Authority (HFA) five year plan, a commitment from the HFA for "requirement for compliance with the NZHIS National Mental Health Information System to be included in 1998/2000 service specifications".

1.5.4 Conclusion 4: Providing NZHIS is able to gain the commitment of the providers, NZHIS is in an excellent position to be able to carry out the development of a secondary database for the provision of aggregate data to effectively monitor the delivery of secondary mental health services.

1.5.5 Conclusion 5: However, NZHIS must ensure that all the purposes of the database are properly contemplated prior to implementation and that the mental health service providers are aware of these purposes so they may be conveyed to individuals receiving services, and whose information is to be provided.

1.6 Part 2: Privacy Impact Assessment

Part 2 of the report assesses privacy issues in relation to the development and operation of the Mental Health Information Database.

This part of the report is constructed in the following way:

- General overview of the project from a privacy perspective.
- Collecting/obtaining information: HIPC rules 1-4, with associated NZHIS response to collection issues and subsequent discussions.
- Storage and security: rule 5, with associated NZHIS response to storage and security issues and associated discussion

- Accuracy: rule 8, with associated NZHIS response to accuracy issues and associated discussion.
- Retention: rule 9, with associated NZHIS response to retention issues and associated discussion.
- Use and disclosure: rules 10 and 11, with associated NZHIS response to use and disclosure issues and associated discussion.
- Unique identifiers: rule 12, with associated NZHIS response to unique identifiers issues and associated discussion.
- Access and correction: rules 6 and 7, with associated NZHIS response to access and correction issues and associated discussion.

1.7 Conclusions to Part 2 of the report:

1.7.1 Conclusion 1: Any centralised database containing identifiable information raises issues concerning the extent of information obtained and the purpose of such a database.

1.7.2 Conclusion 2: Overall, the way the project has been developed indicates that NZHIS is committed to taking a leadership role with respect to the provision of health information services generally, and in this instance the implementation of the MHIP.

1.7.3 Conclusion 3: In doing so it has recognised the need to ensure that its own staff are familiar with the requirements of the Privacy Act and the Health Information Privacy Code. In addition, NZHIS has acknowledged that in order to build a trusting relationship with health service providers, it is important that NZHIS help providers fulfil their obligations when collecting information from individuals.

1.7.4 Conclusion 4: NZHIS has taken the potential privacy impacts seriously and acknowledged the role it needed to play in ensuring that the providers are aware of the purposes of the information and their privacy obligation with respect to their patients.

1.7.5 Conclusion 5: Trust in NZHIS and value in the benefits of the MHIP by both the providers of mental health services and the individuals receiving those services, will be the deciding factor to the ultimate success of the project.

1.8 Recommendations (not in any order of priority)

1.8.1 Recommendation 1: NZHIS needs to document its information management policy regarding the MHIP. This policy should

provide an overview of how the information will be protected from potential privacy intrusions including:

- how NZHIS will ensure that providers are aware of their obligations when collecting information from individuals for the MHIP;
- storage and security safeguards in place to protect the information;
- retention periods for electronic and paper records;
- how accuracy of the information will be achieved;
- restrictions on access to identifiable information by staff of NZHIS and a policy for dealing with unanticipated requests for information held on the database;
- protocol for dealing with research projects;
- restrictions on the linking, by NHI number, of information obtained from the MHIP;
- a procedure enabling individuals to access their personal information and request correction;

1.8.2 Recommendation 2: NZHIS should consider the possibility of appointing a group to monitor the implementation of MHIP on an on-going basis, including monitoring how effective the project is in supplying the statistics necessary to measure the implementation of the National Mental Health Strategy. Such a group could also have responsibility for protecting the information and considering requests for access for research projects and official information requests. For example, NZHIS may chose to invite interested groups to be represented on the group such as Mental Health Commission, the Office of the Privacy Commissioner, and mental health consumer groups.

1.8.3 Recommendation 3: NZHIS needs to develop education materials such as posters and pamphlets, use of web site for both providers and individuals to gain an awareness and understanding about the MHIP. These materials should explain:

- the objectives of the project and why specific information needs to be collected;
- how the information will be protected, and who will be able to use the information;
- individual's right to access and correct information held by NZHIS.

NZHIS should work with the Office of the Privacy Commissioner in developing these materials.

- 1.8.4 Recommendation 4:** NZHIS needs to provide on-going training for staff to ensure that they are aware of how personal health information should be protected from potential privacy risks.
- 1.8.5 Recommendation 5:** NZHIS needs to consider whether it is necessary to retain information about deceased persons in an identifiable form as there will be no need to add further information to those records.
- 1.8.6 Recommendation 6:** NZHIS needs to ensure that a field is included on the database to provide an alert where an individual has requested the correction of information or the inclusion of a statement of correction. This will alert those considering disclosing information for research purposes of the possible inaccuracy of the information.

Part 1: Background to the Mental Health Information Project

2. Introduction

Databases have the potential to monitor and enhance the value of health care services, consequently improving the outcomes for those receiving such services.¹ Good quality information provides a base for assessing performance of a system. However, it has also been noted that the usefulness of the databases for planning and co-ordination of health care and the benefits to the individual concerned should not be assumed without investigation and informed debate.²

Over the last 40 years mental health services in New Zealand have shifted from institutional care toward providing community-based services. During this period there has been much criticism regarding the delivery of the service including the lack of provider responsiveness to the needs of consumers, caregivers and their families.

Over the last four years the Ministry of Health has made significant efforts to identify the needs to be addressed in the delivery of mental health services. The aim of the Mental Health Information Project is to provide complete accurate and timely information on secondary mental health services³ and alcohol and drug services.⁴

2.1 Summary of the Mental Health Information Project

2.1.1 In September 1997, the Minister of Health authorised the New Zealand Health Information Service ("NZHIS") to develop a high-level database containing information on the provision of secondary mental health and alcohol and drug services.⁵ The need to develop such a database flowed from the acknowledged need for national-level information about the mental health sector.⁶

¹ *Health Data in the Information Age: Use Disclosure and Privacy*; Molla S Donaldson; Kathleen N Lohr, Ed. Committee on Regional Health Data Networks, Institute of Medicine, National Academy Press, Washington DC (1994) 61. Improving outcomes may include making available information on access to care, costs, appropriateness, effectiveness and quality of health care services and health care providers.

² *Medical Record Databases: Just what you Need?* Report prepared for the Privacy Commissioner by Robert Stevens, April 1998, 1.

³ Secondary mental health services are defined as services provided by specialist community and hospital based organisations in the public and private sectors.

⁴ <http://www.nzhis.govt.nz/projects/mental.html>

⁵ Ibid.

⁶ This statement was made following a pilot project. The object of the pilot project was to ascertain whether information could be collected in a way that was cost effective and which would have a minimal impact on provider organisations. The pilot phase confirmed that it was possible to extract and store data and to report on the information obtained from mental health

2.1.2 The object of the Mental Health Information Project ("MHIP") is to provide complete, accurate and timely information on secondary mental health services. It is intended that this will:

- allow adequate monitoring of the implementation of the National Mental Health Strategy;⁷
- provide a database for research into the provision of mental health services;
- provide aggregated information to providers, consumer groups, the Health Funding Agency ("HFA"), the Mental Health Commission and other interested parties in the health sector.

2.1.3 Although it was initially contemplated that the database could, in the future, be used for clinical purposes in the treatment of individual patients, this proposed use has now been excluded from the scope of the project.

2.1.4 Information to be collected and collated relates to secondary mental health services, and drug and alcohol services which are funded by the HFA. These secondary services are provided by Hospital and Health Services ("HHS")⁸ as either inpatient or community services, or by non-government organisations ("NGO").

3. National Mental Health Strategy

Looking Forward

3.1 In June 1994 the Ministry of Health released the document *Looking Forward: Strategic Directions for the Mental Health Services*.⁹ This document provided the mental health strategy and outlined the goals, principles and national objectives that were intended to reshape New Zealand's mental health services. Acknowledging the shift away from institutional care towards community-based care as the most cost effective way of providing mental health services, the Government stated a commitment to the community based model backed by in-patient services for acute and secure care.

⁷

Paragraph 3.

⁸

Hospital and Health Services were previously referred to as CHEs or Crown Health Enterprises.

⁹

3.2 In *Looking Forward* the Ministry identified that two of the problems with the existing mental health service were:

- *a lack of provider responsiveness to the needs of consumers, caregivers, and their families;*
- *a lack of a systematic database that would show who uses the mental health services, and a lack of detailed information about who would potentially use the mental health services.*¹⁰

3.3 Two goals were set to guide the work of the mental health services. These goals were to:

- decrease the prevalence of mental illness; and
- increase the health status of and reduce the impact of mental disorders on the individual, their family and caregivers and the community.

3.4 Fourteen principles were identified to define the quality standards to be met by mental health services. The principles which most closely relate to the need to develop some form of centralised database were those:

- *giving priority to cost effective services that provide the best value in terms of health gains;*
- *encouraging service provision to be integrated at all levels and to be focused on achieving maximum wellness and independence for all consumers.*

3.5 Five key strategic directions incorporating the national objectives were set out in the document. These directions were:

1. Implementing community-based and comprehensive mental health services;
2. Encouraging Maori involvement in planning, developing and delivering mental health services;
3. Improving the quality of care;
4. Balancing personal rights with protection of the public;
5. Developing a national alcohol and drugs policy.

3.6 The aim of *Strategic Direction 3: Improving the Quality of Care*¹¹ was:

- *To establish and revise mechanisms for the monitoring of community mental health needs and services;*

- *To promote co-ordination between all agencies involved in the mental health system and to ensure that clear lines of accountability exist;*
- *To develop data collection and analysis systems which provide adequate information for continued long-term planning within the mental health system;*
- *To review and revise if necessary the Government's objectives every five years.*

3.7 *Strategic Direction 5: Developing a National Alcohol and Drugs Policy*¹² also identifies the need to monitor the effectiveness of the alcohol and drug services. It was stated that the National Minimum Dataset should be extended to monitor the performance of these services and to assess their ability to meet consumer demand.¹³

3.8 The Mental Health Strategy Advisory Group 1996 reported to the Minister of Health in 1996 that the progress towards goals in *Looking Forward* needed to be measurable. The Advisory Group recommended the adoption of a goals and targets approach. Such an approach would involve the establishment of measurable goals and objectives and the development of targets and milestones which could be used to map progress towards objectives.

The Advisory Group generally endorsed the allocation of priority issues and strategy development. Gaps in the *Looking Forward* document were identified in the areas of:

- consumer and Pacific Island perspectives;
- mental health promotion;
- primary mental health;
- child and adolescent mental health; and
- intersectorial issues.¹⁴

Moving Forward

3.9 Three years after *Looking Forward* the Ministry of Health produced the *Moving Forward: The National Mental Health Plan for More and Better Services*.¹⁵ This document is also referred to as the National Mental Health Plan (the "Plan"). The purpose of *Moving Forward* was to ensure that *Looking Forward* was implemented, dividing the process into two parts:

¹²

Ibid. 24.

¹³

Paragraph 14.

¹⁴

Mental Health Strategy Advisory Group - Statement to the Minister of Health, April 1996.

..

- *First Steps*; and
- *Next Steps*.

3.10 *Moving Forward* recognised that in the previous three years although more mental health services had been provided it was difficult to measure the quality of those services.

3.11 The Plan aimed to achieve more and better mental health services that worked together with other health and social services so that the right people got services and those services meet their needs.¹⁶ The document sets out strategic directions which contain national objectives and targets.

3.12 Specifically, the Plan included an additional strategic direction to cover the infrastructure necessary for delivering more and better services including data collection and analysis, *Strategic Direction 6: Developing a Mental Health Infrastructure*.¹⁷

3.13 Under *First Steps* there are three National Objectives for *Strategic Direction 6* and four under *Next Steps*.

3.14 The most relevant to the development of the MHIP is National Objective 6.2¹⁸ (*First Steps*):

- *To improve the accuracy, timeliness and appropriateness of mental health data collection, in order to help monitor the achievement of a number of targets in the National Mental Health Plan.*

3.15 Acknowledging that the information currently being collected is limited in terms of accuracy and coverage¹⁹ the aim of this objective is to collect national data on services in ways that are consumer based, flexible, timely and accurate, and to allow access to the information derived from the data at agreed levels of security.

3.16 The target is that by July 2000 *there will be a national health data-collection process which:*

- *provides accurate and timely information that can be used to help monitor a number of targets in the Mental Health Plan;*
- *includes mental health and drug and alcohol data collection.*

¹⁶

Ibid. 9.

¹⁷

Ibid. 31.

¹⁸

Ibid. 32.

..

3.17 Under *Next Steps* the relevant provision is found in National Objective 6.7.²⁰

- *To improve the health status of New Zealanders and to enhance the quality of mental health decision-making by providing up-to-date knowledge based on research information.*

4. National Mental Health Standards

4.1 The National Mental Health Standards (Standards) project was funded by Mental Health Services, Ministry of Health. It was described as a sub-project of the National Mental Health Strategy *Moving Forward*. The Standards apply to all mental health services. Mental health service was defined as *an organisation that provides, as its core business, treatment or support to people with mental illness or mental health problems.*²¹

4.2 The purpose of the Standards is to establish a consistent level of care and support throughout the country. The document includes a form for conducting self assessment/audit on the implementation of the Standards and suggests that in addition an external audit be undertaken before 2000.

4.3 Monitoring of the performance in regard to the criteria set out in each of the twenty standards is the responsibility of the mental health service. The information obtained is to be used by the provider for improving their service delivery.

4.4 The Standards and the form for self assessment indicate an intention on the part of the Ministry for mental health services to monitor their own clinical service delivery.

5. New Zealand Health Information Service

5.1 New Zealand Health Information Service (NZHIS) has been given the task of developing and maintaining the MHIP database.

5.2 NZHIS is a group within the Ministry of Health responsible for the collection and dissemination of health-related information. It is a health agency under the Health Information Privacy Code 1994. It is also a public sector agency and subject to the Official Information Act 1982.

5.3 NZHIS has as its foundation the goal of making accurate information readily available and accessible in a timely manner throughout the health sector.

5.4 The vision of NZHIS is to be recognised as the world-leader in the provision of health information services, and to support the health sector's ongoing effort to improve the health status of New Zealanders. It sees the effective and timely use of information as crucial to achieving this vision.

5.5 High quality information is vital to both the provision of services and the efficient operation of the health and disability support sector. The Health Information Strategy for the Year 2000²² provides the framework for the development and maintenance of health information to meet national requirements. The strategy aims to ensure that an accurate, timely and consistent set of data is available nationally, while protecting the confidentiality of information and avoiding undue compliance and collection costs on the sector.

5.6 The Ministry of Health has given NZHIS responsibility²³ for:

- the collection, processing, maintenance, and dissemination of health data, health statistics and health information;
- the continuing maintenance and development of the national health and disability information systems;
- the provision of appropriate databases, systems and information products;
- the development and provision of health and disability information standards and quality-audit programmes for data;
- co-ordination of ongoing national health and disability information collections and proposals for their development;
- analysis of health information and advice on the use of information obtained from NZHIS.

5.7 The guiding principles for national health information are:

- the need to protect patient confidentiality and privacy;
- the need to collect data once, as close to the source as possible, and use it as many times as required to meet different information requirements;
- the need for standard definitions, classification and coding systems;
- the requirement for national health data to include only that data which is used, valued and validated at the local level;

²²

Health Information Strategy for the Year 2000; <http://www.health.govt.nz/> ; *Privacy Impact Assessment and Commentary on the Health Intranet Project for New Zealand Health Information Service*, paragraph 3.

..

- the need for connectivity between health information systems to promote communication and integrity;
- the need to address Maori issues.

6. "The Mason Report" - Inquiry under section 47 of the Health and Disability Services Act in respect of certain mental health services (May 1996)

- 6.1** The purpose of the Ministerial Inquiry was to consider the availability and delivery of aspects of mental health services relating to semi-acute and acute mental disorder. In particular, it was to consider recent recommendations from previous inquiries and international reports, consider amendments to the Mental Health (Compulsory Assessment and Treatment) Act 1992) and review how the Health Information Privacy Code was being used by mental health service providers.
- 6.2** The Ministerial Inquiry also considered the rights of family members, the use of drugs and alcohol, and the provision and co-ordination of services.
- 6.3** In the report, numerous recommendations were made. The most relevant recommendation relating to the development of a national database of mental health information was the requirement for the development of a new organisation to act as a catalyst to improve the performance and lift the priority given to Mental Health in New Zealand.²⁴ This organisation was to provide national leadership and direction in the delivery of mental health services including the promotion of research to enable planning on an informed basis for mental health needs in New Zealand. This recommendation was implemented by the formation of the Mental Health Commission.

7. Mental Health Commission

- 7.1** The Mental Health Commission Act 1998 establishes a Mental Health Commission comprised of three commissioners being one full time chairperson, a second commissioner who is an experienced mental health professional and a third commissioner who is to be a consumer or family representative with an interest in mental health.
- 7.2** The role of the Mental Health Commission is to ensure the implementation of the national mental health strategy, and by carrying out that task, to improve services that affect people with mental illness and to improve outcomes for people with mental illness and their families and caregivers.²⁵

²⁴

Inquiry under section 47 of the health and Disability Services Act 1993 in respect of certain mental health services. Report of the Ministerial Inquiry to the Minister of Health Hon Jenny Shipley, May 1996, 102

..

7.3 Functions of the Commission are found in section 6 of the Act and include:²⁶

- reporting to the Minister of Health ("Minister") on the implementation of the national mental health strategy (section 6(1)(a));
- reporting to the Minister when requested on any matter relating to the implementation of the national mental health strategy (section 6(1)(b));

7.4 The matters to be included in the report are:

- the extent which the Ministry of Health ("Ministry") has exercised leadership in the implementation of the mental health strategy;
- the extent to which the Health Funding Authority ("HFA") (previously regional health authorities) has exercised leadership in the implementation of the mental health strategy

7.5 Mental Health Commission's Blueprint for Mental Health Services in New Zealand²⁷ sets out the service developments needed to ensure that mental health services and the mental health workforce are developed so that in time²⁸ they deliver a range of services provided by the right combination of people responding appropriately to the needs of those affected by mental illness, including their families/whanau.²⁹

7.6 In addressing infrastructure issues the Commission notes the lack of good information about:

- what services are being provided;
- where those services are being provided;
- for which diagnosis; and
- for whom.³⁰

7.7 However, it notes that this lack of information is being remedied. It states:

The Ministry of Health and New Zealand Health Information Service(NZHIS) have completed a successful pilot^[31] of the new national mental health data collection system, and the Minister of Health has now approved full national implementation which will be completed by the end

²⁶ Mental Health Act 1998 section 6 Appendix 3.

²⁷ Blueprint for Mental Health Services in New Zealand. *How things need to be*. November 1998, Mental Health Commission.

²⁸ Ibid. Five years from the date of the document.

²⁹ Ibid. Foreword vi.

³⁰ Ibid. 9.7 Mental Health Information, 81.

³¹ The pilot phase of the MHIP took place between March and May 1997. This phase confirmed that it was possible to extract and store data, and to report on the information obtained from mental health service providers, and that it could be done in a

of 1999. The new system collects information about services used by clients and is linked to the client's National Health Index (NHI) number.

All CHE^[32] and NGO mental health service providers will provide data on:

- *descriptive information about their client group (age, ethnicity, domicile code, gender)*
- *diagnosis - to get a clearer picture of the problems which are being addressed by mental health services*
- *service provided-based on the National Mental Health Common Base Definitions*
- *referral source*
- *where the service is being provided*

Information collected will be made available to all those who provide data and to the Ministry of Health, Mental Health Commission, and [HFA] through a series of standard reports. Issues of privacy are being addressed as part of the project to ensure clients get good information about their rights, and about what data is being collected and how it will be used.

This new Mental Health Information Service will greatly aid service planning and measurement of progress towards achievement of the goals, objectives and targets of the National Mental Health strategy. For the full benefits of the data collections to be realised it is vital that providers forward data which is as accurate as possible.

8. Legal requirements

There are several enactments which concern the management of personal health information, including information contained on a database such as the one contemplated by NZHIS. The Privacy Act and Health Information Privacy Code set out controls for the management of such information. However, other Acts may impinge on these controls, for example by requiring information to be collected or disclosed in certain circumstances for specified purposes.³³

8.1 Privacy Act 1993

The Privacy Act came into force on 1 July 1993. It aims to protect personal information about identifiable individuals in accordance with international guidelines already developed overseas. Underlying the Act is the idea that

³²

Hospital and Health Services were previously referred to as CHEs or Crown Health Enterprises.

³³

For example, Misuse of Drugs Act 1975, s.20; Medicines Act 1981, s.49A. Other enactments may also contain provisions

individuals should be able to exercise some control over the way in which their personal information is managed by others. This requires agencies holding personal information to be open with the individual about the way in which it will be managed.

In particular, the Act:

- (a) 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 his or her 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.

- (b) 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.

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.

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.

8.2 Health Information Privacy Code 1994

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 taking into account the particular nature of the information involved.

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 was subsequently issued in June 1994 replacing the Temporary Code. The Health Information Privacy Code 1994 (HIPC) modified all of the information privacy principles taking into account the sensitive nature of health information. 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 principles in the HIPC are referred to as rules.³⁴ The numbering of the rules follows the numbering of the information privacy principles.³⁵

The Code applies to health agencies in their management of identifiable health information.

Health information: The Code applies to the following information or classes of information about an identifiable individual:³⁶

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

The Ministry of Health is a health agency as defined by the HIPC. NZHIS, as part of the Ministry of Health, is also a health agency as it holds personal

³⁴ Health Information Privacy Code rules, appendix 2.

³⁵ The Health Information Privacy Code 1994 was last amended September 1998.

health information. The HIPC applies to the way NZHIS manages health information about identifiable individuals. Information on the MHIP database will be identified by the NHI number. As the NHI number may be linked to an identifiable individual, the information on the database will fall within the definition of health information.

The rules of the Code should not be considered in isolation. The Code 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 told of that purpose. For instance, while immediate liability might fall with a provider for breach of rule 3 (collection of information from individual), the responsibility lies with the ultimate receiver of the information to ensure that the provider knows the facts and the obligation to make the individual aware of the purposes.

There are specific provisions within the HIPC rules regarding the collection, use and disclosure of health information for statistical or research purposes. Unless the particular research project is one of the purposes for obtaining the information and the information is collected directly from the individual, the HIPC requires that:

- if the research project requires the approval of an ethics committee, approval must have been given before the information may be collected, used or disclosed; and
- the information must not be published in a form that could reasonably be expected to identify the individual concerned.

The savings provision of the Privacy Act (section 7) applies to the Health Information Privacy Code 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 Code. However, even though the information may be required, for instance to be disclosed, there will still be a requirement (unless also specified in the other enactment), for the individual to be informed of that information flow even though she or he may not be able to veto the action. However, the means of collection must not be unfair, unlawful or intrusive.

Although the HIPC sets a framework for how personal health information should be managed, the Privacy Commissioner still has the power to vary the code or issue a code to cover a specific activity if he considers it necessary.

8.3 Health Act 1956

The Health Act contains several provisions which relate to the management of personal health information. Only the provisions relevant to NZHIS's role in maintaining the MHIP database are referred to below.

8.3.1 Section 22C gives a discretionary power to an agency providing health services or disability services or a purchaser of such services to disclose information to specified persons for specified purposes.

8.3.2 Section 22C(2)(g)(ii) provides that an employee of the Ministry of Health may request information for the purpose of compiling statistics for health purposes. NZHIS may request information for the MHIP under this provision.

8.3.3 Section 22D enables the Minister of Health to require any purchaser or hospital and health service (HHS) to provide specified returns or other information concerning the condition or treatment of, or the health services or disability service provided to any individual in order to obtain statistics for:

- health purposes; or
- the purposes of advancing:
 - * health knowledge;
 - * health education; or
 - * health research.

8.3.4 This information must be provided in an anonymous form unless the individual has consented to the provision of the information or the identifying information is essential for the purpose for which the information is sought. This information may be compiled in statistical form by NZHIS. However, to ensure the information is stored against the correct health care user it must be supplied to NZHIS with an NHI number attached.

8.3.5 Section 22D does not enable collection from a non-government organisation (NGO).

8.3.6 Section 22F provides that every person who holds health information of any kind shall, at the request of the individual, or their representative, or person that is providing or is to provide health care services to an individual, disclose the information. Where there is a refusal to provide the information, the person whose request is refused may complain to the Privacy Commissioner.

8.3.7 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. This section would not be applicable to collecting information for the MHIP as the information will need to be provided in an identifiable form, usually with the NHI number as the unique identifier, so that subsequent information may be added to the record.

8.4 Hospitals Act 1957

Section 139A of the Hospitals Act enables the Director General of Health to request certain information concerning the condition or treatment of patients in a private hospital in order to obtain statistics for medical purposes or for the purpose of advancing medical knowledge, education or research.

8.5 Official Information Act 1982

NZHIS, as part of the Ministry of Health, is subject to the Official Information Act (OIA). Underlying the OIA is the principle of availability of official information, although the Act does provide some grounds for withholding official information. The definition of official information is broad and includes information held by NZHIS. This would include personal health information found on the National Health Information Systems (NHIS). A request for information by a third party would be dealt with under this Act.

A request for personal information by the individual (or her representative) must be considered under the Health Information Privacy Code or section 22F of the Health Act.

Any person may make a request for official information. NZHIS would have to consider the request taking into account any of the withholding grounds under section 6, which provide conclusive reasons for withholding official information, and section 9 which provides other reasons for withholding official information. If any of the section 9 reasons are used

then the grounds for withholding information have to be balanced against any other considerations which render it desirable, in the public interest, to make that information available.

One of the grounds for withholding information is to protect the privacy of natural persons including that of deceased natural persons (section 9(2)(a)). Obviously, the information held on the MHIP database will have significant privacy interests and it would be difficult to find public interest factors of sufficient weight to outweigh the privacy interest and hence justify making the information available. In fact it could be considered that there are public interest factors indicating that this information should not be made available. Of course, each request must be assessed on its own merits and occasionally the request may be such that there is a public interest in some information being made available to a third party.

9. Professional and Ethical Codes of Practice

9.1 Health professionals have duties also to ensure that they adhere to their own professional codes of practice and conduct. Many of these codes create standards that are idealistic. Health professionals are then faced with balancing the discretion provided by legislation, enabling the disclosure of personal information, against the ethical standards imposing a duty to respect the secrets which have been confided in health professionals, even after the patient has died.

10. Standards New Zealand

10.1 There are international standards for the security and privacy of information held on information systems which also apply in New Zealand. One such standard is the Australia/New Zealand Standard on "Information Security Management" AS/NZS 4444.

10.2 The three basic components of information security are identified as:

10.2.1 *confidentiality*: meaning the need to protect sensitive information from unauthorised disclosure or intelligible interception;

10.2.2 *integrity*: requiring safeguards to protect the accuracy and completeness of information and computer software; and

10.2.3 *availability*: ensuring that information and vital services are available to users when required.

11. Health Research Council Guidelines on research involving personal information

11.1 The Health Research Council has developed some guidance notes for those anticipating research involving personal information. The standards set by the guidance notes are generally more stringent than those required by the HIPC.³⁷

11.2 These guidance notes will be relevant if a researcher wishes to search the MHIP database for a particular group of people. For example, to identify a group of people diagnosed with a similar condition.³⁸

11.3 The function of these guidance notes are:³⁹

- *To highlight matters in the HIPC which are especially relevant to health research;*
- *To provide guidance for health researchers, ethics committees and custodians or health information where the HIPC leaves them with a discretion. The guidance notes indicate matters which should be taken into account in making decisions in such cases;*
- *To deal with matters beyond the provisions or framework of the HIPC. The notes recommend good practice, in the use of personal information for research, which goes beyond the requirements of the Code.*

12. Database management

12.1 The Oxford English reference Dictionary defines database as *a structured set of data held in a computer especially one that is accessible in various ways*. Elsewhere it has been defined as a large collection of information held on a computer.⁴⁰ Generally a database is organised in such a way that information may be added to update and expand a record and information may be retrieved rapidly by authorised users for various purposes. The use of the information will depend on the purpose of the database.

12.2 Databases provide an important solution for managing large quantities of personal information. However, the temptation always exists to collect lots of information, often as a result of optimising the use of database software packages with multiple fields and linking features. In some cases information use is determined by posing the question 'we have the information, what can we do with it?'. In contrast, determining the

³⁷

<http://www.hrc.govt.nz/ethguid9.htm>.

³⁸

This illustrates the importance that the information contained on the database is accurate.

³⁹

<http://www.hrc.govt.nz/ethguid9.htm> page 3.

⁴⁰

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objectives for collecting and retaining information at the development phase and first asking 'what do we want to achieve, how much information do we need to be able to achieve that purpose?' may streamline database development. This would also be consistent with the HIPC.

12.3 Obviously, it is impossible to make people aware of the purposes of the database if these have not been decided at the time when the information is collected.

12.4 Unlimited collection of information for unanticipated purposes may lead to future frustrations for agencies wishing to use that information. An agency which has the ability to use personal information in a new way may be thwarted if that potential use or disclosure was not ascertained at the time of collection.

12.5 The structure and content of a database will depend on the purpose for which it has been developed. Planning is an essential first step in developing the database.

12.6 Databases containing health information can be divided into two categories:⁴¹

12.6.1 *Primary patient record* used by health care professionals who provide clinical patient care services. The purpose of the database is to review patient data or document observations, actions, or instructions by health care providers;

12.6.2 *Secondary patient record* is derived from the primary record and contains selected data elements to aid non-clinical users (i.e. persons not involved in direct patient care) in supporting, evaluating, or advancing patient care.

12.7 The MHIP database will be a secondary patient record. Information will be obtained from primary records but the database will be held quite separately from the clinical or primary patient record.

*[Secondary files] are not under the control of a practitioner or anyone designated by the practitioner, nor are they under the management of any health institution (e.g. the medical records department of a hospital). Furthermore they are not intended to be **the** major source of information about specific patients for the treating physicians. Secondary databases*

*facilitate reuse of data that have been gathered for another purpose (e.g. patient care, billing, or research) but that, in new application, may generate new knowledge.*⁴²

12.8 Attributes of a database can be divided into *comprehensiveness* and *inclusiveness*⁴³.

12.8.1 *Comprehensiveness* describes the completeness of the patient record or the amount of information held about that particular person. For instance this may include:

- demographic information such as age, gender, ethnicity;
- administrative information;
- details of health risks and health status;
- medical history;
- current management of health conditions;
- outcomes.

12.8.2 *Inclusiveness* refers to the populations included in a database:

- national;
- geographic area;
- care setting e.g. hospital, community;
- medical condition, e.g. Cancer Registry, trauma;
- age or other demographic characteristic.

12.9 The usefulness of a database is directly related to the quality of the information it contains. The information must be accurate and regularly updated. Where information is added to an existing record, there needs to be a mechanism for updating the correct record. Consequently, such records cannot be made anonymous. At best the identifiers may be encrypted and decrypted to enable the information to be updated.

12.10 Furthermore, if organisations providing information, in this instance the mental health service providers, are not convinced about the purposes of the database, or perhaps do not trust the management of the database the integrity of the information may be compromised. A lack of commitment to provide adequate, accurate and timely information imperils the usefulness and integrity of the database.

⁴²

Health Data in the Information Age: Use Disclosure and Privacy; Molla S Donaldson; Kathleen N Lohr, Ed. Committee on Regional Health Data Networks, Institute of Medicine, National Academy Press, Washington DC (1994) 42.

13. Databases and the privacy legislation

13.1 The following are suggestions of checks which may be taken into account when considering database development:

- 13.1.1** Define the purpose of the database;
- 13.1.2** Identify legislation which may impact on the development and use of the database;
- 13.1.3** Consider ethical issues. Professional codes of practice sometimes set higher standards than those required by legislation;
- 13.1.4** Identify industry codes of practice or standards which need to be considered;
- 13.1.5** Identify the agency's policy on the management of personal information;
- 13.1.6** Ensure that staff who are going to be involved using the database are aware of its potential scope and limitations and are given the opportunity to be included in the development phase;
- 13.1.7** If the information is already held, identify what the current practice is for managing personal information;
- 13.1.8** Identify what has motivated the need for change;
- 13.1.9** Identify who will be responsible for developing and maintaining the database;
- 13.1.10** Consider the privacy implications of the project and identify whether there may be individual resistance. If so, identify ways in which privacy intrusions may be reduced and protections implemented;
- 13.1.11** Define what sort of information will be held. Identify whether the information may be considered sensitive by the individual;
- 13.1.12** Determine how much information needs to be collected to achieve the objectives of the database;
- 13.1.13** Ascertain whether the information will be collected directly from the individual or via a third party. When information is to be

collected by another agency, ensure background details are provided to the other agency to enable it to explain to the individual the purpose of the information flow;

- 13.1.14** Ascertain how the individual or the representative of the individual, for example the parent of a child, will be informed of the purposes the agency may make of their personal information, including identifying any third parties information may be disclosed to. This may be included on an application form, part of an information booklet or explained orally at the time of collection;
- 13.1.15** Determine how the individual will be informed of her or his right to access and correction of their personal information held by the agency and develop procedures to enable such access and correction (Rules 3, 6 and 7 of the HIPC);
- 13.1.16** Decide whether it is necessary to assign a unique identifier to enable the agency to carry out any one or more of its functions efficiently;
- 13.1.17** Consider storage and security safeguards which need to be implemented to protect the information. For example:
 - operational (secure physical site, staff training);
 - technical (authorised access, passwords, screen-savers);
 - disciplinary action (warning for misuse, dismissal);
 - audit trails to detect misuse.
- 13.1.18** Decide how long the information should be retained including considering any legislative requirements;
- 13.1.19** Develop procedures to ensure that information is accurate before it is used. One of the greatest difficulties in managing large databases containing personal information is maintaining its accuracy;
- 13.1.20** Develop staff training programmes prior to implementation of the database;
- 13.1.21** Appoint a person or committee to decide when personal information may be used or disclosed outside the scope of the original objectives;

- 13.1.22 Develop procedures for dealing with third party requests for personal information. In the public sector third party requests for information will have to be considered under freedom of information legislation;
- 13.1.23 Define lines of staff accountability in relation to collection, maintenance and release of information;
- 13.1.24 Practical training programmes need to be developed for staff dealing with information requests under both privacy and freedom of information legislation.

14. Current monitoring of mental health data

- 14.1 Currently, information about in-patient mental health data is collected as part of the National Minimum Dataset (NMDS) maintained by NZHIS. This database contains information from psychiatric hospitals, hospitals or services that provide care for people with intellectual disability, psychiatric units or public hospitals and facilities that are licensed under the Alcoholism and Drug Addiction Act (1966).⁴⁴
- 14.2 Since community-based mental health information programmes are not included, the NMDS underestimates the number of people receiving secondary mental health services. In addition, the NMDS does not contain information from NGOs providing secondary mental health services.
- 14.3 Consequently, the mental health data statistics available from the NMDS are not sufficient to be able to provide the type of analysis required by the national mental health strategy.

15. Purpose of the Mental Health Information Project

- 15.1 The July 1998 issue of the Mental Health Information Project Newsletter⁴⁵ states that:

The aim [of the project] is to provide complete, accurate and timely information on the provision of specialist mental health services. When the project is fully implemented, we will provide a range of reports to providers of secondary and community mental health services, as well as health agencies such as the Health Funding Authority, the Ministry of Health and the Mental Health Commission. These reports will provide a variety of

information regarding the provision of these health services, such as usage and trends.

- 15.2** Information to be collected relates to the provision of secondary mental health and alcohol and drug services funded by the Health Funding Authority.
- 15.3** Information will be collected on a national basis from all the hospital and health services and over 450 NGOs providing mental health services.
- 15.4** Information will be supplied on a regular basis, using the NHI number as an identifier. This information may be supplied in either electronic or paper form, using the NHI number to ensure that there is no duplication of records. Using the NHI will also enable on-going information to be linked to a particular individual. However, all the reports will be based on aggregated data so that individuals cannot be identified.
- 15.5** It is crucial that NZHIS is clear about the purposes of the MHIP database, including potential future uses. If these are not contemplated at the development stage, and prior to collection of any information, subsequent unanticipated use may be prevented or at least impeded.

16. Content Mental Health Information Database

- 16.1** The database consists of six primary tables recording details of:
 - 16.1.1** Health care users:
 - NHI;
 - date of birth;
 - date of death;
 - gender;
 - ethnicity;
 - domicile code indicating the area in which the person lives.
 - 16.1.2** Diagnosis:
 - organisation diagnosing the individual;
 - date of diagnosis;
 - clinical coding system used;
 - type of diagnosis (e.g. provisional, principal, other);
 - diagnosis code.
 - 16.1.3** Legal status:
 - organisation making the assessment for legal status;
 - legal status code.

- date of legal status.

16.1.4 Service provided:

- organisation providing service to person;
- group or team providing service to person;
- service of treatment provided to person;
- date service starts;
- date service ends;
- flag indicating information is suppressed in the national system. (The default setting is that the information will be suppressed.)

16.1.5 Access to services:

- location of service provided (e.g. inpatient, outpatient, community);
- number of times service provided in reporting period;
- type of service provided (e.g. bed day, attendance);
- period of data reported.

16.1.6 Referrals:

- organisation person referred to or from;
- date of referral;
- type of referral (to or from mental health service).

16.2 At an early stage of the project it was considered necessary to include a suppression flag as a privacy protection if the information on the database was to be used in the future for clinical purposes. This was to enable individuals who did not want their details used for clinical purposes to suppress this use. As already discussed, it is not longer one of the purposes of this project to use the database for clinical purpose. Consequently, a suppression flag is not necessary as identifiable information on the database will be encrypted.

16.3 Non-government organisations will only provide details of legal status or diagnosis if this is information which they obtain clinically. In most cases NGOs do not employ clinicians so the information on legal status and diagnosis will be obtained only in relation to contact with the HHS. However, the role of NGOs is evolving, so the flexibility to allow this information to be picked up from NGOs is included in the design on the data collection.

17. Conclusion Part 1

- 17.1** The Ministry of Health has made a commitment to ensure that mental health services are available to those who need them. In order to monitor the success of implementing this commitment, it has been considered necessary to measure the delivery of secondary mental health services by both public sector and non-government organisations.
- 17.2** One of the objectives of the MHIP is to provide a mechanism for monitoring the implementation of the mental health strategy with respect to the delivery of secondary care services.
- 17.3** Although there is no statutory requirement for providers to supply this information, the funding agreement for 1998/99 includes, as part of the performance measures for the HFA five year plan, a commitment from the HFA for "requirement for compliance with the NZHIS national mental health information system to be included in 1999/2000 service specifications".
- 17.4** Providing NZHIS is able to gain the commitment of the providers, NZHIS is in an excellent position to be able to carry out the development of a secondary database for the provision of aggregate data to effectively monitor the delivery of secondary mental health services.
- 17.5** However, NZHIS must ensure that all the purposes of the database are properly contemplated prior to implementation and that the mental health service providers are aware of these purposes so that they may be conveyed to individuals receiving services, and whose information is to be provided.

Part 2: Privacy Impact Assessment

18. General overview of the project from a privacy perspective

- 18.1** As discussed in Part 1, the origins of the MHIP are found in the national mental health strategy and the need, identified in the Mason Report and by the Mental Health Commission, for a collection of national mental health information.
- 18.2** Privacy concerns and risks associated with the MHIP arise out of the way the information is collected and how it will be managed and used once contained on the database.
- 18.3** The purpose of the MHIP is to provide statistical information, reports and analysis about the trends and delivery of secondary mental health services both nationally and on a provider basis. One of the key benefits of this project is the regular supply of reports to the provider both about their own services, and also regional and national trends. The reports will be based on aggregated information so that people cannot be identified.
- 18.4** NZHIS has also envisaged that from time to time researchers may also request to use the database for research purposes. NZHIS has procedures for dealing with this type of request for information.⁴⁶
- 18.5** A distinction should be made between the role of NZHIS in developing the MHIP and the use of the National Mental Health Standards. The Standards have been developed to ensure consistent provision of mental health service by providers. Providers are encouraged to assess and audit their clinical delivery of care to individuals against these standards.⁴⁷ Consequently, measurement of mental health services providers delivery of clinical care is outside the scope of the MHIP.
- 18.6** Health information is sensitive and mental health information even more so because of the stigma that sometimes attaches to a person identified as having a mental illness whether or not this is shown to be the case. This stigma has been acknowledged to the extent that the Mental Health Commission has been given the role of reducing the stigma associated with mental illness and the prejudice shown to people with mental illness and their families and caregivers.

- 18.7** It had previously been suggested that, at some time in the future, information about individual consumers obtained by NZHIS may be made available to clinicians.⁴⁸ This possibility raised significant privacy issues relating to the amount of information required to be collected and the accuracy of that information. A database developed for the purpose of providing reports and statistics, has different information requirements to a database to be used for clinical purposes. *It is no longer an objective of the project to provide identifiable information for clinical purposes.*
- 18.8** Furthermore, NZHIS would not be the most appropriate agency to be providing a database of information for clinical purposes, or, in other terms, a primary patient record.⁴⁹ Indeed this has never been considered as a possibility. However, NZHIS is able to develop the MHIP database as a secondary patient record⁵⁰ to facilitate statistical analysis and reporting on the delivery of mental health services by secondary health providers.
- 18.9** Generally, the management of the information contained on the database will fall within the provisions of the Health Information Privacy Code 1994 ("HIPC"). The HIPC and in particular the rules do not specify how databases may be used. What the rules do provide is a framework which enables agencies to implement their desired database objectives.
- 18.10** Increasingly, as personal information becomes a commodity of significant value, agencies, in this instance the mental health services providers and NZHIS, need to be aware of the privacy impacts of a proposal. Taking individuals' concerns seriously may enhance trust in the provider, building the relationship between it and the individual, and between the provider and NZHIS. In contrast, failing to address privacy concerns may lead to complaints and undermine the objectives of the MHIP. An extreme scenario would be an individual deciding not to seek treatment because of distrust of the mental health service provider, or the NZHIS.
- 18.11** The policy underlying the development of the database associated with the MHIP needs to be explored to establish clearly what its parameters may be and the extent of information required to achieve the objectives of the MHIP. It has been suggested that when considering the privacy impact of a proposal the following seven questions could be posed:⁵¹

- 1. What is the purpose of the information?*
- 2. Will collection achieve a compelling public health purpose?*

⁴⁸ <http://www.nzhis.govt.nz/projects/mental.html>

⁴⁹ Paragraph 12.5.1.

⁵⁰ Paragraph 12.5.2.

⁵¹ *Health Data in the Information Age: Use Disclosure and Privacy*; Molla S Donaldson; Kathleen N Lohr, Ed. Committee on

3. *Will collection result in effective health policy; that is, might it drive people underground if they fear the consequence of disclosure?*
4. *Who will have access to the information? Can it be disclosed by force or law? What will be the effect of negligent disclosure?*
5. *What impact will it have on human rights - is there a stigma to individuals or communities?*
6. *Are there less invasive alternatives?*
7. *What safeguards are available to reduce the risk?*

18.12 These questions will be addressed below.

19. Collecting/obtaining information: HIPC Rules 1-4

19.1 There is no statutory provision requiring the development of the MHIP, although the project was authorised by the Minister of Health in September 1997. Consequently, provision for collecting, storing, retaining, using and disclosing information, and providing the right to access and request correction of it, must be considered under the existing legislation.

19.2 In order to update existing records, identifiable information will need to be collected. Under section 22D the Minister of Health could require the Health Funding Authority or a hospital and health service to provide non-identifiable information, or identifiable information if it was essential for the MHIP or if the consent of the individual had been obtained. However, relying solely on this provision does not address the need to collect information from the non government organisations providing secondary mental health services which are not covered by a section 22D notice.⁵²

19.3 NZHIS may request information from a provider of mental health services under section 22C(2)(g)(ii) the Health Act for statistical purposes.⁵³

19.4 The information could also be provided under rule 11 of the HIPC, if disclosure of the information by the provider was one of the purposes for which the information was obtained, or directly related, or the disclosure falls within one of the exceptions to rule 11.⁵⁴

19.5 Under both the Health Act and the HIPC the disclosure of information to NZHIS is discretionary on the part of the provider. Consequently, the success of the MHIP will depend on mental health service providers agreeing to provide the information to NZHIS.

⁵² To date, no such notice has been given by the Minister.
⁵³ Paragraph 8.3.
..

- 19.6** The Health Funding Authority now includes a provision in the funding contracts with providers requiring the providers to supply information to NZHIS for the MHIP database. This will add to the weight of having to provide such information, although providers still need to exercise their discretion when deciding whether to disclose the requested information.
- 19.7** However, the question remains open about whether the Health Funding Authority can *require* the provider to supply the information when section 22C of the Health Act provides a health agency with a *discretion* to provide the information requested.
- 19.8** Such a condition will not entitle the Health Funding Authority to identify information from the database, as the purpose of NZHIS collecting the information is limited to statistical and research purposes. If information were to be provided to the Health Funding Authority, or any other organisation, in an identifiable form, then the purpose for that information flow would need to be ascertained and individuals made aware of the purposes of the information flow at the time the information was collected by the mental health services provider.⁵⁵
- 19.9** The HIPC requires openness in the process of collecting personal health information. The requirements of the Code are set out in rules 1-4. These rules directly link with the other rules in the Code. For instance, the purposes for which information is collected directly relate to how that information may subsequently be used or disclosed. Deciding what information is required, the purposes for which it is required and telling the person about those purposes ensures that there are fewer difficulties in using information subsequently.
- 19.10** The collection issues discussed below concern NZHIS collecting information for the purposes of compiling and maintaining the mental health information database. Information is collected from providers who have collected the information directly from the individual.

20. Purpose of collection: Rule 1

- 20.1** Rule 1 of the HIPC states that health information must not be collected by any health agency unless the information is collected for a lawful purpose and that purpose is connected with a function or activity of the health agency. In addition, the collection of information must be necessary for that purpose.

- 20.2** The National Mental Health Strategy sets out the need for an information database. The purpose of the MHIP is to provide national-level information about the secondary mental health, alcohol and drug services. The MHIP will provide a mechanism for measurable analysis of the delivery of mental health services.
- 20.3** In addition section 22C of the Health Act provides a lawful purpose for NZHIS to collect the information, being for the administering of the Health Act or the Hospitals Act and for compiling statistics for health purposes.
- 20.4** NZHIS has defined the purpose of collating the information on the database as:
- enabling adequate monitoring of the implementation of the national mental health strategy;
 - providing a database for research into the provision of mental health services;
 - providing aggregated information to providers, consumer groups, the HFA, the Mental Health Commission and other interested parties in the health sector.
- 20.5** One of the roles of NZHIS is the responsibility for the collection and dissemination of health related information on a national basis.⁵⁶ Collecting information for the purposes of developing a database as part of the MHIP would be consistent with its role.
- 20.6** Research is also an important part of measuring and analysing of the delivery of services. It will be important that providers are made aware that this is also one of the purposes of the MHIP, although safeguards will be in place to protect the use of the information for research purposes.⁵⁷
- 20.7** There are no statutory provisions which require providers to provide the information for the MHIP database. NZHIS will have to rely on the co-operation of the mental health services providers to enable a comprehensive database with accurate and up to date information to be established.

21. Source of health information: Rule 2

- 21.1** Rule 2 of the HIPC requires that where a health agency collects health information, it must collect the information directly from the individual.

- 21.2** The rule then provides several exceptions including where the agency believes on reasonable grounds that the individual concerned authorises collection of the information from someone else having been made aware of the matters set out in rule 3(1).⁵⁸
- 21.3** There are two exceptions which are relevant to NZHIS collecting information indirectly:
- 21.3.1** Rule 2(2)(d): that compliance is not reasonably practicable in the circumstances of the particular case;
- 21.3.2** Rule 2(2)(g): that the information will not be used in a form in which the individual concerned is identified, or in the case of statistical and research purposes that it will not be published in a form that could reasonably be expected to identify the individual concerned.
- 21.4** The nature of NZHIS and its role means that it is not in a position to collect information directly from the individual. Instead, NZHIS will have to rely on the information being collected by the provider of mental health services. The provider will have to comply with the obligations set out under rule 3. However, for the provider to be able to fulfil its obligations, NZHIS will have to ensure that the provider is aware of the purposes for which information is going to be disclosed to NZHIS. This will include any disclosures of information about identifiable individuals NZHIS may subsequently make.
- 21.5** A third party agency obtaining information from a source other than the individual can use the information only if the use is consistent with the purposes for which it was obtained by that agency. In other words, individuals need to be made aware that one of the purposes the mental health services provider is collecting the information is to disclose information to NZHIS for statistical and research purposes. NZHIS can only use the information consistently with the objectives of the MHIP and cannot initiate the use or disclosure of that health information for other purposes.
- 21.6** For instance, if NZHIS collects information for statistical and research purposes it cannot then use that information for other purposes unless the authorisation of the individual has been obtained or the use or disclosure falls within one of the exceptions found in the HIPC and any prerequisites

for use and disclosure are satisfied. The only other exception is where the disclosure is required by law.

22. Collection of information from individual: Rule 3

22.1 The HIPC places an onus on the provider of health services, as collector of personal health information, to ensure that the individual is aware of the information flows and the purpose of those flows.

22.2 Rule 3 sets certain requirements for a health agency collecting information directly from the individual. As discussed above, the nature of NZHIS's functions means that it will not be in position to collect information directly from the individual.

22.3 However, NZHIS has a responsibility to ensure that a provider of mental health services is aware of the purposes of the MHIP. When a provider collects information the provider needs sufficient information about the MHIP to ensure that the individual is made aware that one of the purposes of collecting the information is to provide information to NZHIS for entry on the MHIP database. If it is not practicable to tell the person at the time the information is being collected, then she or he must be made aware as soon as practicable after it is collected.

22.4 Once a provider agrees to provide information to NZHIS as part of the MHIP, and has taken reasonable steps to ensure that the individual is made aware of this information flow and the purpose of it, the individual does not have any right to veto that disclosure as the requirement of rule 3 is to ensure awareness and not obtain authorisation.

22.5 As the supply of the information is not mandatory under law, the supply of information needs to be considered voluntary. However, the individual must be told of the consequences of not supplying the information. For example, if the provision of funding is conditional on the supply of information to a third party, then the consequence of not supplying information may be that the provider does not receive funding. This may mean that the individual has to pay or pay more to the provider to receive treatment.⁵⁹

23. Manner of collection: Rule 4

23.1 Rule 4 of the HIPC states that health information must not be collected by unlawful means or by means that in the circumstances of the case are unfair

⁵⁹ Review of the National Health Index Number: Privacy Considerations. Report prepared for NZHIS, February 1999. Paragraphs

or intrude to an unreasonable extent upon the personal affairs of the individual concerned.

- 23.2** The responsibility of ensuring that the information is collected by means which are in a lawful, fair and not intrusive will lie with the health agency collecting the information, the provider.

24. NZHIS response to collections issues

- 24.1** NZHIS has been working with mental health service providers to ensure that they understand the objectives of the MHIP. This has been an exercise in building the relationship between NZHIS and providers. Initially, employees from NZHIS meet with the information technology management team, clinical team leaders and staff working in the mental health area. At this stage NZHIS provides an overview of the project. At the request of the mental health service provider, NZHIS will provide further presentations to staff regarding the MHIP.

- 24.2** In addition to discussing the technical aspects of the MHIP, employees from NZHIS have been explaining to providers the information requirements from a privacy perspective.

- 24.3** Newsletters about the MHIP are freely available on the NZHIS web site.⁶⁰

- 24.4** Generally, providers are being told that the information being collected is about the type and amount of secondary mental health services being used, including, for instance, the number of nights spent in a residential home, the number of group sessions attended and details of gender, age and ethnicity. The providers are told that the information will be used to show how mental health services are being used and to help ensure that appropriate mental health services are being provided.

25. Collection issues: Discussion

- 25.1** The first issue which needs to be addressed is whether it is necessary for NZHIS to have a database of identifiable information to achieve the objectives of the MHIP.

- 25.2** Taking into consideration the National Mental Health Strategy, and the need to provide a mechanism for measuring its implementation, it is appropriate to say that a database, as a secondary patient record,⁶¹ is an appropriate tool to monitor the implementation of the strategy.

- 25.3** Privacy risks may arise if other uses of the information are suggested in the future. For example, the suggestion that the information on the database could be used by providers simply to find out where an individual had previously received care would be an extended use of the database and not within the scope of the MHIP and not within the functions of NZHIS.
- 25.4** Furthermore, even if NZHIS were to contemplate this as one of the purposes of the database, it may be difficult to include such a use as being consistent with NZHIS's functions. It would also be difficult to link the use to the objectives of the MHIP.
- 25.5** NZHIS will not be the health agency collecting the information directly from the individual. Consequently, it will need to rely on the mental health service providers to ensure that individuals are aware of the information flows and the purpose and extent of those information flows.
- 25.6** Openness is the key to acceptability of information flows for specified purposes. Openness is also crucial for building trust between both the individual and the provider and the providers and NZHIS. Individuals need to be aware of what information is being collected about them and who or which other agencies will have access to that information and for what purposes.
- 25.7** Trust will be an important aspect of the success of this project. Individuals will need to trust those who are providing mental health services to properly manage their health information. If this trust is not present the risk is that someone may not seek appropriate care for fear of being labelled with a mental illness.
- 25.8** NZHIS will have to gain the trust of the mental health service providers to ensure that the information provided is accurate and complete, and that only relevant information is provided. This will be reflected in the quality of the information used to provide the statistics and reports to measure the implementation of the National Mental Health Strategy. Consequently, the success of the project will depend on the acceptance and participation by mental health services providers.
- 25.9** Providers will want reassurance from NZHIS that the information it obtains from individuals, on behalf of NZHIS, will be used consistently with the purposes of the MHIP. Mental health service providers will also need to be convinced of the usefulness of the MHIP. A lack of interest or belief in the project's objectives may directly or indirectly cause the project to be sabotaged by inaccurate or incomplete information.

- 25.10** While the immediate liability for breach of the collection rules might lie with the provider, responsibility lies also with the NZHIS ensuring that the provider knows the purposes of supplying NZHIS with the information. This will enable the provider to comply with its obligation to ensure the individual is aware of the purposes of disclosing information to NZHIS.
- 25.11** The HIPC places the responsibility on the mental health care provider collecting the information directly from the individual to ensure that the individual is aware that health information is being collected about them and exactly what those information flows that information may be subject to. NZHIS, having taken on responsibility for the development of the MHIP, needs to be involved in helping providers fulfil their obligations.
- 25.12** To ensure the success of the project, NZHIS will need to work with providers to produce education and training materials to ensure that both the provider is aware of its responsibilities when collecting the information directly from the individual and that individuals are also aware of the project, its objectives and the information flows.
- 25.13** With the existing pressures from the changing structure of the health sector already facing many health care providers it will be important that NZHIS, as leader of the project, co-ordinates education programmes and materials for mental health care providers and for individuals. These materials need to clarify the purposes of the MHIP.
- 25.14** Overall, the providers need to be convinced that there is a benefit to both individuals and the providers in participating in the project.

26. Storage and security: Rule 5

- 26.1** A health agency holding health information must ensure that the information is protected, by such security safeguards 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.
- 26.2** The words 'reasonable in the circumstances' indicate that the standards required will depend on the sensitivity of the information. Mental health information is particularly sensitive and so security and storage safeguards will be very important

26.3 NZHIS as administrator and holder of the information will need to ensure that there are adequate storage and security safeguards to prevent both internal and external unauthorised access to the information contained on the database.

26.4 Security safeguards raise operational and technical challenges.

26.4.1 Operational threats arise from inappropriate uses and disclosure of personal information by individuals within the organisation and from outsiders. Operational threats may depend on physical access to the premises, although purely technical attacks may take place without requiring physical access.

26.4.2 Consequently, technical threats are a subset of operational threats, relating more to the type of software and electronic mechanisms for protecting information such as access control, authentication and encryption. Technical safeguards protect information from internal misuse and external attack.

26.5 At one end of the breach of the security spectrum is the innocent misuse of personal health information by authorised employees while at the other end is the intentional unauthorised attack by outsiders on the information system.

26.6 For the present, security threats will only arise internally as no access by external agencies is contemplated at this stage.

26.7 Vulnerabilities of the MHIP database may be categorised as follows:

26.7.1 Internal threats:⁶²

- authorised users making innocent mistakes:⁶³
 - * leaving an active screen unattended;
 - * discussion concerning personal health information in a public place.
- opportunist unauthorised users taking advantage of the innocent mistakes of others:

⁶²

See *For the record: Protecting Electronic Health Information* Committee on Maintaining Privacy and Security in Health Care Applications of the National Information Structure, National Academy Press, Washington DC (1997), p 59-60.

⁶³

The examples provided are just some illustrations of how information may be misused. Some examples fall into more than one

- * curiosity about a friend, relative, neighbour, co-worker, high profile person.
- authorised users deliberately abusing access rights:
 - * curiosity about a friend, relative, neighbour, co-worker, high profile person;
 - * information obtained for personal reasons rather than work-related.
- abuse of access rights for personal gain:⁶⁴
 - * access may be by authorised users, or by users with limited user rights who are able to access unauthorised information;
 - * information is deliberately obtained for a commercial purpose.
- abuse of access rights for vengeance:
 - * access may be by authorised users, or by users with limited user rights who are able to access unauthorised information;
 - * information is deliberately obtained for a specific purpose, not associated with the objectives of the MHIP.

26.7.2 External threats would be limited to an unauthorised physical intrusion of the site where the MHIP database is to be held.

- unauthorised physical intruders, no access rights:
 - * outsiders who walk into NZHIS presenting themselves as employees or authorised users and start using computer systems.

⁶⁴

The London *Sunday Times* reported in November 1995 that the contents of anyone's electronic health record in Great Britain could be purchased on the street for about £150. In New Zealand, the Crimes Act 1961, section 105A makes it an offence for an official to corruptly use or disclose any information acquired in her or his capacity to obtain directly or indirectly an

27. NZHIS response to the storage and security issues

- 27.1** At this stage the MHIP database will only be accessible by NZHIS staff. Only those updating and entering new records will be able to see the information in an unencrypted form and only the database administrator/manager will hold the de-code table for unencrypting the information.
- 27.2** All other NZHIS staff who have authorised access to the database for statistical analysis will see the information in an encrypted form.
- 27.3** The MHIP database is not to be linked by any external network enabling access by other health agencies. If, in the future, other agencies were to be allowed access to the database or copies of the database, this would be in an encrypted form so that the information would be anonymous.
- 27.4** Physical access to NZHIS premises is protected by access cards. Other than a reception area, areas where access to the NHIS is available is limited to those with authorised physical access. In addition, only those with authorised computer access to specific databases are able to access those databases. Access to identifiable information on computer systems is limited to those involved in updating the information or the database administrator/manager. Analysts are only able to access encrypted information.
- 27.5** NZHIS is currently providing on-going training to its staff on the safe management of personal information.

28. Storage and security issues: Discussion

- 28.1** One of the most effective ways of ensuring the security of information is to develop a "culture" within an organisation which recognises the importance of protecting health information. Staff training is essential.
- 28.2** Generally speaking, internal security and storage threats are countered by education, training, deterrents and obstacles, preventing those with authorised access misusing those access rights either inadvertently or deliberately. External threats are countered by restricting physical access and technical safeguards to restrict access to computer systems.
- 28.3** The HIPC requires storage and security safeguards to be reasonable in the circumstances. NZHIS must be satisfied that its own storage and security safeguards are sufficient to adequately protect the information. In some circumstances information will be supplied by providers in hard copy

format rather than electronic format. NZHIS needs to ensure that if it retains the hard copy information, that this information is also stored securely.

28.4 Organisational security safeguards such as those noted below should be implemented:

- staff training;
- identification of authorised users;
- providing access controls and privileges of users;
- audit trails to identify misuse;
- disciplinary action, warning for misuse, dismissal;
- automatic log off after a certain period;
- system backup disaster recovery where information is lost.

28.5 Security safeguards should also be in place to identify when there has been a misuse of authorised access rights. This may be easier to identify when the information is in electronic format as monitoring footsteps can be developed as part of the system. Systems for monitoring access to hard copy information should also be implemented.

28.6 Storage and security issues are an important aspect of gaining support for the MHIP. NZHIS will need to convince both users and individuals that there are sufficient physical and technological safeguards in place to protect the information while it is held by NZHIS.

28.7 Consequently, in taking on a leadership role NZHIS needs to be seen to be taking the security and storage issues seriously. In other words it is not sufficient to say that NZHIS has a particular policy. It must also implement that policy and enforce proper sanctions, such as warnings or dismissal, if the policy is not complied with.

28.8 NZHIS must have in place the means to identify, audit and monitor users so that misuse can be detected

28.9 Monitoring users will in itself be a type of surveillance so that employees, contractors, and agents need to be aware of how NZHIS monitors use of the MHIP database. The knowledge that monitoring takes place is a deterrent in itself.

29. Accuracy: Rule 8

29.1 Rule 8 requires NZHIS to ensure that any personal health information it makes available is not used without taking reasonable steps in the

circumstances 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. In other words, if the information is going to be used in an identifiable form, care must be taken regarding the accuracy of the information.

29.2 In fact, the purpose of compiling the information is to provide statistical and aggregate data. Only when the information is used for research purposes will there be issues associated with the accuracy of the information as the information will be identifiable. If inaccurate information is used to compile statistical data this will not impact on the individual. However, the accuracy of the information will have an impact on the usefulness of the statistical information.

29.3 NZHIS does not have the ability to check the accuracy of the information supplied with the individual. In fact to do so would be quite intrusive in privacy terms, and outside the scope of NZHIS's functions. Therefore, responsibility for the accuracy of the information rests with the mental health service providers.

29.4 As discussed earlier, one of the purposes of the MHIP is to report back to the mental health service providers, statistical or aggregate information about the services they provide. By giving providers feedback regarding their services, the providers are more likely to see the value in providing accurate information to NZHIS.

30. NZHIS response to accuracy issues

30.1 NZHIS is setting up regular auditing of mental health service provider sites to help those agencies provide high quality information for the MHIP. There will be an on-going programme to assess the data quality.

30.2 It has been accepted by NZHIS that not all providers will be able to supply all the information requested by NZHIS straight away. Consequently, data received from providers may not be complete. NZHIS will develop a gaps and issues database to hold information about the data collected. This will ensure that when data is analysed people will be aware of any gaps or assumptions behind the data.

30.3 In the area of mental health there are always concerns about attaching a particular diagnosis to an individual. NZHIS acknowledges that in some instances contact with a specialist mental health service may not result in a specific diagnosis. To allow for this, the diagnostic categories include codes which acknowledge relational problems and other conditions which

may be the focus of clinical attention. The use of these codes will be more common in services which assess and treat children and young people.

- 30.4 Data will be provided to NZHIS monthly and must be received by the 20th day of the following month, i.e. data for January 1999 must be received by 20 February 1999.

31. Accuracy: Discussion

- 31.1 Generally, privacy risks associated with this project include the fact that a person may be labelled with a particular diagnosis and that the label sticks. Using inaccurate information in an identifiable form may have an adverse outcome, or a potential adverse outcome, for the individual.
- 31.2 Extreme caution will need to be taken in providing that there is every opportunity to ensure that the information is updated regularly so that it retains its accuracy.
- 31.3 Another way of checking information is accurate is to ensure that individuals are aware of their right to access their personal information held by NZHIS and request correction.⁶⁵
- 31.4 Trust is an important aspect in ensuring that providers supply information that is accurate. Once again this is linked to the relationship that NZHIS has with the providers and the providers with individuals. Both individuals and mental health service providers need to be satisfied that the objectives of the MHIP are worth pursuing.
- 31.5 The quality of the information, which relates to accuracy, will depend on the confidence the providers have in the MHIP and that NZHIS will administer the MHIP database in accordance with the project's objectives.
- 31.6 If there is a lack of trust in the security of the system, or the way the information may be used there will be an increased risk that the quality of the information supplied will be inadequate to monitor the implementation of the National Mental Health Strategy and achieve the project's objectives.
- 31.7 Accuracy issues relate to using the information in an identifiable form. From a privacy perspective, this will be relevant where the database is to be used for research purposes and identifiable information is required. If the information is inaccurate then this may make the information unsuitable for

research purposes. In addition, there is the potential for an adverse outcome for individuals incorrectly selected for research projects.

31.8 All other uses of the information relate to compiling statistical and aggregate data. Obviously, if the information provided is inaccurate this will have an impact on the quality of the statistics although it is unlikely that there will be an adverse outcome for particular individuals.

31.9 There will be occasions where identifiable information is requested for unanticipated purposes. In those circumstances, the accuracy of the information is an important factor to be taken into account and NZHIS may want to either refer such a request to another agency, or check with the agency which provided the information about its accuracy before disclosing the information.⁶⁶

32. Retention: Rule 9

32.1 Rule 9 states that a health agency must not hold health information longer than is required for the purposes for which the information may lawfully be used. The purposes for which NZHIS requires the information is to monitor the implementation of the National Mental Health Strategy. This will be an ongoing purpose.

32.2 Under the Health (Retention of Health Information) Regulations 1996, an obligation is placed on the providers of health or disability services regarding how long health information may be retained. It imposes a minimum period of 10 years beginning the day after the date shown in the health information as the most recent date on which a provider provided health or disability services to the individual. As NZHIS is not a provider of health care services these regulations will not apply. However, the provisions of the HIPC will apply.

33. NZHIS response to retention issues

33.1 NZHIS has decided not to place a time limit on how long it will retain the information. This is because to monitor the delivery of mental health service, NZHIS needs to retain the information long term to provide ongoing statistical information.

33.2 There will be provision on the database to enter the date of death of an individual. NZHIS intends to retain information about deceased individuals.

⁶⁶

Generally, unanticipated requests for information will be made under the Official Information Act. This is discussed in more

34. Retention: Discussion

- 34.1** Providing NZHIS can justify the need to retain the information on the database for providing on-going statistics that will be a lawful purpose for retaining the information. However, there may be a time in the future when certain information will not need to be retained. For instance the records of deceased individuals. NZHIS needs to consider whether it is appropriate to consider a time limit for retaining the information of deceased individuals after their date of death. Information about deceased individuals can be made non-identifiable, as there will be no need to add further information to these records.
- 34.2** In addition, NZHIS needs to consider how long it needs to retain any hard copy information supplied by mental health service providers. Once the information has been entered onto the database, and verified for accurate entry, there should be no need to retain this information.
- 34.3** From a security point of view this is important as retaining the hard copy adds to the risk of potential breaches of security and storage safeguards. Hard copies of information will require additional storage safeguards which may create an unnecessary risk (and cost), if there is no need to retain the hard copy of the information.

35. Use and disclosure: Rules 10 and 11

- 35.1** The HIPC places limits on the use and disclosure of health information (rules 10 and 11). Generally, a health agency has the discretion to use or disclose health information if that is one of the purposes for which it was obtained or directly related to those purposes. Consequently, it is very important to establish at the outset the intended purposes of collecting information. These purposes have been specified in the MHIP objectives.
- 35.2** All the rules in the HIPC are interrelated, but particularly the collection and the use and disclosure rules. For instance, with the collection rules the individual must be told of the information flows and the purpose of those flows at the time the information is collected. Information may subsequently be used or disclosed if it is consistent with those purposes.
- 35.3** However, a health agency obtaining information for one purpose may not then use that information for another purpose without the authorisation of the individual unless another exception to one of the rules applies. Alternatively, the health agency would have to rely on a statutory provision to enable the information to be used for a different purpose.

35.4 As already discussed under security and storage safeguards, compiling individual information creates a valuable record, in which other parties may have an interest. Wherever possible, the MHIP must provide adequate safeguards to protect the information from third party requests for information, unrelated to the purpose of the project. NZHIS will have to consider third party requests for information under the Official Information Act 1982.

36. NZHIS response to use issues

36.1 NZHIS has specified that the purposes of obtaining the information are to:

- enable adequate monitoring of the implementation of the National Mental Health Strategy;
- provide a database for research into the provision of mental health services;
- provide aggregate information to providers, consumer groups, HFA, the Mental Health Commission and other interested parties in the health sector.

36.2 By defining the scope of the project NZHIS has limited the extent to which the information may be used.

37. NZHIS response to disclosure issues

37.1 Generally, the information disclosed by NZHIS will be in a statistical or aggregate format and consequently the information will be anonymous.

37.2 NZHIS has a protocol for dealing with the provision of information to researchers. Any recipient of the information must fulfil the following requirements:

37.2.1 The research protocol must be approved by an accredited ethics committee. This means an ethics committee approved by the Health Research Council or the Director-General of Health;

37.2.2 A copy of the approved research protocol must be provided to NZHIS;

37.2.3 The recipient must complete a declaration prior to receiving information about identifiable individuals from NZHIS

- 37.3** The declaration made by the recipient requires the recipient to undertake to:⁶⁷
- 37.3.1** *Abide by the terms of the research protocol approved by an accredited ethics committee;*
 - 37.3.2** *Use the information provided by NZHIS only for the purpose approved by an accredited ethics committee and as agreed in the job specification;*
 - 37.3.3** *Provide a secure storage environment and restrict access to personal information supplied by NZHIS. Access to such information should be limited to members of the research project team (the personal information must not be provided, sold or otherwise transferred to any third party in any shape, manner or form);*
 - 37.3.4** *Provide the NZHIS with an advance copy of any article, documents, analyses, compilations, or any form of material produced from the personal information released by the NZHIS intended for publication. It is the responsibility of the author(s) of any publications to ensure that information is not published in a manner which could reasonably be expected to identify any individual concerned. However, should the NZHIS be concerned that privacy provisions may be breached it has the right to delay publication until the issue has been resolved.*
 - 37.3.5** *Acknowledge the NZHIS as a source of information;*
 - 37.3.6** *Destroy all personal information on completion of the project and notify the Manager, Information Services, NZHIS when this has been done;*
 - 37.3.7** *Comply in all respects with the relevant requirements of the Privacy Act 1993 and the Health Information Privacy Code 1994.*
- 37.4** From time to time requests for official information are made to NZHIS for identifiable information compiled on the National Health Information Systems. Each request is dealt with on its own merits, but generally, information is withheld to protect the privacy of natural persons, including deceased natural persons and the need to protect information which is
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subject to an obligation of confidence and where making the information available would be likely to damage the public interest.

38. Use and Disclosure: Discussion

38.1 NZHIS has clearly confined the extent to which the information compiled on the MHIP database may be used and disclosed. In addition it already has in place safeguards to protect information disclosed for research purposes.

38.2 Before NZHIS could contemplate initiating any use or disclosure of identifiable information outside the scope of the project's objectives it would have to address the following questions:

38.2.1 Is there any statutory authority:

- requiring;
- providing a discretion;⁶⁸ or
- prohibiting,

disclosure of the information?

38.2.2 If there is no statutory authority, has the authorisation of the individual been obtained?

38.2.3 If it is not practicable to obtain the authorisation of the individual, is use or disclosure permitted under rule 10 or rule 11(2);

38.2.4 How much information needs to be disclosed to achieve the purpose of the disclosure?

38.2.5 To whom should the information be disclosed? Who is the appropriate person or authority to affect the purpose?

38.3 In certain circumstances it may be appropriate to seek the authorisation of the Privacy Commissioner under section 54 of the Privacy Act to use or disclose personal information even though that use or disclosure would otherwise be in breach of rule 10 or 11. In deciding whether or not to give the authorisation the Commissioner must be satisfied that either:

- that the interest in the use or disclosure of the information outweighs any interference with the privacy of the individual; or

- that the use of disclosure involves a clear benefit to the individual concerned that outweighs any interference with the privacy of the individual.

38.4 One of the suggestions for using the information that has been discussed between NZHIS and providers is the use of the information for clinical purposes. This has now been rejected as one of the purposes of the project. However, this does not mean that the information could not be used for clinical purposes. It could be used for clinical purposes providing the authorisation of the individual was obtained.

38.5 For example, many people receive a variety of mental health services from numerous providers. Not all individuals may remember from whom they have received mental health services. In such cases providers have suggested that it would be useful to know who else has provided services to a particular individual. If providers were to seek this information from NZHIS they could either do so by obtaining the individual's authorisation or by suggesting the individual makes a request for her or his personal information held on the MHIP database by NZHIS.

38.6 This is a much better solution than incorporating the clinical purposes as part of the objectives of the project. Information may be disclosed as required and on the authorisation of the individual. Obviously, if the individual did not want a provider to know who else has provided to her or him, she or he retains the ability to veto the disclosure of the information. This is consistent with section 22F of the Health Act which requires information to be communicated between different providers of health services unless the holder of the information has reasonable grounds for believing the individual does not want the information disclosed.

38.7 From time to time NZHIS may be asked to provide information from the MHIP database to other health agencies, such as the Health Funding Authority. In such cases the information might be requested in either an identifiable or unidentifiable form.

38.8 However, to be consistent with the objectives of the MHIP, the information may only be provided for purposes consistent with the objectives of the MHIP. Generally, that would be for statistical purposes. If the information is required for statistical purposes, there will be no need to provide identifiable information, as identifiable information is only required by NZHIS to enable it to update the information. Consequently the information should be encrypted so that the name and NHI number cannot

be identified. It is important that the recipient agency does not have the ability to unencrypt the information.

- 38.9** If identifiable information is disclosed, NZHIS must know the purposes the information is to be used for by the recipient. It would also need to consider whether information should be provided in an identifiable format when the same purposes could be achieved by the recipient agency by providing non-identifiable information.
- 38.10** However, if NZHIS provides identifiable information without ascertaining the purpose of the disclosure and the recipient agency uses the information for anything other than statistical purposes then NZHIS may be vulnerable to complaints regarding the disclosure of information for purposes outside the scope of the MHIP.
- 38.11** The recipient agency may also be vulnerable to complaints, if it obtains information on the basis that the information is for statistical purposes, but in fact uses the information for other purposes.

39. Requests for official information

- 39.1** Third party requests for information need to be considered under the Official Information Act rather than rule 11, although this rule may be used to provide guidance to whether or not there may be grounds for withholding the information.
- 39.2** Although each request must be considered on its own merits, in most cases there will be grounds under section 9 of the Official Information Act to withhold the information to protect the privacy of natural persons. In addition, there is a public interest, in order to maintain the integrity of the database, that this sort of information should not be made available.
- 39.3** If information were to be made available it is quite likely that this would have a flow on effect to the providers of mental health services, who may be reluctant to supply the information.
- 39.4** Once again the importance of maintaining the trust of the providers is essential to the success of the MHIP, as there is no compulsion for the mental health service providers to supply the information.

40. Unique identifiers: Rule 12

- 40.1** Rule 12 sets out several provisions which concern the use of unique identifiers. 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.
- 40.2** Unique identifiers are a means of distinguishing one individual from another. Unlike a name, where there may be several people with the same name, a unique identifier provides a means of accurately linking and indexing information about an identifiable individual. The NHI number is a unique identifier.
- 40.3** Using a unique identifier when communicating health information between, say, providers who are able to link the number to the person, prevents an opportunist unauthorised user from immediately identifying a particular piece of information to a named person. However, it does not make the information unidentifiable.
- 40.4** There is no statutory provision which requires all individuals to have an NHI number. However, this number has become established as the main identifier used in the provision of health care services.

41. NZHIS response to unique identifier issues

- 41.1** The NHI number is considered to be the most suitable unique identifier for the MHIP, as records will be updated by a variety of different service providers. Using an alternative unique identifier would create a huge administrative burden on providers.

42. Unique identifiers: Discussion

- 42.1** Administratively, it is appropriate for NZHIS to use the NHI as the common unique identifier for obtaining and updating information on the MHIP database. An alternative unique identifier system is not a practical option.
- 42.2** From time to time information for inclusion on the MHIP will be obtained by NZHIS from other sources. An example is the date of death. As this information is also provided with an NHI number attached, this will enable NZHIS to update the MHIP database.
- 42.3** The privacy risks associated with the use of unique identifiers, and in particular with the NHI is the facility to link information that was

previously held separately, simply because compiling the information into one record was inhibited by uncertainty about the identity of individuals.

42.4 Information with a unique identifier attached is still identifiable information for any one who has the key to link the number to an individual. As there is an increase in the use of the NHI number and more health agencies have access to the NHI database the ability to link an NHI number to an individual increases.

42.5 NZHIS has been open about what information will be collected and the purposes. The greatest concerns lie in other organisations obtaining the information from the MHIP database with an unencrypted NHI number which allows that other agency to link information it may also have about the individual.

42.6 Consequently, NZHIS must ensure that information it obtains for the MHIP database, is not made available to any other agency with an unencrypted NHI number attached.

43. Access and Correction: Rules 6 and 7

43.1 The HIPC creates a right for individuals to access personal health information held about them and request correction of that information.

43.2 Under rule 3, when information is being collected, individuals have a right to know which agencies will hold their personal health information. As part of the MHIP, individuals are able to request access to their information held by NZHIS.

43.3 Individuals have a right to ensure that they know what personal health information is held about them by different health agencies. The right to access information helps to keep those holding the information accountable to the individual about the way in which it manages personal information.

43.4 An individual would be entitled to make an access request to NZHIS for a copy of her or his personal information. If that information were incorrect the individual has the right to request correction of that information, or have a statement of correction attached to the record.

44. NZHIS response to access and correction issues

- 44.1** To date, NZHIS has not received many request by individuals for access to their information. However, once an individual has been able to show some form of identification, access is generally provided.
- 44.2** Where an individual requests a correction be made to the information, the request for correction has to be referred to the agency which supplied the information. The correction is subsequently made on the relevant NZHIS database once updated information is supplied by the provider of the information.

45. Access and correction: Discussion

- 45.1** The type of information compiled on the MHIP will be very sensitive. Consequently, it is important that individuals are aware of their rights to access and request correction of their information.
- 45.2** Even though NZHIS is not in a position to correct the information directly, it could consider providing a field on the database which allows the entry of a flag to indicate that the individual is not in agreement with some of the information contained on the database.

46. Conclusions

- 46.1** Any centralised database containing identifiable information raises issues concerning the extent of information obtained and the purpose of such a database.
- 46.2** Having measured the MHIP against the HIPC rules, it is useful to now address the questions raised in paragraph 18.11.
- 46.3** *What is the purpose of the information?*
 - 46.3.1** NZHIS have clearly defined the purpose of the database as a secondary database for providing statistical and aggregate information and for providing a database of research into the provision of mental health services. This purpose is consistent with the objectives of the National Mental Health Strategy. NZHIS is an appropriate agency to be carrying out this project.
 - 46.3.2** Providing clinical information would have been beyond the scope of the MHIP and beyond the functions of NZHIS. It is

appropriate that this is no longer a potential use of the MHIP database.

46.4 *Will collection achieve a compelling public health purpose?*

46.4.1 Depending on the success of NZHIS in obtaining complete and accurate information for the database, and the use of that information to measure and assess the implementation of the National Mental Health Strategy, it is possible to say that collecting information for the objectives of the MHIP will achieve a compelling public health purpose. That purpose being the monitoring of the National Mental Health Strategy.

46.5 *Will collection result in effective health policy: that is, might it drive people underground if they fear the consequence of disclosure?*

46.5.1 There will always be a risk that if an individual considers the actions of a provider of health services inappropriate that the individual will seek health services elsewhere, or not seek any health services. Consequently, to avoid the risk of someone deciding not to seek mental health services, it will be essential that individuals are fully aware of the purposes of the MHIP and understand that safeguards are in place to protect their personal information.

46.6 *Who will have access to the information? Can it be disclosed by force or law? What will be the effect of negligent disclosure?*

46.6.1 Only authorised staff of NZHIS will have access to identifiable information contained on the MHIP database. Such access will be provided to those who need to update the database. Analysts working for NZHIS will only be able to view encrypted information.

46.6.2 The only other person entitled to access the information will be the individual, or that person's agent. All other anticipated disclosures of identifiable information will be subject to the criteria set out under the research protocol.

46.6.3 The information is vulnerable to requests made under the Official Information Act. If a request is made for identifiable information, it may only be withheld in certain circumstances, and where there is no overriding factor which renders it desirable in the public interest to make the information available

However, in most circumstances it should be possible to withhold the information to protect the privacy of natural persons. Indeed, routinely releasing the information on request would have serious implications on the ability of NZHIS to be able to administer the National Health Information Systems in a way which protects the personal information contained on those databases.

46.6.4 If personal information is disclosed either negligently or deliberately a complaint may be made to the Privacy Commissioner regarding an interference with privacy. In addition, it is a criminal offence for an official to corruptly use or disclose any information acquired in her or his capacity to obtain directly or indirectly an advantage or pecuniary gain for her or himself or for any other person.

46.7 *What impact will it have on human rights - is there a stigma to individuals or communities?*

46.7.1 It is acknowledged that there is a stigma associated to any person diagnosed with having a mental illness. The Mental Health Commission has taken on the role of reducing such stigma. However, there will always be a risk that information compiled about the delivery of secondary mental health services has the potential to further stigmatise those individuals receiving treatment if the information is not properly safeguarded from the disclosure of identifiable information.

46.7.2 The objective of the MHIP is to be able to measure the implementation of the National Mental Health Strategy, which should result in better provision and targeting of mental health services.

46.7.3 In balancing the risk of further stigmatisation against the benefits of better service provision, account must be given for providing safeguards to protect the information and minimising the risk of stigmatisation. NZHIS has done this by limiting the use and disclosure of identifiable information.

46.7.4 Without safeguards to protect the information there is a risk that the quality of information provided may be compromised as providers and individuals will not want to participate. In turn this will affect NZHIS's ability to obtain accurate and complete information and compromise its ability to provide useful statistics

measuring the implementation of the National Mental Health Strategy.

46.8 *Are there less invasive alternatives?*

46.8.1 NZHIS has taken privacy considerations very seriously. However, because each record needs to be updated it is necessary to collect identifiable information. If NZHIS only collected statistical information from providers, each set of information obtained would only provide a frozen picture of the delivery of services at any one particular time. It would not enable NZHIS to identify trends or patterns of service delivery or identify particular needs.

46.8.2 Consideration was also given to the use of a different unique identifier, other than the NHI number. However, as the NHI number is increasingly being used by health service providers, the administrative aspects of developing another unique identifier specifically for the mental health sector is not a practical alternative at this stage.

46.8.3 However, protections will be in place to ensure that, other than in the case of research projects, information will not be provided by NZHIS with an unencrypted NHI number.

46.9 *What safeguards are available to reduce the risk?*

46.9.1 NZHIS has confined the scope of the MHIP, limiting the information to be collected to that sufficient to measure the implementation of the MHIP and enable research projects which are also concerned with the provision of mental health services.

46.9.2 NZHIS has worked within the framework of the HIPC to measure the development of the project alongside the requirements of the health information privacy rules.

46.10 Overall, the way the project has been developed indicates that NZHIS is committed to taking a leadership role with respect to the provision of health information services generally, and in this instance in the implementation of the MHIP.

46.11 In doing so it has recognised the need to ensure that its own staff are familiar with the requirements of the Privacy Act and the Health Information Privacy Code. In addition NZHIS has acknowledged that in

order to build a trusting relationship with health service providers, it is important that NZHIS help providers fulfil their obligations when collecting information from individuals.

46.12 NZHIS has taken the potential privacy impacts seriously and acknowledged the role it needs to play in ensuring that the providers are aware of the purposes of the information and their privacy obligation with respect to their patients.

46.13 Trust in NZHIS and value in the benefits of the MHIP by both the providers of mental health services and the individuals receiving those services, will be the deciding factor to the ultimate success of the project.

47. Recommendations (not in any order of priority)

47.1 Recommendation 1: NZHIS needs to document its information management policy regarding the MHIP. This policy should provide an overview of how the information will be protected from potential privacy intrusions including:

- how NZHIS will ensure that providers are aware of their obligations when collecting information from individuals for the MHIP;
- storage and security safeguards in place to protect the information;
- retention periods for electronic and paper records;
- mechanism for secure destruction of records;
- how accuracy of the information will be achieved;
- restrictions on access to identifiable information by staff of NZHIS and a policy for dealing with unanticipated requests for information held on the database;
- protocol for dealing with research projects;
- restrictions on the linking, by NHI number, of personal information obtained from the MHIP;
- a procedure enabling individuals to access their personal information and request correction.

47.2 Recommendation 2: NZHIS should consider the possibility of appointing a group to monitor the implementation of MHIP on an on-going basis, including monitoring how effective the project is in supplying the statistics necessary to measure the implementation of the National Mental Health Strategy. Such a group could also have responsibility for protecting the information and considering requests for access for research projects and official information requests. For example, NZHIS may chose to invite interested groups to be represented on the group such as Mental Health Commission, the Office of the Privacy Commissioner, and mental health consumer groups.

47.3 Recommendation 3: NZHIS needs to develop education materials such as posters and pamphlets, use of web site for both providers and individuals to gain an awareness and understanding about the MHIP. These materials should explain:

- the objectives of the project and why specific information needs to be collected;
- how the information will be protected, and who will be able to use the information;
- individual's right to access and correct information held by NZHIS.

NZHIS should work with the Office of the Privacy Commissioner in developing these materials.

Health agencies should be encouraged to have adequate training programmes.

- 47.4 Recommendation 4:** NZHIS needs to provide on-going training for their staff to ensure that they are aware of how personal health information should be protected from potential privacy risks.
- 47.5 Recommendation 5:** NZHIS needs to consider whether it is necessary to retain information about deceased persons in an identifiable form as there will be no need to add further information to those records.
- 47.6 Recommendation 6:** NZHIS needs to ensure that a field is included on the database to provide an alert where an individual has requested the correction of information or the inclusion of a statement of correction. This will alert those considering disclosing information for research purposes of the possible inaccuracy of the information.

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Appendix 1

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.

Appendix 2

Mental Health Commission Act 1998, Section 6

- (1) The functions of the Commission are—
 - (a) To report to the Minister, from time to time or at intervals agreed between the Minister and the Commission, on the implementation of the national mental health strategy; and
 - (b) To report to and advise the Minister, when requested by the Minister, on any matter relating to the implementation of the national mental health strategy specified by the Minister in the request; and
 - (c) To work with all those involved in the care and treatment of people with mental illness and their families and caregivers—
 - (i) To promote better understanding, by the community, of mental illness; and
 - (ii) To reduce the stigma associated with mental illness and the prejudice shown to people with mental illness and their families and caregivers; and
 - (iii) To eliminate discrimination on the ground of mental illness against people with mental illness and their families and caregivers; and
 - (d) To promote employment in the mental health field as a desirable career choice; and
 - (e) To work with all those involved in training for employment in the mental health field—
 - (i) To promote the provision of training opportunities of an appropriate range and quality; and
 - (ii) To promote the obtaining and maintaining, by people employed in the mental health field, of skills of an appropriate range and quality.
- (2) The Commission must ensure—
 - (a) That each report under subsection (1)(a) covers one, some, or all of the matters described in subsection (3); and
 - (b) That every year it presents at least one report under subsection (1)(a) on each of the matters described in subsection (3).
- (3) The matters referred to in subsection (2) are—
 - (a) The extent to which—
 - (i) The Ministry has exercised leadership in the implementation of the national mental health strategy by way of its performance of the tasks described in paragraphs (b) to (g):
 - (ii) Regional health authorities have exercised leadership in the implementation of the national mental health strategy by way of their performance of the tasks described in paragraphs (e) to (g):
 - (b) The extent to which the Ministry has established, through negotiations with regional health authorities, specific targets and milestones for each of the strategic directions in the national mental health strategy:
 - (c) The Ministry's performance in—
 - (i) Measuring delivery by regional health authorities, with respect to each of the strategic directions in the national mental health strategy, against the targets and milestones; and
 - (ii) Responding to any failures by regional health authorities to meet the targets and milestones:
 - (d) The Ministry's performance in measuring progress by regional health authorities towards clearly communicating to providers, people with mental illness and their families and caregivers, and communities—
 - (i) The changes needed in order to implement the national mental health strategy; and
 - (ii) The roles to be played and the responsibilities to be undertaken by those providers, people with mental illness and their families and caregivers, and communities:
 - (e) The progress made by the Ministry and regional health authorities in promoting co-ordination and collaboration among providers to ensure that services that affect people with mental illness are provided consistently and effectively:

- (f) The extent to which the Ministry, every regional health authority, and every other government agency that has responsibilities in relation to the delivery of services that affect people with mental illness and their families and caregivers is implementing the national mental health strategy—
 - (i) Through the provision of services directly by it; or
 - (ii) Through the standards it sets for the provision of services by parties which it funds to provide those services or from which it purchases services:
- (g) The effectiveness of systems put in place by the Ministry and regional health authorities to ensure—
 - (i) That Government funding for mental health services is not diverted to other purposes; and
 - (ii) That Government expenditure on mental health services has demonstrable effects.