

On the Record

A PRACTICAL GUIDE TO HEALTH INFORMATION PRIVACY

Prepared by the Privacy Commissioner, October 1999

2nd edition, July 2000



Introduction

Introduction

The accumulation on the record of details about a person's health, disabilities or treatment constitutes information of the greatest sensitivity. While people may choose to tell friends or relatives about these matters, for the holders of the records, they have always been regarded as carrying with them obligations of accuracy, confidence, security and responsibility. Until the advent of the Privacy Act - and then the Health Information Privacy Code - these duties were governed by ethical and legal obligations, which were often ill-defined and not well understood. The Health Information Privacy Code built upon the information privacy principles in the Privacy Act and provided a coherent, principled set of minimum standards which govern the conduct of those who handle people's health information.

Despite wide consultation certain surprise occurred when the Code was issued. It was not long before quite fanciful interpretations were made by a few professionals, often without reading the Code, on the basis that any law-based code of conduct would displace the doctor's discretion with an arbitrary set of rules. That is not so. The rules simply apply good practice. This guide, based on practical experience and actual cases, may help to demystify the Code. For the sake of coherence it tends to refer to health situations but it applies to disabilities information as well.

However, *On the Record* is not a substitute for good training and I commend the workshops provided by my staff as a good foundation for those who might subsequently reinforce their understanding or obtain help in a new situation by reference to this practical guide.

The guide has been designed for busy professionals. It need not be read from cover to cover, as material has been repeated to give the same answers in several locations. The comprehensive table of contents will help readers to find them easily, as will the quick reference guide to some of the more common issues and their location in the notes. The guide will not provide the answers to every situation as situations can be so varied and complex but also because professional judgement and discretion cannot be legislated.

I want to acknowledge the work done by several people in the preparation of these notes. Most of the drafting was undertaken by Sarah Kerkin, recently my Executive Officer. Helpful comment was provided by: Simon Robb, recently of Health Waikato; the New Zealand Medical Association; the Health and Disability Commissioner; the Mental Health Commission; the New Zealand Society of Physiotherapists; Ron Paterson, then with the Ministry of Health; and Sarah Mackenzie of the Wellington South Community Law Centre.

The cartoons drawn by Chris Slane were donated by the artist.

This publication is designed to be used now. It is also intended to incorporate suggestions for additions or improvements in later versions to make it more useful. I trust this guide will remove any doubts about how privacy law applies to people's health records. They are so important for the health and well-being of patients as well as the professional practice of those who serve them.

Bruce Slane
Privacy Commissioner
October 1999

Quick Reference Guide

B

Quick Reference Guide

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Some examples of questions these guidance notes will answer...

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Preliminary Comments



Preliminary Comments

This guide is designed to assist health agencies in dealing with personal health information. The aim is to help agencies devise policies for:

- collecting, using and disclosing health information;
- dealing with requests by third parties for information about patients;
- dealing with requests by patients for access to and correction of their information.

The Health Information Privacy Code 1994 (the Code) applies to everyone working in the health sector who handles health information. The term “agency” refers to all health service providers and their employees. Employees need to comply with the Code, otherwise their actions may lead to a complaint being made about the agency which employs them.

The Code sets out 12 rules which provide a framework for the management of personal health information. The rules are interlinked, so that policies concerning collection of information can affect what happens when it is disclosed.

Some rules set out a principle, then provide exceptions to it (see in particular rules 2, 3, 10 and 11).

The starting point for any application of the Code is that wherever possible, people should know what is happening to their information and retain a measure of autonomy in that process.

Those parts of the Code which have given rise to complaints or have been subject to misunderstanding are covered. Individual rules may contain additional exceptions which are not addressed here. Therefore, this guide should be considered to supplement the Code; it does not replace the Code.

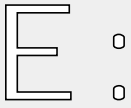
This guide considers the issues agencies face when dealing with personal health information. Practical issues are canvassed and example fact situations are given. The examples are generally based on actual cases, but the real names are not used and in some cases the facts have been altered slightly.

Agencies which are subject to the Official Information Act, such as public hospitals, should also consider their obligations under that Act.

References to section numbers in Acts have been contracted to ‘s’ for a single section and ‘ss’ for multiple sections.

The Code co-exists with ethical obligations. It does not override them, and ethical obligations do not override the Code. Legally, health agencies must comply with the Code and with the Code of Health and Disability Services Consumers’ Rights. They must also comply with their professional codes of ethics.

The Code allows agencies to set their own policies for collecting, using and disclosing health information. Agencies should take responsibility for their policies and be open when explaining a decision which has been made in accordance with such a policy.



Definitions

What agencies are covered by the Code?

The Code applies to health agencies, which include health and disability service providers and their employees. Agencies can range from health professionals in practice on their own to private and public hospitals.

What information is covered by the Code?

The Code covers health information about an identifiable individual, including information about:

- a person's health or disabilities;
- a person's medical history;
- any health or disability services provided to someone;
- patients which is collected while providing health and disability services to them. This might include collecting addresses for billing purposes or information relevant to subsidy entitlement.

What are "representatives"?

Representatives are frequently referred to in the Code and the word can take on different meanings in different circumstances:

- where a person is dead – their personal representative [executor or administrator of the estate];
- where a person is under 16 – a parent or guardian; or
- where neither of the above apply but the person is unable to give consent or exercise his or her rights – someone who seems to be lawfully acting on the person's behalf or in his or her interests.

In these notes, reference to a person includes that person's representative unless otherwise stated.

What is an "interference with privacy"?

In investigating a complaint made under the Code, the Privacy Commissioner must consider whether an interference with privacy has occurred. In a complaint about access to personal information by the person concerned, the Commissioner will consider whether the agency had a proper basis for the decision complained about.

In any other complaint, the Commissioner will consider whether the agency has breached a rule and whether the breach:

- has caused loss, detriment, damage or injury to the person, or may do so;
- has adversely affected the person's rights, benefits, privileges, obligations or interests, or may do so;
- has resulted in significant humiliation, significant loss of dignity, or significant injury to the person's feelings, or may do so.

Collecting health information



Collecting health information

General

Rules 1 to 4 of the Code concern the collection of personal health information.

If an agency is open about its information handling policies and conveys these at the time of collection, people will know why information is being collected. Subsequently, the agency should not have problems when the information is used or disclosed in accordance with those policies.

Rule 3 requires people to be made aware of proposed uses and disclosures of the information. It is not necessary to obtain people's consent to such purposes.

EXAMPLE 1

OPENNESS IN COLLECTION PROCEDURES AVOIDS PROBLEMS LATER

An alcohol and drug rehabilitation unit wants to be able to disclose the fact of discharge to patients' "first contact" person. If this is the unit's policy and patients are made aware of it, then the unit will not have a problem in contacting these people on discharge.

- The unit could use direct discussion, posters, brochures or advice on forms to inform patients of the policy.

The rules relating to use (rule 10) and disclosure (rule 11) relate back to the purposes in collecting information. For instance, health information can be used or disclosed if that use or disclosure was a purpose for obtaining the information in the first place.

So, if an agency collects information for particular uses or disclosures and those purposes are clearly set out in a policy, they will be clearly established for the later use or disclosure.

Unsolicited information

Unsolicited information is information volunteered rather than sought.

The Code does not regulate the receipt of unsolicited information. If a health professional receives information from someone other than the patient, perhaps through a letter or telephone call, it is not covered by rules 1 to 4. But once the information is held by the agency, it is subject to the rules about storage, accuracy, use and disclosure. The patient may also request access to or correction of it (rules 6 and 7).

Where unsolicited information is received about a patient, it may be good practice to note the manner in which it was received. Verification of the information and its accuracy with the patient may be appropriate, particularly if the information is to be used as a basis for treatment or some other action.

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Be open about purpose to avoid problems with use and disclosure

EXAMPLE 2

RECEIVING UNSOLICITED INFORMATION

During a consultation, Dr Jones' patient, John, tells her that he believes his neighbour, Sue, beats her children. John says he regularly sees the children with extensive bruising to their faces. Sue and her children are also patients of Dr Jones. Has Dr Jones breached the Code by receiving this information?

- No. The Code only applies to the collection of information. John volunteered the information without any request from Dr Jones.

NB. If Dr Jones sought more information from John, that would be a collection subject to the Code. She could rely on exceptions to rule 2 (discussed below) to collect the information from John. For instance, it might not be practicable to obtain the information from Sue, or doing so might prejudice the purposes of the collection.

EXAMPLE 3

DISCLOSURE IS A PURPOSE OF RECEIVING INFORMATION

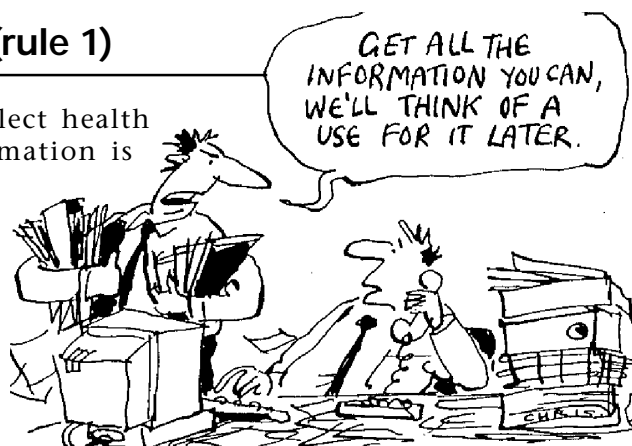
Dr Jones is concerned for the children as she too had noticed extensive bruising. She decides to call on Sue to see how she is coping and to examine the children. Would she breach the Code by using the information in this way?

- John gave the information to Dr Jones because he was concerned for the children's welfare. It could be assumed that she received the information to monitor the situation in this way.
- Rule 10 allows information to be used in a particular way if that is one of the purposes for which it was obtained.

NB. If Dr Jones believed the child was at risk, she could report the information to the Department of Child, Youth and Family Services or the police. If she did so in good faith, the Children, Young Persons and their Families Act 1989 would protect her from civil, criminal and disciplinary proceedings (page 22).

Necessity and purpose (rule 1)

Health agencies must not collect health information unless the information is collected for a lawful purpose connected with a function or activity of the agency and the collection is necessary for that purpose. Agencies should be able to demonstrate their purposes in collecting information and how the collection is necessary for those purposes.



Rule 1 links to other rules so that if a health agency has made a good attempt at explaining its purposes as required by rule 3, people are more likely to understand why the collection of the information is necessary and how the information will be used and disclosed. If the purposes are clearly established at collection, downstream use and disclosure for those purposes should not present any problems.

EXAMPLE 4

NECESSITY AND PURPOSE IN COLLECTION

A trust providing housing for people with mental illnesses receives funding from the Health Funding Agency and Work and Income New Zealand. The funding contract requires the trust to forward statistical information about ethnicity and iwi affiliations. The information is forwarded in non-identifiable form. The trust does not use this information for its own operations. Is it necessary for the trust to collect this information?

- The information is required for statistical purposes and is collected by the trust as the only agency in direct contact with the people concerned. The purpose seems lawful and collection by the trust seems necessary to carry out that purpose. The collection is connected with the trust's activities.

Collecting from someone other than the individual concerned (rule 2)

Generally, information about patients should be collected from those patients. However, rule 2 lists a number of exceptions to this general principle. Some of these are:

- Where the patient has authorised collection from someone else.

Practical points to consider are that the patient should understand what is to be collected, from whom it is to be collected (collection may be restricted to a particular person), the purposes for obtaining the information, and who will receive it. (These requirements are similar to those found in rule 3.) The extent of the authorisation required should be clearly understood.



Some agencies have tried drafting very wide authorisation clauses to allow them to collect from health professionals. Clauses that are too broad may not convey enough information to allow a patient to give a meaningful authorisation. Agencies might find that health professionals are unwilling to make information available on such a clause because they may not believe that the patient has understood what would be collected by the agency.

- Where collecting information from patients would prejudice their interests, prejudice the purpose of collection, or prejudice the safety of any person.

The patient may not be honest with the agency, so that necessary accurate information about the patient's health, effectiveness of medication and so forth, may not be obtained.

- Where collecting the information from the patient is not reasonably practicable.

The patient may not know the information or another person's perspective on symptoms and the effect of particular medication may be required. A truthful answer may not be forthcoming or the practitioner may not have any direct contact with the patient.

Information does not have to be collected directly from patients

EXAMPLE 5

COLLECTING INFORMATION FROM A PATIENT'S FAMILY

Frank is receiving treatment as a voluntary patient. The psychiatrist suspects that his condition may stem from an incident in his childhood. If so, this would affect the approach taken to Frank's treatment. Frank does not seem to know of any incident which may be relevant. Can his family be contacted for help?

- Frank could be asked to authorise such an approach. The psychiatrist could ascertain whom he would prefer to be approached.
- If Frank did not authorise this, the psychiatrist could approach the family for the information because it was not practicable to obtain the information from Frank, given that he did not seem aware of any incidents.
- The psychiatrist should tell Frank about any information collected from his family as he may have a different perspective on it.

Verification of the information and its accuracy (rule 8) with the patient may be appropriate, if practicable. Patients may disagree with information collected from another source. Alternatively, they may provide a different interpretation.

Under rule 6 patients can request access to the information, and rule 7 provides a right to request correction (discussed below at pages 36 and 39).

Sometimes it may be necessary to collect information about a patient from other agencies which have treated that patient. Section 22F of the Health Act 1956 requires health information to be made available, except in some limited circumstances (see page 26). It expressly allows information to be transferred between health agencies for treatment purposes. If it is not passed on when it should be, a complaint may be made to the Privacy Commissioner.

Right 4(5) of the Code of Health and Disability Services Consumers' Rights gives patients the right to co-operation among providers to ensure quality and continuity of services. Co-operation would include the sharing of information with other providers, so this may be a purpose for having the information when a patient's treatment requires co-ordination among providers. If information is not passed on when it should be, consumers could complain to the Health and Disability Commissioner.

A promise of confidentiality to someone who provides information will not necessarily be recognised as a withholding ground if the patient requests access to the information.

Collecting from the individual concerned (rule 3)

Where information is collected directly from patients, agencies must take reasonable steps to ensure they are made aware of a number of matters, including:

- the fact information is being collected.

It is not always obvious that information is being collected, or that it is being collected in a particular way.

For instance, if a video or audio recording is being made, is the recording equipment in plain view and has the patient's attention been drawn to it?



*Consider
verifying
information
with the
patient*

- the purpose of collection.

This may be explained directly, or by way of posters, pamphlets or brochures. Clarify the purposes in collecting the information. For instance, collection for care and treatment or related administrative purposes such as billing is self-explanatory, whereas collection for other purposes, such as training and research or chaplaincy is not necessarily clear. This should be drawn to the patient's attention.

- the intended recipients of the information.

People should be told about the agency's practices and any particular disclosures proposed to be made.

It is not necessary to list every possible purpose or every possible recipient, no matter how remote. However, people should get a general indication of who is likely to see the information and the reasons for that.

Clinical staff are obvious recipients, whereas students, researchers or peer reviewers are not as obvious.

Members of a care team (other professionals in related fields or family members) may not be obvious, depending on the circumstances.

- the consequences of not supplying the information. For instance,

A particular treatment may not be continued effectively without it.

If the person has applied for a subsidy or benefit, it may not be possible to process the claim without it.

- the patient's rights of access and correction given by rules 6 and 7 of the Code.

Clear explanations should be given to either the patient or representative.

Rule 3 may be fulfilled by:

- an oral explanation in appropriate language
- notices on display
- explanatory letters or brochures or readable statements on forms the person is filling in

There are exceptions to fulfilling rule 3 requirements:

- Compliance by the agency would prejudice the interests of the patient or prejudice the purposes of collection. For instance,

The patient is likely to modify behaviour in such a way as to prevent an effective diagnosis or assessment of the treatment.

- Compliance is not reasonably practicable in the particular circumstances. For instance,

An explanation would delay the provision of emergency treatment.

The patient is not capable of assimilating an explanation when it is offered.

The explanation might cause a violent reaction.



Collecting health information

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*Use posters,
pamphlets
and
explanations*

If it is not practicable to give an explanation when the information is collected, it should be done as soon as practicable afterwards (rule 3(2)).

It is not necessary to repeat a recent explanation every time information is collected for the same purpose (rule 3(3)).

Compliance with rule 3 will help prevent misunderstandings which can be critical when it is proposed to disclose information.

EXAMPLE 6

OPENNESS AVOIDS MISUNDERSTANDINGS

Ellen had a blood test which established that she would be a suitable kidney donor for her sister. The specialist told the sister that Ellen was a suitable match. Ellen had not decided whether she wanted to donate her kidney and felt very pressured by her family following the disclosure. The specialist believed that by agreeing to have the blood test, Ellen had consented to the disclosure of the results to her sister.

- Had the specialist told Ellen he would give the results to her sister, Ellen could have asked him not to disclose until she had decided what to do. At the least, she would have been prepared for the disclosure.

NB. In this case the hospital gave the Privacy Commissioner an assurance that in future it would not disclose the status of a potential organ donor to a patient without the donor's written consent.

Manner of collection (rule 4)

Health information may not be collected by unlawful, unfair or unreasonably intrusive means.

- **Unlawful collection.** Would the collection breach another Act? For instance,

Mental Health (Compulsory Assessment and Treatment) Act, s 68 restricts the use of video tape or audio tape to record patients.

The recording must be done with the patient's prior consent, or consent from the patient's representative where the patient is not capable of giving consent.

If a recording breached s 68, that collection would have been made by unlawful means.
- **Unfair collection.** For instance,

The patient has been misled as to the purpose of the collection.

The patient has been threatened or coerced in the process of the collection.
- **Intrusion to an unreasonable extent on the affairs of the individual concerned.**

If a patient is uncomfortable with one way of collecting information, find out whether it could be collected in another way.

Patients should not be asked intimate questions which are not necessary for treatment or diagnosis.

EXAMPLE 7

VIDEOTAPING CAN BE AN UNFAIR COLLECTION

Hine visited a counsellor who often videotaped counselling sessions. The tapes were used in training courses. The counsellor told Hine that only small excerpts were used and the client would not normally be identifiable. Hine felt compelled to agree to the videotaping. During the session she disclosed sensitive information about an abusive relationship. She later discovered that this segment of the tape was used in a training session and that she was identified.

- This was a collection by means which were unreasonably intrusive and possibly also unfair. Information was disclosed that identified Hine. She consented on the basis that she would not be identified and felt pressured to agree.

EXAMPLE 8

COLLECTING INFORMATION AT RECEPTION

Philip attends a medical clinic for the first time. The receptionist asks him a number of questions for their records. His answers are entered directly into the computer. Philip is asked for contact details and about any existing medical conditions. The reception area is small, and a number of people are present and can hear the discussion.

- This may amount to an unreasonable intrusion into Philip's affairs. The receptionist could have asked Philip to fill in a form, or taken him aside so others could not hear his answers.
- Right 1 of the Code of Health and Disability Services Consumers' Rights provides that consumers have the right to have their privacy respected. This example raises issues about physical privacy - the surroundings in which Philip was asked to provide information - as well as information privacy.

The issue raised in example 8 is also relevant to pharmacies. People often have to discuss their prescriptions or over the counter medication with pharmacists - perhaps so the pharmacist can ensure the customer knows how to use it or not to mix it with particular drugs. People may feel embarrassed if this conversation is conducted in a way that can be overheard by other customers.



Collecting health information

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*Can other
people
overhear
conversations
with
patients?*

Holding personal information

Security safeguards

Rule 5 of the Code requires agencies to take reasonable security safeguards against:

- Loss;
- Access, use, modification, or disclosure, without the agency's authority;
- Other misuse.

EXAMPLE 9

ACCESS TO PATIENT FILES BY STAFF

A patient with a history of mental illness has been admitted for an urgent appendectomy. Her notes contain a detailed history of past treatments going back many years. During a quiet night a nurse not involved with the patient's care browses through the notes.

- Access to the notes should be restricted to those treating the patient. The agency should consider whether it was necessary to obtain all the notes for this admission, how the nurse obtained the file and the need for further staff training.

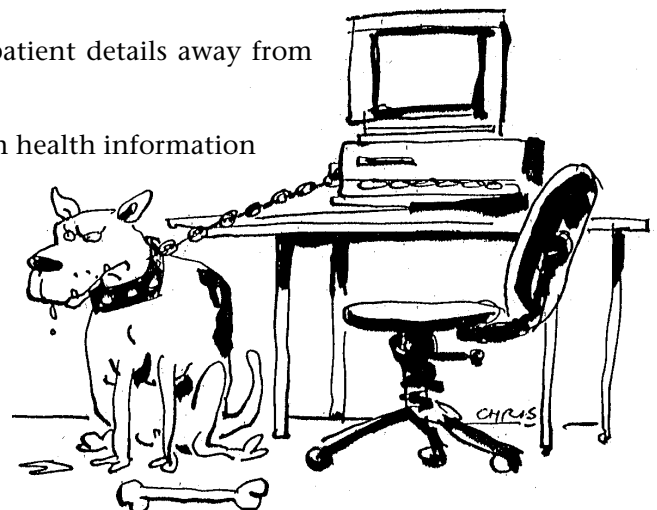
Staff training enhances respect for patient information

If agencies have to give information to someone to allow a service to be provided, they have to do everything reasonably within their power to prevent an unauthorised use or disclosure of information by the other person. For instance,

- If an agency stores medical records with a contractor, an agreement could be signed with the contractor that it will allow only duly authorised staff from the agency access to the records.

Consider how information is stored and identify weak points about storage procedures. Practical steps can be taken to protect information, which might include:

- Physical security
 - Keeping white boards which show patient details away from public areas;
 - Physically securing the areas in which health information is stored;
 - Locking filing cabinets and unattended rooms;
 - Restricting access to storage areas to authorised personnel;



- Positioning computer terminals so they cannot be seen or accessed by unauthorised personnel;
- Using screen savers and security screens so terminals cannot be seen by visitors.
- Systems
 - Implementing document tracking systems, so that it is always known who has removed a document from storage, when it was removed, and when it was returned;
 - Using passwords and restricting access to health information stored on computers;
 - Ensuring regular changes to passwords;
 - Ensuring that any access leaves a footprint which can be audited.
- Staff Training
 - Training staff on the need for security of patient records and when information may be accessed, used and disclosed.
- Fax Machines
 - Implementing controls on the type of information which may be sent by fax and making telephone calls before transmission, to ensure the information is immediately uplifted and not left lying on the fax machine;
 - Programming fax machines with frequently called numbers to minimise the risk of incorrect dialling.
- E-mail
 - If your e-mail programme allows you to use ‘nicknames’ or save frequently used addresses, do so to minimise the risk of inadvertently sending information to the wrong person;
 - Encrypting sensitive files;
 - Remembering that e-mail is akin to a postcard: people can get into the system and read it.

EXAMPLE 10

LEAVING CONFIDENTIAL INFORMATION IN PUBLIC ACCESS AREAS

The receptionist is responsible for sending out accounts to patients. In readiness for collection by the courier, she leaves a stack of window envelopes containing accounts. The top one is for a well-known personality whose friend sees his full name through the window of the envelope.

- Patient information should be kept away from the public counter where it could be read by others. Similarly, computer screens should not be readable from the public side of the counter.

EXAMPLE 11

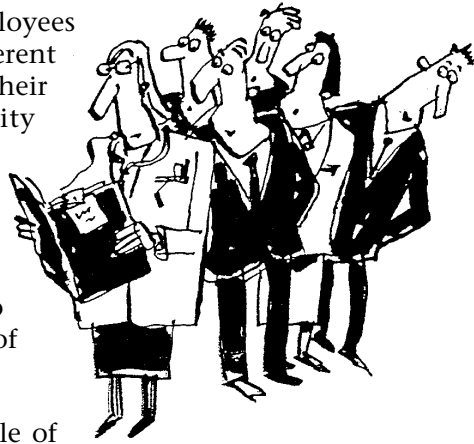
PROTECTING INFORMATION FROM UNAUTHORISED ACCESS BY CUSTOMERS

A pharmacy keeps a register of restricted medications. People purchasing restricted items must fill in their names, addresses, phone numbers and the name of the medicine. The register is a large book and has several entries for customers to a page, so these details can be read by anyone filling in their own details.

- Customers could be taken to one side and asked to provide the details to a staff member, who could transfer them into the register. Alternatively, other people's details could be covered when customers fill in their own details, or a separate page could be dedicated to each person.

Health information is sensitive. Not all employees should be able to read entire patient files. Different information is needed for staff to carry out their functions, so appropriate levels of availability should be arranged. For instance,

- Administrators dealing with billing do not need to see clinical notes.
- Hospital chaplains and volunteer visitors do not need to see clinical notes or have details of treatment without patient authorisation.
- Clinical staff may not need to see the whole of the historical medical record or to have it to hand at all times.



Storage and security policies should be known by all staff. They can then respond appropriately to patient concerns.

How long can information be kept?

Rule 9 provides that health information must not be kept longer than is required for the purposes for which it may lawfully be used. Documents may be kept if that is desirable for providing health or disability services to patients.

Health (Retention of Health Information) Regulations 1996.

Health information must be kept for at least 10 years from the last date of treatment or care.

- Rule 9 does not override the Regulations.



The Regulations allow information to be transferred to another provider in this time. If a patient moves to another town, the records may be forwarded to a new agency.

The Regulations do not prevent agencies from transferring information to the patient or (where the patient is deceased) to their personal representative.

Not all staff need to see clinical notes

Using personal information

3

Using personal information

Accuracy (rule 8)

Before using information, agencies must take reasonable steps to ensure information is:

- accurate
- up to date
- complete
- relevant
- not misleading

This can be particularly important where information has been obtained from a source other than the person concerned.

What is reasonable may vary, depending on the proposed use for the information and its impact on the patient.

If a diagnosis has changed, some note about that on earlier records may avoid having a professional act on the inaccurate first assessment.

Using information (rule 10)

Information obtained in connection with a purpose may be used by the agency for that purpose in accordance with rule 3. The patient should have been told of this purpose. Rule 10 also allows uses which are “directly related” to the purpose for obtaining the information. For instance, information obtained for care and treatment may also be used for administrative purposes related to that care and treatment.

Agencies may have to use information in a way which was not anticipated when it was obtained. Rule 10 lists a number of instances in which information may be used for another purpose. If one of them applies, the agency has a discretion to use the information for that purpose. It cannot be compelled to do so.

Rule 10 allows information to be used for another purpose if it is necessary to prevent or lessen a serious and imminent threat to public health or public safety, or the life or health of an individual.

Information may be used if it is necessary for the maintenance of the law by a public sector agency or for the conduct of proceedings. These exceptions are also contained in rule 11 (disclosure) and are discussed in more detail below.

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Information can be used if that is a purpose for collection

Disclosing information to third parties

Disclosing health information can pose special problems, especially where people are suspicious or wary of health agencies. Agencies have to balance retaining a patient's trust and fulfilling functions as health professionals, which may sometimes include acting in what is believed to be a patient's best interests even if the patient disagrees.

Disclosure can become a problem because agencies:

- have to disclose
- want to disclose
- have been asked to disclose.

*Disclosures
may be
required by
law*

You have to disclose

Agencies may have to disclose because that is required by law.

The Health Information Privacy Code does not derogate (detract) from any law which authorises or requires information to be made available. Such a law must be followed.

If a law requires disclosure the information must be made available. Words like "shall" or "must" indicate that the disclosure is required.

Health professionals must also ensure any disclosure they make complies with their codes of ethics. Many codes of ethics will allow disclosure if it is required by law. If in doubt, professionals should check with their professional body.

In most cases, there will be nothing to prevent the agency from telling the patient that the disclosure has to be made.

Some statutory provisions require disclosure. For instance,

Land Transport Act 1998, ss 18 and 19

Registered medical practitioners and registered optometrists must notify the Director of Land Transport Safety Authority if they consider that a patient is likely to drive and whose mental or physical condition is such that, in the interests of public safety, the patient should not be permitted to drive or should only be allowed to drive subject to some limitations.

If a person who holds a driver licence becomes subject to an inpatient compulsory treatment order or becomes a special patient, the person in charge of the hospital must notify the Director of Land Transport Safety Authority of that.

Cancer Registry Act 1993, ss 5, 6 & 7

Where a cancer test indicates that someone has cancer the person in charge of the laboratory where the test was carried out must report it to the Director-General of the Ministry of Health for the purposes of the cancer registry.

The Director-General can require more information to be provided by a medical practitioner or the person in charge of a hospital if the initial report is incomplete.

Civil and criminal proceedings will not lie against anyone who makes information available in compliance with ss 5 and 6.

Tuberculosis Act 1948, s 3

Medical practitioners must notify the Medical Officer of Health if they believe a patient has tuberculosis.

Health and Disability Commissioner Act 1994, s 62

The Health and Disability Commissioner can require health or disability service providers to make information available for an investigation conducted by the Commissioner.

The Privacy Commissioner has similar powers to require information for investigations conducted under the Privacy Act.

You want to disclose

Unless required to disclose by law, agencies do not have to disclose information. They can choose not to disclose. But if they want to disclose, they must find a provision that allows it. Some statutes authorise (permit) disclosure. They do not require agencies to disclose, but give them a choice. Words like “may” indicate that the statute authorises disclosure.

The distinction between laws which require disclosure and laws which authorise disclosure is important. Some codes of ethics may allow disclosure only if it is required by law and might be breached if the disclosure is only authorised by law. In this way, the Code is more flexible, because it recognises disclosures that are authorised **or** required by law.

In most cases there will be nothing to prevent the agency from telling the patient that the disclosure will be made.



**Rule 11
allows
disclosure
where it is
a purpose**

Some statutory provisions authorise (permit) disclosure.
For instance:

**Children, Young Persons and Their
Families Act 1989, ss 15 and 16**



Anyone who believes a child or young person is at risk of some harm, ill-treatment, abuse, neglect or deprivation can report the matter to a social worker or the police. This provision does not require the disclosure, but permits it to be made. It protects professionals from civil, criminal or disciplinary proceedings if they disclose in good faith.

Health Information Privacy Code 1994, rule 11

If agencies want to disclose information and there is no law requiring or authorising it, they must consider rule 11 of the Code.

If the agency does not want to give out the information, it should state why. It would not be because of the Privacy Act or the Code, but would be for other reasons such as policy or confidentiality.

Rule 11 allows disclosure where that was a purpose for obtaining the information. These disclosures can be identified because they form part of regular procedures, are commonly made, or can be reasonably anticipated. For example:

- disclosing relevant information to other members of treatment teams such as nurses or occupational therapists;
- disclosing details to the first contact person, including medication details;
- referring the patient to other health agencies, such as a physiotherapist.

These purposes should be discussed with the patient in accordance with rule 3. If this is done, patients will not be surprised when the information is disclosed.

Agencies may disclose information if that is one of the purposes for obtaining the information. In setting purposes, agencies should remember right 4(5) of the Code of Health and Disability Services Consumers' Rights, which gives consumers the right to co-operation among providers to ensure quality and continuity of services. Co-operation would include the sharing of information with other providers where that was necessary for their treatment, so this would be a purpose for having the information. That should be communicated to the patient when the information is collected.

Agencies might have a policy of disclosing information to family members or friends who may have varying levels of involvement with the individual's treatment. The individual concerned should be told (in accordance with rule 3) that information may be so disclosed.

Other reasonably anticipated disclosures, for example, may be to a health funder for audit purposes, or to ACC if a patient has a claim related to his or her treatment. Again, the patient should be told about this in accordance with rule 3.



EXAMPLE 12

ANTICIPATED DISCLOSURES

Some people seek drugs from GPs for the purposes of abuse. When they consider they have encountered such a person, some practices pass on a warning to other practices and pharmacists in the area. It is unlikely that such a person would agree to this information being passed on. Would this disclosure breach the Code?

- Provided the agencies are open with their policies, the Code would allow disclosure of this information. Perhaps agencies could display posters in waiting rooms informing people about the network.

Rule 11 also allows disclosure if:

- it is to the individual concerned or his or her representative (where the individual is dead or cannot exercise his or her rights).
- it is authorised by the individual concerned or his or her representative (where the individual is dead or cannot exercise his or her rights).

Health professionals may be presented with an authorisation signed by their patient which is vague or very broad. If they doubt the patient has understood what would be collected and disclosed on the basis of the authorisation it is open to them to speak to the patient before disclosing any information.

- the information is sourced from a publicly available publication.

Publicly available publications include public registers, newspapers or the telephone book.

Information about patients in hospital can be disclosed in general terms about their presence, location, condition and progress. This is subject to a veto by the patient or representative.

Registered health professionals can disclose the fact of a patient's death to an appropriate person such as a representative, spouse and so forth.

It is not always practicable or desirable to get a patient's authorisation to disclose information. For instance the patient might:

- be unconscious
- not be competent
- have refused to give an authorisation.

In these circumstances, rule 11 will allow disclosure where certain exceptions apply. For instance:

- Registered health professionals may give information to: a person nominated by the patient; or the principal caregiver; or a near relative in accordance with recognised professional practice. Disclosure must not be contrary to the patient's (or the representative's) express request (rule 11(2)(b)).
- Information may be disclosed if it is necessary to prevent or lessen a serious and imminent threat to public health or public safety, or the life or health of any individual, including the patient (rule 11(2)(d)).

The threat must be serious.

The threat must be imminent.

Authorisations to disclosure must be clear

It must be a threat to public health or public safety, the life of a person or health of a person.

The information must be given to someone who can act to prevent or lessen the threat.

Only the information necessary to achieve that purpose should be given. It might not be necessary to disclose all of the information.

EXAMPLE 13

DISCLOSING INFORMATION TO LESSEN A SERIOUS AND IMMINENT THREAT

A doctor has a patient who drives a passenger bus. The patient has a heart condition and the doctor is concerned about safety of passengers. The doctor tells another patient that the bus driver is not fit to drive. The doctor attempts to organise a petition to have the driver barred from driving passenger service vehicles.

- The doctor would have to consider whether there was a serious and imminent threat to public safety.
- The doctor may have had grounds for believing there was a serious and imminent threat, but the disclosure is unlikely to prevent or lessen that threat because it was not made to an appropriate authority. The disclosure would breach rule 11 of the Code.
- Under the Land Transport Act 1998 the doctor would be required to notify the Land Transport Safety Authority if he thought the patient was not safe to drive but intended to do so. Disclosing in accordance with that requirement would not breach the Code.
- The doctor would have to consider how much information had to be disclosed to the Land Transport Safety Authority. If he disclosed more than was required by the Land Transport Act, that extra disclosure might breach rule 11.

- Information may be disclosed to an individual's principal care giver of the individual's release, or imminent release from compulsory status under the Mental Health (Compulsory Assessment and Treatment) Act 1992.

"Principal caregiver" is defined in clause 3 of the Health Information Privacy Code 1994. This exception should not be seen as a substitute for developing a clear discharge plan that addresses the issue of disclosure to family members.

- Information may be disclosed if it is necessary to avoid prejudice to the maintenance of the law by a public sector agency or for the conduct of proceedings (rule 11(2)(i)). For instance,

Police maintaining the criminal law.

Public sector agencies such as the Department of Social Welfare or Immigration Service maintaining the laws they administer.

If the disclosure is to be made in proceedings, check whether the information is subject to the Evidence Amendment Act (No 2) 1980, which prohibits the disclosure of some information. (This and other useful laws are included in the Health Information Privacy Code booklet).

This exception allows agencies to disclose on their own initiative. It does not affect the powers public sector agencies may have to request or require information of the health agency.

EXAMPLE 14

DISCLOSING INFORMATION FOR COURT PROCEEDINGS

A doctor who treated a family was asked by the husband to write a report about the wife for use in custody proceedings. The doctor wrote a report describing the wife's medical and social history, including some details of psychiatric instability. The doctor concluded by supporting the husband's application for custody.

- This information may well be subject to s 32 of the Evidence Amendment Act (No 2) 1980, which prohibits the disclosure of some information in Court. The Code allows disclosure if there is a belief on reasonable grounds that it is necessary for the conduct of proceedings. The doctor would not have reasonable grounds for believing that the disclosure was necessary if the Evidence Amendment Act prohibited the disclosure being made.

- Information may be disclosed if the agency believes the individual is (or is likely to become) dependent on controlled drugs, prescription medicines or restricted medicines. This applies only to disclosures made by a registered health professional to the Medical Officer of Health for specific purposes set out in the Misuse of Drugs Act 1975 and the Medicines Act 1981 (rule 11(2)(j)).
- Information may be disclosed by the agency if it is in accordance with an authorisation granted under section 54 of the Privacy Act 1993 (rule 11(2)(k)).
- Information may also be disclosed for research and statistical purposes if it will not be published in a form which could reasonably be expected to identify the individual concerned (rule 11(2)(c)). If ethical committee approval is needed for the research, that must be obtained before the information is disclosed.

Before disclosing information, the agency should be satisfied about the security safeguards taken to protect the information and the way in which the individual concerned will be protected.

The Code of Health and Disability Services Consumers' Rights gives consumers the right to be informed if they are participating in teaching or research programmes.

Rule 3 requires reasonable steps to be taken to alert a person to the collection if information is being collected directly from the person or from the representative of that person.

- Information can also be disclosed if required for a professionally recognised quality assurance programme or for risk management assessment and the information will not be published in a form which would identify individuals except as required by law (rule 11(2)(h)). For risk management, the disclosure must be limited to the person assessing the risk.

Disclosure under the Code is discretionary: just because an exception would allow a disclosure, it does not follow that the disclosure has to be made.

The remedies in the Privacy Act apply only where there is an interference with privacy. A disclosure is an interference with privacy if it breaches rule 11 and results in some adverse outcome for the person concerned, perhaps by adversely affecting their interests, or by causing significant humiliation, hurt feelings or loss of dignity. Not every breach of rule 11 amounts to an interference with privacy, because not every breach will result in an adverse outcome.

*Disclosure
for research
purposes*

Ethical duties

Ethical duties of confidentiality may well differ from the exceptions in the Code. If an exception in the Code allows a disclosure and the health professional is subject to a code of ethics those duties should be considered. They may inhibit disclosure or require that certain procedures be followed. If the course of action is dictated by ethical considerations, they should be given as the reason to the person asking for the information.

You have been asked to disclose

Problems can arise when disclosures are neither routine nor anticipated. The problem frequently arises because the information has been requested. Agencies may be asked to disclose information, perhaps because:

- the police are investigating a matter;
- the media are following up a story;
- a social worker is investigating a case of suspected abuse; or
- a family wants information about a relative who is receiving treatment.

Some statutory provisions which require or authorise (permit) disclosure can be triggered by a request. Agencies cannot disclose in reliance on these provisions unless they have actually received a request.

Agencies must appreciate the difference between a provision which requires disclosure and one which authorises (permits) disclosure. If it only permits disclosure, agencies can refuse the request if they do not want to disclose. This can impact on some codes of ethics which may allow disclosure if it is **required** by law, but not if it is only **permitted** by law.

If agencies are asked to disclose and they are not required to do so by law, they cannot be compelled to disclose. If agencies choose not to disclose, they should take responsibility for the decision and give the real reason. It is not helpful or accurate to say the information cannot be disclosed because of the Privacy Act or the Code when the agency does not want to make the information available.

Some statutes which are triggered by requests include:

Health Act 1956, s 22D

The Minister of Health can require hospitals and health services and funders to disclose information about the condition or treatment of, or health or disability services provided to, any person.

The Minister can require disclosure only for the purpose of obtaining statistics for health purposes or for the purposes of advancing health knowledge, health education or health research.

Information which would make the person identifiable may not be provided unless the person (or representative) consents to the disclosure or the identifying information is essential for the purposes for which the information is sought.

Health Act 1956, s 22F

This requires disclosure unless an exception applies. Caregivers and representatives can use it to obtain information.

Health professionals can use it to obtain relevant information from other health professionals. For instance, it can be used if a patient transfers to a new clinic and the notes are needed from the old clinic for the patient's medical history.

Information must (with exceptions) be disclosed on request to:

- the individual about whom the information is held; or
- the individual's representative; or
- any other person providing health or disability services to the individual.

A request may be refused if there are reasonable grounds to believe that the patient does not want the information to be disclosed to the representative or to the person providing health or disability services.

If a request is made by the patient, it must be treated as an access request made under rule 6 of the Code (discussed below at page 36).

If a request is made by the patient's representative, the agency should consider rule 11(4) of the Code which allows it to refuse the request if:

- disclosure would be contrary to the patient's interest;
- the agency has reasonable grounds for believing the patient does not want the information disclosed;
- one of the withholding grounds in ss 27-29 would apply if the request had been made by the patient (discussed below at page 38).

If the withholding grounds do not apply the information **must** be disclosed in accordance with the request. Even if the withholding grounds do apply, the agency can disclose the information if it wants to because reliance on the withholding grounds is discretionary: agencies may withhold but are not required to do so.

Note that guardians of children under 16 may consent to medical, dental and surgical procedures (Guardianship Act 1968, s 25(3)). The Code of Health and Disability Services Consumers' Rights gives consumers the right to be fully informed when giving consent. This should be considered when dealing with requests by guardians for information if they have been asked to consent to a child's treatment.

EXAMPLE 15

SECTION 22F: REQUESTS BY CAREGIVERS

Brian is a 65 year old man with severe emphysema. He is to be discharged after a stay in hospital. His wife, Rose, plans to look after him in their home. She has asked their GP for information on Brian's day to day needs.

- Rose is Brian's caregiver, so her request is subject to s 22F.
- Unless the GP is aware that Brian does not want the information disclosed, there does not seem to be any reason to withhold it from Rose.

EXAMPLE 16

SECTION 22F: REQUESTS BY FAMILY MEMBERS NOT INVOLVED IN CAREGIVING

Jill, Brian and Rose's daughter, calls the GP. She says Rose is having difficulty with Brian's oxygen tanks and that she lets Brian's friends smoke when they visit him. Jill says Rose will not let her help care for Brian and fears Rose cannot cope alone. She would like information about Brian's care so she can try to help her mother.

- Jill does not seem to be involved with Brian's care. Nor does she seem to be his representative. Therefore, s 22F does not apply to her request.
- The GP could consider whether exceptions in rule 11 allowed disclosure, but would also have to consider ethical constraints on disclosure.
- It might be possible to resolve Jill's concerns without disclosing any information. The GP could act on her concerns by giving Rose more advice and instructions, encouraging her to seek help if she needs it, and generally monitoring the situation.

**Official
Information
Act applies
to public
sector
agencies**

Victims of Offences Act 1987

Section 11A of the Victims of Offences Act 1987 enables victims of certain serious offences to request notification of the escape or discharge of a person compulsorily detained in a hospital because of the offence.

Official Information Act 1982

This must be considered if the agency is subject to the Official Information Act and has received a request from someone who is not:

- the subject of the information; or
- that person's representative or agent.

The Official Information Act applies to public sector agencies specified in the First Schedule to the Act and to agencies specified in Parts I and II of the First Schedule to the Ombudsmen Act. In the health sector, they will include the Ministry of Health, the Health Funding Authority and public hospitals.

The information must be "held" by the agency. If the information is held solely as an agent for someone else, then it may not be "held" for the purposes of the Official Information Act. For instance, an agency that stores records for another organisation and does not use the information itself may not "hold" the information. If the other organisation was subject to the Official Information Act the request would need to be transferred.

If the request would require the generation of new information, that information may not be held for the purposes of the Official Information Act:

- a request for a report done by the agency would be subject to the Official Information Act;
- a request for comment on an issue might require the generation of new information, so it may not be "held" by the agency for the purposes of the Official Information Act.

The general principle underlying the Official Information Act is availability of information. However, there are withholding grounds.

Section 9(2)(a) allows information to be withheld if it is necessary to protect the privacy of a natural person, including a deceased natural person. The Ombudsmen (who review refusals of requests made under the Official Information Act) have said that when considering s 9(2)(a), agencies must consider whether it is necessary to withhold the information to protect the privacy of the individual or individuals concerned. In assessing whether withholding is necessary in the circumstances of a particular case, agencies should:

- identify the actual privacy interest requiring protection;
- assess the strength of the privacy interest in the circumstances of the particular case;
- identify any considerations favouring disclosure of the information in the public interest;
- assess the relative strength of such considerations favouring disclosure; and
- consider whether in the circumstances of a particular case, they outweigh the need to withhold the information to protect personal privacy.

(“Protection of Privacy under the Official Information Legislation” (1997) 3(4) *Ombudsmen Quarterly Review*, 1.)

In a particular case, the information may well relate to a matter of privacy but due to other circumstances, such as when the information will be published shortly, the Ombudsmen may not consider it is **necessary** to withhold the information to protect the individual’s privacy.

If an agency withholds information under s 9(2)(a), the Ombudsmen are obliged to consult the Privacy Commissioner before forming a final opinion on the matter. The Privacy Commissioner will comment on the privacy interests in the information and the relative public interest in release.

The Ombudsmen recognise there are, in most cases, strong privacy interests attaching to health information and consider that the public interest in disclosure has to be stronger to outweigh the privacy interest (*Report of the Ombudsmen for the year ended 30 June 1996*, at 34).

EXAMPLE 17

OFFICIAL INFORMATION ACT – PUBLIC INTEREST IN DISCLOSURE

A woman alleged she was assaulted and treated for particular injuries at a local hospital. The man accused of assaulting the woman was convicted. He sought information to assist in a petition to the Governor-General against an unjustified conviction. He asked the hospital whether it had a record of a person being treated for the particular injuries at the particular time. The hospital declined to say whether it had any such information. In fact it did not.

- The Ombudsman concluded that the public interest in disclosure of the fact that there was no record outweighed the privacy interest in withholding the information. He took into account the discrepancy between the victim’s statement and the hospital’s record, and the fact that the victim had given contradictory evidence in a later case.
- In the interests of justice, the man should have access to the information so the Governor-General could be given the relevant facts.

(*Report of the Ombudsmen for the year ended 30 June 1996*, at 34-35.)

If information is released in good faith under the Official Information Act, civil and criminal proceedings will not lie against the agency which released it.

Health Act 1956, s 22C

Agencies providing health or disability services are permitted to disclose health information to specific people if it is required for their functions. The disclosure is not required. Some of these people are:

- medical officers of penal institutions
- probation officers
- social workers
- care and protection co-ordinators
- police officers

Section 22C allows information to be disclosed in response to a request. It does not allow information to be volunteered without a request.

Information may also be disclosed to the employees of a funder (such as the Health Funding Authority). But in those cases disclosure of the information must be essential for carrying out that funder's functions under the Health and Disability Services Act 1993.

A process for dealing with requests

If agencies receive a request for health information about someone and the request has not been made by the individual concerned, they need to consider whether:

- the disclosure is required by law;
- a request has been made under the Official Information Act.

If it is required by law the disclosure must be made. If the request is to a public sector agency under the Official Information Act, consider whether any of the withholding grounds apply. Section 9(2)(a) would nearly always be relevant.

If there is no such requirement to disclose information, agencies can consider whether they want to disclose. They can decline to do so. They may have an established relevant policy on such requests.

If agencies give reasons for the decision, they should give real reasons. Blanket statements such as "because of the Privacy Act" are seldom justifiable. If there is a concern about the effect disclosure would have on the patient, the explanation should refer to the clinical reasons for not disclosing, or to the potential damage to the therapeutic relationship, or to the agency's policies.

If an agency wants to disclose, it should consider whether the disclosure is authorised by law or by the Code. If it is not, then the information should not be disclosed.

Ethical obligations parallel these legal obligations and must also be considered.

Special issues relating to disclosure

5

Special issues relating to disclosure

Disclosure to caregivers

31

Sometimes patients do not want their families or friends to be given information about their illnesses or treatment or about their presence in a hospital. They may not want information to be passed to other health professionals who will be monitoring their treatment and recovery. Their concerns might be dealt with in a number of ways discussed under the headings which follow.

Where disclosure is a purpose

Agencies may consider a purpose for obtaining health information is to pass on necessary information about care of the patient to caregivers or other people who should be aware of certain aspects of care, such as medication requirements. The Code permits this disclosure as it is one of the purposes for which the information was obtained.

Developing a treatment plan with the patient's involvement enables the desired disclosures to be discussed. There is no need subsequently to approach the patient for an authorisation to disclose information in accordance with the plan.

Agencies should take responsibility for the policy on which their decisions are based. If they have a policy to make some disclosures, patients should be told about it. If agencies have a policy not to disclose certain information, or they choose not to do so in the particular circumstances, those policies should be made clear. They form the basis of the decision not to disclose.

Where an individual vetoes disclosure

If information was obtained for a particular disclosure, such as to a caregiver, the disclosure may be made despite a patient's veto although ethics would need to be considered. If the purposes did not include disclosure of certain information, the agency has to consider other options including whether one of the exceptions to rule 11 applies. Discussion with the patient is often a good starting point.

If an agency considers disclosure is not in the individual's best interests, perhaps because of family dynamics or because of potential harm to the therapeutic relationship, the person requesting information should be advised that the decision not to disclose has been made on clinical grounds.

Disclosure to caregivers can be a policy

SCENARIO

A public hospital receives a request from a parent of a 12 year old receiving counselling for behavioural problems associated with suspected abuse. The parent has asked for information about the child's progress and for statements made during the counselling sessions. She was reluctant to enter counselling and did so only on the basis that everything said in the sessions would be confidential. The child has no contact with the parent and has said she does not wish any information to be disclosed. The hospital is reluctant to disclose because it would undermine the trust built up between the child and counsellor.

EXAMPLE 18

DISCLOSING A CHILD'S COUNSELLING NOTES TO NON-CAREGIVERS

- The hospital should consider the basis of the request. Is it a request on behalf of the child or by the parent on her or his own behalf?
- The parent may be the child's legal representative for the purposes of the Code because the child is under 16, so a request should be treated under s 22F of the Health Act. The hospital should consider rule 11(4) of the Code, which gives a discretion to refuse to disclose information if there are reasonable grounds to believe the child does not want the information to be disclosed. In this case, there are.
- The hospital must consider the Official Information Act. There is a privacy interest which needs to be protected, so s 9(2)(a) applies. It is not clear that there is a public interest in disclosure which overrides the privacy interest. The information might be withheld from the requester.
- None of the grounds in the Code allowing disclosure seem to apply. Even if they did, the hospital has a residual discretion to refuse to disclose. Because the hospital does not wish to disclose, it is not required to do so.

EXAMPLE 19

DISCLOSING A CHILD'S COUNSELLING NOTES TO CAREGIVERS

The same scenario as above, except that the parent requesting the information is the child's primary caregiver.

- The request could be treated under s 22F. Refusal of requests by caregivers is allowed if the child does not want the information to be disclosed.
- In the circumstances, it would seem appropriate to explore the child's reasons for not wanting the information to be disclosed and the parent's reasons for wanting it. It may be possible to find some middle ground which both would find acceptable.
- If not, the hospital would have to consider whether disclosure of limited information about a patient's progress to caregivers is one of the purposes for obtaining the information. If so, that information could be disclosed notwithstanding the child's concerns.
- The hospital must consider the Official Information Act. There is a privacy interest which needs to be protected, so s 9(2)(a) applies. The hospital would have to consider whether there is a public interest in disclosure which overrides the privacy interest.
- A limited release or summary of information might be appropriate.

Disclosure to the media

Agencies, particularly hospitals, may be approached by the media for information about a patient.

The Code allows a limited release of personal information to the media.

- Information may be disclosed in general terms concerning the presence, location and condition and progress of a patient in a hospital on the day on which the information is disclosed. Disclosure must not be contrary to the patient's (or representative's) express veto (rule 11(1)(e)).
- A person's identity and a brief description of the nature of injuries sustained in an accident may be disclosed by a hospital to an accredited reporter for the purpose of publication or broadcast. Disclosure may not be made if it would be contrary to the patient's express veto (rule 11(2)(f)) (The veto may be given by a representative). This provision applies where it is not desirable or practicable to obtain the patient's (or the representative's) authorisation.

Agencies subject to the Official Information Act have to consider requests by journalists for information about patients under that Act. Requests must be for information which is held by the agency. The information may be held in records, or in a report or correspondence. Requests for a comment on a particular issue rather than for specific information may not be subject to the Official Information Act because the agency would have to create the information before it could respond to the enquiry. Such requests would have to be dealt with under rule 11 of the Code.

Requests for information which exists and is held must be considered under the Official Information Act. Section 9(2)(a) allows information to be withheld if it is necessary to protect the privacy of any person, whether living or dead. Agencies seeking to rely on 9(2)(a) must:

- identify the actual privacy interest requiring protection;
- assess the strength of the privacy interest in the circumstances of the particular case;
- identify any considerations favouring disclosure of the information in the public interest;
- assess the relative strength of such considerations favouring disclosure; and
- consider whether in the circumstances of a particular case, they outweigh the need to withhold the information to protect personal privacy.

(‘Protection of Privacy Under the Official Information Legislation’ (1997) 3(4) *Ombudsmen Quarterly Review*, 1.)

The Ombudsmen recognise there are, in most cases, strong privacy interests attaching to health information and consider that the public interest in disclosure has to be stronger to outweigh the privacy interest (Report of the Ombudsmen for the year ended 30 June 1996, at 34).



EXAMPLE 20

MEDIA REQUESTS SUBJECT TO THE OFFICIAL INFORMATION ACT

A reporter is researching a story on Martin, whose application for a free wheelchair was refused by a public hospital. She asks the hospital for any reports on his case. The hospital has several reports and memoranda on this issue.

- The request is subject to the Official Information Act. The hospital will consider whether it ought to withhold part or all of the information under s 9(2)(a) to protect Martin's privacy.
- If the information is made available to the reporter in good faith, the Official Information Act will protect the hospital against civil and criminal proceedings for making the information available.
- The hospital might send all of the information to Martin and suggest the reporter seek it from him.

EXAMPLE 21

MEDIA REQUESTS NOT SUBJECT TO THE OFFICIAL INFORMATION ACT

The reporter asks the hospital to justify why it refused to give Martin a wheelchair when it had recently given a wheelchair to someone else. Martin has alleged that he was treated unfairly.

- The reporter has asked the hospital to comment on allegations of unfairness. This would effectively require it to create new information. Disclosure of this information would be subject to the Code rather than the Official Information Act.
- The hospital could seek Martin's authorisation to disclose the information.
- The hospital could send its response to Martin and suggest the reporter seek it from him
- The hospital could give the reporter its policy on access to free wheelchairs without including any personal information.

Decisions on such requests need to be made as soon as practicable - and in any case within 20 working days unless the agency extends the time in accordance with the Official Information Act.

Disclosure in the public interest

There may be a compelling interest in disclosure, perhaps to avert a suicide or to warn that a patient in the community poses a risk (generally or to a particular person).

If a threat is both serious and imminent, the Code will permit a disclosure. The following issues should be considered:

- Is it desirable or practicable to get the individual's authorisation? If not, consider whether:

There is a serious threat to public health or public safety or to someone's life or health;

The threat is imminent;

It is necessary to disclose health information to lessen or prevent the threat.

- The information should be disclosed only to a person or agency who can act to lessen or avert the threat.
- It may not be necessary to disclose all of the information to avert the threat. Only that information which is necessary to do so should be disclosed.

There may also be a compelling interest in disclosure of certain information to the police or some other public sector agency with a function of maintaining a law. The following issues should be considered.

- Is it desirable or practicable to get the individual's authorisation? If not, consider whether:

It is necessary to disclose health information to avoid prejudice to the maintenance of the law;

The disclosure will be made to a public sector agency which maintains the law in question.

- It may not be necessary to disclose all of the information to avoid the prejudice. Only as much information as is necessary to do so should be disclosed.

EXAMPLE 22

DISCLOSING INFORMATION FOR POLICE INVESTIGATIONS

The police are investigating a series of sexual offences believed to be committed by one man. They write to every medical practitioner in the greater Auckland region asking for any information which might lead to the apprehension of the offender. A practitioner believes that one of her patients might be the offender.

- It may not be practicable for the practitioner to discuss this with the patient, as he might disappear, which means it would not be desirable to obtain his authorisation for the purposes of the Code. If the practitioner did discuss the matter with the patient and he refused to go to the police or allow her to do so, it would not be practicable for her to obtain his authorisation for the purposes of the Code. The practitioner would have to consider the following.
- Section 22C(2)(f) of the Health Act 1956 authorises (permits) disclosure of information if it is required by any member of the police for the purposes of exercising or performing any of the police officer's powers, duties or functions.
- The Code does not derogate from any enactment which authorises or requires information to be disclosed. Section 22C is a law authorising disclosure so, if the disclosure is made in accordance with that section, there will be no breach of the Code.
- If the disclosure was not made in reliance on s 22C or if there had not been an approach from the police, the practitioner would have to consider rule 11 of the Code. She could disclose if she had reasonable grounds to believe that the disclosure was necessary for an investigation being conducted by the police (rule 11(2)(i)). The reasonableness of the grounds would include the basis for believing that the patient was an offender. The stronger the grounds, the more likely that the disclosure is necessary. The practitioner must disclose only sufficient information for the police to maintain the law. This will not usually require disclosure of all aspects of the patient's medical history, current condition or treatment. It may require only the release of a name and address.

Requests for personal information by the individual concerned

Patients don't have to explain why they want information

Right of access to personal information (rule 6)

People have a right to access information about themselves. This right is given by rule 6 of the Code, as well as by s 22F of the Health Act. A request made under s 22F for personal information is to be treated as a request made under rule 6 of the Code.

The right to access is important both from a privacy perspective and from a treatment perspective. Several of the rights in the Code of Health and Disability Services Consumers' Rights are concerned with the communication of information and with informed consent. So, when considering a patient's request for personal health information, agencies should consider whether a refusal would hinder the patient's ability to give informed consent to a procedure.

People do not have to explain why they want information. However, their reasons for requesting information may become relevant when balancing different privacy interests (perhaps where there is information about two people and the agency has to decide whether releasing information about the other person would be unwarranted).

Requests by patients for access to their personal health information are treated differently from requests for disclosure by third parties for information about a patient. The individual's right of access is subject only to some withholding grounds contained in the Privacy Act.

Health information held by the agency may not be held solely on the patient's medical file. It might appear on other records, such as a family file or accounting records.

Mentally retained information may be subject to an access request, provided it is readily retrievable. A request for this information may have to be fairly specific to help the agency respond. Issues like the age of the information and the amount requested will be relevant to whether the information is retrievable. People cannot necessarily be expected to remember in detail events which occurred a number of years ago. But they may remember that they had a particular conversation, or that a specific issue was discussed at a meeting a few weeks or months ago. Signposts on files to information will also be relevant. For instance, a note on a file to see a particular person for information about an issue indicates that the information is retrievable.

A request cannot be refused on the basis that the individual does not "own" the records or that they "belong" to the agency.

The Code gives individuals a right to access information, not to demand original documents.

The Health (Retention of Health Information) Regulations 1996 contemplate that appropriate disposal of health information might include giving the notes to the individual. If an individual requests old information that the agency no longer wishes to keep and does not have to keep, the agency could consider giving the individual the records.

Requests by parents and guardians

Parents and guardians do not have an automatic right of access to their children's medical records.

Requests from parents and guardians as representatives should be considered under s 22F of the Health Act. In the case of very young children there would seldom be reason to withhold the information from a parent as a representative of the child.

In some cases it can be difficult to grant a request by parents or guardians where abuse is suspected or where older children may not wish their health information to be disclosed. Agencies should then consider rule 11(4) of the Code, which provides that a request under s 22F may be refused if the request is not made by the person concerned and:

- the disclosure of the information would be contrary to the person's interest;
- the agency has reasonable grounds for believing that the person does not or would not wish the information to be disclosed; or
- one or more of the withholding grounds in ss 27 to 29 of the Privacy Act would have applied, had the request been made by the person concerned.

Responding to requests for personal health information by the person concerned

Decisions on requests must be made as soon as practicable and no later than 20 working days after receiving the request. People may ask for their requests to be treated with urgency, and should explain the urgency.

Access can be granted in a number of ways:

- inspection of the documents
- providing a copy of the documents
- hearing or viewing audio or video tapes recordings
- supplying transcripts
- supplying a summary of the information
- orally

Access should be granted in the manner requested, unless it would:

- Impair efficient administration
- Contravene a legal duty the agency has in respect of the document



Parents don't have automatic right to children's information

- Prejudice the interests protected by the withholding grounds (ss 27-29 of the Privacy Act)

Agencies should adopt procedures to ensure that information intended for a patient is received only by the patient or, if the request was made by the patient's agent, by the patient or the agent.

EXAMPLE 23

ENSURING INFORMATION IS RECEIVED BY THE RIGHT PERSON

Two people asked their insurance company for printouts of their claim histories. The receptionist printed out both accounts and hand addressed two envelopes. She accidentally switched the documents, so they received each other's information.

- Had the insurance company had a policy of using window envelopes, this mistake would not have occurred.

Agencies should ensure that where a request is made by an agent that the agent either has a written authorisation or is otherwise duly authorised to make the request.

- The person may have told the agency to deal with the agent.
- The agency could call the patient and confirm that the information should be given to the agent.
- The agent may be a professional person, such as a lawyer, who has confirmed that an authorisation is held.

Charging

Public sector agencies must not require any charge to be paid for making information available in response to a request under rule 6. This means public sector agencies dealing with requests made under rule 6 cannot charge for:

- any assistance given to the person making the request
- the making of the request
- transferring the request to another agency
- processing the request
- making the information available

Private sector health agencies must not generally charge for these services either, but there are some exceptions. Private sector health agencies may make a reasonable charge for providing a copy of an X-ray, video recording or CAT scan photo. They may also make a reasonable charge where they have made the same information available within the last 12 months. Otherwise, a charge must not be made for making information available in response to a request under rule 6.

Reasons to withhold information

The only reasons available to refuse a request from the patient for access to health information about herself or himself are contained in ss 27 to 29 of the Privacy Act. Some of the more common reasons are explained below:

- Information may be withheld if its release would be likely to prejudice the maintenance of the law (s 27(1)(c)).

“Would be likely” means there should be a distinct or significant possibility of the risk (prejudice to the maintenance of the law) eventuating.

This withholding ground can be used to protect the identity of an informant who has contacted a health agency. For instance, a patient is concerned that his neighbour abuses her children. He does not wish to go to the Department of Child, Youth and Family Services, but thinks something should be done. He tells his doctor and asks her to look into the matter and contact the Department if it seems appropriate. His identity could be withheld from the neighbour.

- Information may be withheld if its disclosure would be likely to endanger the safety of any individual (s 27(1)(d)).

There should be a distinct or significant possibility of the risk (to a person’s safety) eventuating.

There must be a link between disclosure and endangering safety.

Consider providing a summary which does not refer to that information or use the words likely to endanger a person’s safety.

- Information may be withheld if its disclosure would involve the unwarranted disclosure of the affairs of another individual or of a deceased individual (s 29(1)(a)). This requires a balance to be struck between the privacy interests of the requester and the other person.

Consider whether the information about the other person can be separated. If it cannot, consider what would make the disclosure unwarranted.

Has the other person made any allegations about the requester? Generally allegations should be released but information about the other person’s thoughts and feelings may be withheld.

EXAMPLE 24

UNWARRANTED DISCLOSURE OF THE AFFAIRS OF ANOTHER INDIVIDUAL

Tony asked a psychiatric hospital for access to the records about his stay there. While in the hospital, he formed a close relationship with Mele. The records noted Tony’s and Mele’s desire to leave together, which was opposed by staff due to Mele’s instability. The hospital believes Tony is not aware of the extent of Mele’s instability, and wants to withhold that reference from him. Tony particularly wants to know why the hospital opposed their plans to leave together.

- The hospital may withhold the reference to Mele’s instability and the reasons for it because this is sensitive personal information which Tony may not know. It is not information which Mele would reasonably expect to be given to Tony. Release of it would involve an unwarranted disclosure of her affairs.

- Information can be withheld if the agency is satisfied that its disclosure would be likely to prejudice the physical or mental health of the requester (s 29(1)(c)).

The agency must consult the requester’s medical practitioner where practicable.

The medical practitioner should be a person whose primary ethical obligation is to the requester.

The agency is not obliged to adopt the views of the medical practitioner, but must consider them and weigh them with the other evidence.

The information must relate to the requester’s physical or mental health.

Consider how its disclosure would prejudice the requester’s health.

EXAMPLE 25:

RELEASING INFORMATION IS LIKELY TO PREJUDICE HEALTH

Rita is an elderly patient with bipolar disorder and a number of physical ailments which require her to be in regular contact with the hospital and her general practitioner. She has never accepted the diagnosis of bipolar disorder and becomes very agitated and distressed when it is discussed. Her compliance with medication is not good and needs monitoring. Rita distrusts the medical profession and considers the local public hospital is trying to lock her away.

She has asked the hospital for access to her notes. The hospital has concerns about releasing them because the diagnosis of bipolar disorder and her treatment for it is referred to throughout the notes. The hospital has consulted Rita's general practitioner, who agrees that she would become seriously distressed and agitated by the notes and believes it would discourage her from keeping regular appointments with the hospital and her general practitioner.

- The hospital and general practitioner seem to be satisfied that releasing the information would prejudice Rita's mental health by causing her serious distress. They also seem satisfied that it could affect her physical and mental health by dissuading her from visiting the hospital and general practitioner for treatment. This would also make it difficult to monitor her compliance with medication.

- An agency may refuse a request if the information is not readily retrievable, or if it does not exist or cannot be found (s 29(2)).

It can be embarrassing to have to admit that information is not readily retrievable. A proper search has to be made before the request may be refused.

- What steps have been taken to locate the information?
- Has the file been traced?
- Have checks been made with all people who had, or are likely to have had, the file?
- Is the information likely to have been destroyed?

If it appears that the information has been lost because of inadequate security safeguards, the requester could make a complaint that the agency has not taken reasonable security safeguards to protect information against loss (rule 5).

Requests for correction (rule 7)

People have a right to ask for their health information to be corrected.

Agencies also have to take steps on their own initiative to correct information. If information has not been obtained from the individual concerned, it may be appropriate to verify it with that person. If an agency suspects the information is not accurate, it should be checked before it is used.

If an agency is not willing to make a correction, it must, if requested, take reasonable steps to attach a statement of the correction sought. The statement must be attached so that it will always be read with the disputed information.

If steps are taken to correct information or attach a statement, the agency must take reasonable steps to inform everyone who has previously received the information of these steps.

Where a patient disagrees with a diagnosis and wants it removed from the file, it may be appropriate to offer to attach a statement of the correction requested. Removing the disputed diagnosis could render the notes incomplete because they would not reflect the decision made at a particular time or the treatment which followed. If the agency acknowledges that the original diagnosis was wrong it may need to be retained as an accurate record of the diagnosis made at the time, with the later, correct, diagnosis also noted at that place in the record.

Sometimes the disputed information is somewhat dated. A reference to it could be left on the file but the details could be removed or sealed in an envelope so they are not as readily accessible.

The statement of correction has to be provided by the requester. However, agencies have an obligation to provide reasonable assistance and it might be helpful if the agency could prepare a draft statement for the requester's approval. The content of the statement could be taken from the requester's complaint.

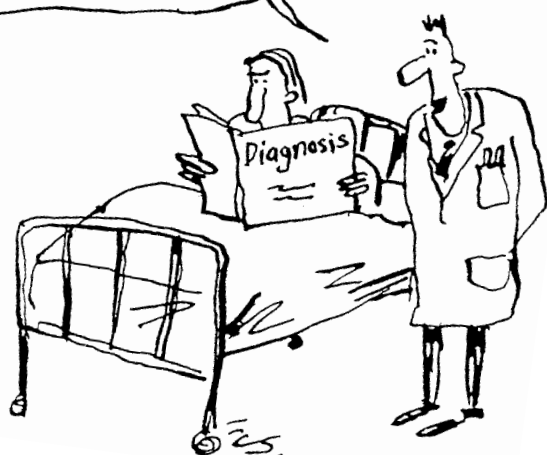
EXAMPLE 26

CORRECTING A DISPUTED DIAGNOSIS

A patient presents with an unexplained illness at a hospital. A diagnosis of Munchausen's Syndrome is made, and a course of psychiatric counselling is recommended. The patient consults an independent psychiatrist who does not agree with the hospital's diagnosis. The patient requests the hospital to remove reference to the diagnosis from the hospital records. The hospital does not wish to do so because it represents a clinical opinion formed at the time of treatment, and explains the subsequent course of treatment.

- It would be appropriate to ask the patient if she would like a statement of correction attached to the file. The hospital could offer to help prepare a statement which includes the independent psychiatrist's diagnosis.

CARE TO GIVE A
SECOND OPINION?



7

Handling internal complaints

Handling internal complaints

Under clause 7 of the Health Information Privacy Code 1994, many agencies are required to have an internal process for handling complaints. The complaint handling process will vary depending on the size and function of the agency, but some time limits and procedures for responding to the complaint are set out in the Code. Smaller agencies may choose to adopt a simpler, less formal process than would be appropriate for larger agencies. An independent or specially designated person may be assigned the role of responding to complaints within larger agencies. Sometimes this will be the privacy officer.

8

Conclusion

Conclusion

The Health Information Privacy Code is only one piece of a framework of legal and ethical standards which are involved in the day to day care of those needing care and treatment. Understanding the Code will assist in making sense of the larger framework. Common sense is perhaps the best entry point to understanding the Code. If an interpretation of the Code seems to lead to a strange result, it may not be correct.

If guidance is needed on specific issues, agencies can call the Privacy Commissioner's enquiries line: 0800 803 909. Agencies in Auckland can call 09-302 8655.

Comments on the guide are welcomed. They should be directed to:

***The Privacy Commissioner
P O Box 466
Auckland***

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