

**CONSUMER VIEWS
ON THE
IMPLEMENTATION OF THE
HEALTH RECORDS ACT (2001)**

**A Report to the
Office of the Health Services Commissioner**

**Prepared by
Health Issues Centre**

October 2002

Acknowledgments

This Report has been prepared by Health Issues Centre, with funding from the Office of the Health Services Commissioner (OHSC).

The report was compiled by Helena Maher and Meredith Carter, based on discussions held over four meetings of the Consumer Reference Group. Health Issues Centre would like to thank all the members of the Consumer Reference Group for their enthusiastic contribution and to thank the staff of the OHSC for their advice and support. Advice was also provided by the Deputy Privacy Commissioner (New Zealand), the Office of the Federal Privacy Commissioner (Australia), the Victorian Information Privacy Commissioner and the Legislative Review Unit of the Department of Human Services, Victoria. Thanks also to Souzi Markos for providing invaluable administrative support.

For further information contact Helena Maher at Health Issues Centre on (03) 9479 5870 or h.maher@latrobe.edu.au

Health Issues Centre Inc.
Level 5, Health Sciences 2
LA TROBE UNIVERSITY VIC 3086

 (03) 9479 5827

Fax: (03) 9479 5977

Email: hic@latrobe.edu.au

Website: <http://www.vicnet.net.au/~hissues>

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PART ONE: INTRODUCTION

Consumer Protection and Privacy

In April 2001, the Victorian Parliament passed the *Health Records Act 2001*. The legislation came into effect from July 2002. The Health Records Act establishes important new standards of consumer protection in relation to the handling and privacy of health information, including the management of disputes over consumer access to their health records.

The *Health Records Act* governs the management of health information regardless of whether the health records have been created by private or public sector agencies. This reflects the fact that consumers use public and private services across a continuum of care in the health sector. A consistent approach to managing health information across public and private services is important to ensuring good quality and safe health care.

Privacy Principles

Central to the Act are 11 Health Privacy Principles that cover the life cycle of health information, from collection through to disposal. The Principles are based on OECD (Organisation for Economic Cooperation and Development) Guidelines on the Protection of Information Privacy developed in the early 1980s and accepted throughout the Western world.

In 1995 the European Union passed a *Data Directive* that required the introduction of consistent privacy legislation by all member countries of the European Union, including the United Kingdom. Subsequent to this European development, many other countries upgraded privacy protection for their citizens. In Australia the *Commonwealth Privacy Act 1988* was amended by the *Privacy Amendment (Private Sector) Act 2000*. Until these amendments were passed, the Commonwealth Act basically applied only to information managed by Commonwealth public sector agencies.

The Information Privacy Principles (IPPs) already existing in the *Privacy Act* continue to apply to the Commonwealth public sector. The Privacy Amendment (Private Sector) Act introduced 10 National Privacy Principles (NPPs) covering minimum privacy standards for handling personal information in the private sector. The NPPs extend the protection of the *Privacy Act* to all health service providers, including providers working outside of health services, such as medical practitioners in prisons, and to private sector businesses and organisations with an annual turnover of greater than \$3 million. Under the amended Privacy Act, large companies and organisations can develop their own privacy codes. However, any codes must include privacy protections that are at least the equivalent of the obligations under the NPPs before the Federal Privacy Commissioner will approve them. Until any such codes are developed, the private health sector and businesses are required to comply with the NPPs.

Health Privacy

The Commonwealth legislation is not specific to the health sector. It applies to personal information in sectors as diverse as insurance, banking and construction. However, the Victorian government accepted that consumers would be better protected by health-specific legislation dealing explicitly with the particular issues arising in this sector. Thus, in addition to passing Victoria's generic information privacy legislation — the *Information Privacy Act 2001*— complementary legislation was passed — the *Health Records Act 2001*. The Information Privacy Act applies only to the public sector, while the *Health Records Act* introduces consistency in collection, access and handling across the public and private sphere. Both Acts promote greater consumer control of personal information collected about them by anyone in the marketplace and workplace, and are consistent with the spirit of the *Commonwealth Privacy Act 1988* and the *Privacy Amendment (Private Sector) Act 2000*.

Under the Victorian scheme, the Victorian Privacy Commissioner is responsible for dealing with general privacy issues. The Office of the Health Services Commissioner (OHSC) is responsible for ensuring compliance with the *Health Records Act* in the public and private sector. This is a logical extension of the OHSC role in protecting the rights of consumers through the investigation

and conciliation of health complaints. Consumers can look to the Health Services Commissioner to ensure that there is consistent compliance with the Health Privacy Principles across all services that collect health information, regardless of whether they are located in the public or private sector.

The Consumer Reference Group

The first meeting of the Consumer Reference Group on the Health Records Act took place in February 2002. The group was convened by Health Issues Centre at the request of the Health Services Commissioner. Its key functions have been to advise the OHSC on consumer needs resulting from the introduction of the legislation, and, on how best to communicate information about the new Act to the community.

The Consumer Reference Group has broad representation from consumer groups involved in health care and advocacy across urban and rural communities in Victoria. Members include consumers with disabilities, from culturally and linguistically diverse communities, Koori liaison workers, representatives from the Office of the Public Advocate, community services, women's health services, older person's groups, the electronic service delivery consumer network and other consumer groups.

The Groups discussion of health information and privacy benefited from the involvement of relevant agencies. The Office of the Federal Privacy Commissioner provided the group with information about the operation of the Commonwealth legislation in relation to health records. Officers of the Victorian Information Privacy Commissioner participated in the group. This was particularly useful given the relationship between the *Information Privacy Act* and the health-specific *Health Records Act*. Officers of the Department of Human Services (DHS) also met with the Group, facilitating its input on the development of regulations that impact on the introduction of the new legislation and providing advice on other relevant health legislation.

With several different Acts now explicitly promoting privacy and consumer control of personal information, management of health information in Victoria is set for major reform. The Consumer Reference Group has provided the Health Services Commissioner with valuable information about how to protect and promote consumer rights to health information privacy.

Organisation of this Report

The first part of the report has introduced the legislative environment affecting consumer privacy in Australia, and some background to the introduction of health-specific legislation relating to health information and consumer privacy.

The second part of the report summarises priority issues for consumers arising from the introduction of the Act, based on discussions from the four meetings of the Consumer Reference Group held between February and August 2002. These issues are discussed in seven sections. The discussion in each of these sections is followed by recommendations to the OHSC from the Consumer Reference Group about the information and education needs of consumers under the new privacy regime. There are also recommendations that address consumer concerns about the information and education of service providers in the public and private sector affected by the *Health Records Act*. To complement these actions, the second section includes recommendations for initiatives to be undertaken with other key stakeholders.

The third section of the report builds on the discussion in Section Two with recommendations about the information and education documents that will be integral to the Communication Strategy. This section also suggests possible methods of communicating with consumers and educating service providers. It makes recommendations about the content and mechanisms of an effective Communication Strategy, with specific attention to the needs of marginalised groups in the community.

The fourth section of the report consists of two appendices. Appendix One is a report of the advice and recommendations from the Consumer Reference Group about the content and

processes for developing and implementing the Communication Strategy. This report is extracted from the minutes of the second meeting of the Consumer Reference Group (*Thursday 28 February 2002*). Appendix Two lists the membership of the Consumer Reference Group.

PART TWO: PRIORITY ISSUES FOR CONSUMERS

Communication Between Consumers and their Practitioners

The Doctrine of Confidentiality

Traditionally, health records have been protected by the doctrine of confidentiality. Under this doctrine, health practitioners decide what information they need from the consumer, whether this information should be disclosed to any other person, and how this access will occur. Confidentiality is an obligation owed to the person who provides the information, whether they are a consumer, practitioner or organisation.

Modern privacy principles take a different approach to the doctrine of confidentiality. Privacy rights entitle the consumer, who is the subject of personal information, to have control of the flow of that information. This shift in control of the information from the health practitioner to the consumer applies regardless of who actually provides the information to the health practitioner. Recent research by the Office of the Federal Privacy Commissioner on community attitudes towards privacy have demonstrated the importance that Australians place on controlling their health information, even when used in relation to their treatment¹.

Another concern with the doctrine of confidentiality has been that it does not address the quality of the information collected. Standard practice has not been regulated to ensure that the information collected is relevant, accurate and up-to-date, that it is kept securely and that only those who need to know can access it within a health organisation. Consumers are keen to see that their health information is well managed. This is critical to good health care. Health records are increasingly the source of more intimate and comprehensive details about an individual than may be found in any other records maintained about them.

This issue is particularly important as the health sector moves into the electronic era. The use of electronic information and communications technologies to manage health information is likely to generate many benefits for consumers in terms of improved quality and continuity of care. However, it also greatly increases the potential for consumer information to be collated, to be combined with information from different sources, and to be used and disclosed — all potentially without the knowledge of the consumer, for purposes which they may or may not consider to be in their interests.

The Management of Health Information

To help minimise these risks, the introduction of the *Health Records Act* (HRA), and the Health Privacy Principles (HPPs) it enshrines, requires health practitioners to follow standard procedures when collecting information from consumers, when using that information and/or sharing health information with other practitioners. In addition, consumers themselves are entitled to know what information is being collected and why, who in an organisation can access their health information, how this information is used and to whom it may be disclosed. Consumers are also entitled to know that due attention is paid to the quality, integrity and security of their health records and what steps they can follow to obtain access to their health records.

Privacy Policies

To support these entitlements, the legislation requires that practitioners and/or organisations develop a policy that explains how health information will be managed; and that this policy is available on request. HPPs 1.2 to 1.6 set out the requirements in relation to collection, and related issues of notification, consent and confidentiality, that need to be addressed in an organisation's policy statement on privacy. Principle 5 requires that organisational policies be set out in a document.

¹ Office of the Federal Privacy Commissioner (2001) [Privacy and the Community](http://www.privacy.gov.au/community/research/index.html) Executive Summary, www.privacy.gov.au/community/research/index.html, accessed 27/08/02

The Principles aim to promote consumer privacy by increasing the transparency of information-handling practices across all sectors that collect health information, and to ensure service providers give thought to how they will implement the Health Privacy Principles. For example: Are consumers given information in a written as well as verbal form?, Is it only available in English?, Does it meet the needs of people with a sight impairment?

Privacy policies should enable consumers to understand the different ways that practitioners may need to collect and manage certain types of information. For example, the policy could set out the type of information that needs to be collected and disclosed to public health registers. Practitioners may put in place increased security arrangements for particularly sensitive information. Such information might range from the address of a consumer at risk of domestic violence from an estranged partner to identifying information about a person being tested for HIV. The privacy policy will also need to reassure consumers who have a chronic condition and see their health practitioner frequently. For example, the policy may set out that though they may have increased access to and control over their personal health information, that arrangements will be in place to ensure that they are not subject, for example, to constant requests to repeat information or give consent to regularly made disclosures.

These policies could also set out any practices in place for providing consumers with access to their records. For example, most pathology laboratories send test results back to the referring doctor and would discourage direct reporting to consumers. Similarly many GP's have in place policies dealing with provision of test results to consumers. These vary but may include requesting consumers attend the practice to receive the results in a consultation. The justification is that this supports good quality care. It enables the GP to ensure that the consumer has an accurate understanding of the results and can provide or arrange any support and/or treatment required where the results indicate this is needed. However, setting out such practices and their justification in a policy helps ensure consumers understand and support such practices and provides an opportunity to discuss alternative arrangements that could be put in place if they feel such practices are inappropriate to their particular situation. (See also discussion re Access, p.11-13 below).

Consumer Consent

Access to clear and accurate information is a necessary condition for informed consent. In order to provide consent, consumers need the opportunity to discuss how a service's information policy will be applied to their health information. For example, consumers often have several different health providers involved in different aspects of their care and may be happy for some aspects of their health records to be shared between all these practitioners, while wanting other aspects to be shared only between specified practitioners. Application of the HPPs should lead to a stronger emphasis on informed consent and shared decision-making between consumers and their practitioners. A participatory approach to decision-making in health care will help to ensure that consumers are aware of, and consent to, the way that their health information is managed. It was clear from incidents noted by the Consumer Reference Group that both consumers and providers need to be educated about the fact that consent generally requires ongoing communication rather than reliance on a one-off authorisation. Such education would be helpful to consumers, and beneficial to the practitioner-patient relationship. The Consumer Reference Group noted examples of:

- treatment being made conditional on a consumer consenting to the service's information management policy;
- incidents of health information being inappropriately accessed by staff; and
- organisations withholding referral letters from consumers because of confusion about who is authorised to give this information to the consumer.

The development of appropriate information policies and their implementation will challenge some health service providers and a culture of paternalism in some organisations. The OHSC could assist the process of cultural change amongst health service providers by developing Information Sheets on best practice information management under the new privacy regime. These Information Sheets need to emphasise the importance of communication to underpin informed

consent and understanding of notification obligations where informed consent is not required. This could include a sample policy for how health services can protect and promote consumer privacy when sharing information.

Restricted Capacity to Provide Consent

Some consumers will lack the requisite mental capacity to provide informed consent. Whilst the HRA does make provision for authorised representatives to provide consent on behalf of a consumer lacking capacity, this may be an area where consideration should be given to the development of formal guidelines by the Health Services Commissioner. For example, the Act does not specify who can assess incapacity or the threshold at which a consumer lacks the capacity to make a complaint. Furthermore, when a consumer is assessed as being incapable of providing consent, the legislation provides a list of authorised representatives who consent on behalf of the consumer. It is not clear from the legislation if this list is hierarchical and/or what process will be followed if there is conflict between people on this list. Finally, health practitioners may need assistance to recognise and assess the fluctuating capacity of people affected by specific diseases and illnesses.

It would be helpful for authorised representatives if the OHSC could provide some guidance about how they should make decisions and fulfil this role.

Privacy and Notification

The HPPs require organisations to take reasonable steps to inform the consumer of how their health information will be managed. There is often confusion amongst practitioners about the difference between notifying consumers about how their health information will be managed, and particular circumstances that require consumer consent.

In some circumstances a practitioner will need to obtain a consumer's informed consent before disclosing their personal information to a third party. However, sometimes informed consent is not required. For example the law may require the collection of personal information and its disclosure to a third party (as in the case of certain communicable diseases). However, it needs to be reinforced that, even in these circumstances, good privacy practice suggests that service providers should nonetheless ensure that the consumer is notified of these requirements. It would be helpful for consumers to know what matters they should expect provider's information policies to address. In addition, independent advice from the Health Services Commissioner to guide the development of these policies is likely to improve compliance by agencies and organisations. It will also increase consumers' confidence if they can make an independent assessment of their practitioner's information management policies.

The Role of the OHSC

The *Health Records Act* (HRA) introduces a series of new obligations on service providers. The support and guidance provided by OHSC on these matters will be crucial to the realisation of the objectives of the Act. As part of this support, OHSC needs to identify the type of data that it will want to collect from practitioners and organisations so it can monitor the implementation of the HRA. This could include data about complaints lodged, numbers of access requests handled and some timeframes for this process, and/or specific actions such as the development of information policies or staff training in implementing the HPPs in their practice.

For example, consumers are concerned that some service providers are now introducing charges for consumer access to their health records. It would be useful to have data that measures the prevalence of this practice and compares charging practices before and after the introduction of the Act. The OHSC may wish to consult consumers about the minimum indicators for measuring provider compliance with the Act.

Issues of Stigma and Discrimination

The way in which information is shared within health services, and systems to protect confidentiality, is of particular concern to consumers. There needs to be increased understanding within the health sector of issues around stigma and discrimination. OHSC may need to develop a training package that gives service providers a framework for communicating effectively around sensitive issues and for protecting consumers' privacy.

Benefits of Improved Communication

Increased transparency in the management of health information is likely to lead to better communication between practitioners and consumers. Following on from this, improved communication has a positive effect on treatment decisions, trust and compliance, and therefore on health outcomes. The provision of specific information to consumers and advice to health practitioners about the objectives of the *Health Records Act*, the application of the Health Privacy Principles and the role of the Health Services Commissioner would be best managed through the development and implementation of a comprehensive Communication Strategy.

Community Attitudes to Privacy

In support of the advice from the Consumer Reference Group, it is interesting to note the findings from research undertaken by the Office of the Federal Privacy Commissioner into community attitudes to privacy. For example, even where disclosure was intended to result in better treatment, "over 40% of people believ(e) that medical staff should *not* discuss a patient's details with other medical staff *without* first seeking the patient's permission"² (italics in original). Research found that consumers look for signals that an organisation will manage personal information well. The survey found that people were more likely to trust an organisation that gave them control over how their information was used (59%), and to trust an organisation that had a privacy policy (55%)³.

Recommendations

1. That the Office of the Health Services Commissioner (OHSC) develop a Communication Strategy about the new *Health Records Act* that targets its content and message to two distinct groups — consumers and providers.
2. That the Consumer Communication Strategy will inform and educate consumers about their rights under the new Act, as detailed in the following report and recommendations.

² Office of the Federal Privacy Commissioner (2001) Privacy and the Community *ibid*.

³ Office of the Federal Privacy Commissioner 31/7/2001 Media Release None of Your Business, www.privacy.gov.au/community/research/index.html, accessed 27/08/02

3. That the Provider Communication Strategy will inform practitioners, health services and other relevant organisations about their obligations under the Act, and provide support and guidance to the development of relevant policies required by the Act, as detailed in the recommendations of this report.
4. That the Health Privacy Principles (HPPs) need to be clearly explained to consumers, using scenarios and examples from consumer perspectives.
5. That the OHSC needs to audit and monitor the impact of the HRA on health service providers' compliance with the HPPs, with particular attention to changes in consumer confidence in the management of how information is disclosed to third parties.
6. That the OHSC Communication Strategy educate consumers about the importance of consent as a key concept underpinning the Health Privacy Principles (HPPs), the exceptions to this concept, the issues around notification and the obligations on service providers arising from the HPPs.
7. That the OHSC develop a training program for the health sector, and other organisations and agencies that collect and hold health information, about working sensitively and effectively with people affected by discrimination and stigma.
8. That the OHSC develop Information Sheets about best practice systems for managing the collection, use and disclosure of health information by organisations that collect and hold such information.
9. That OHSC develop examples of protocols for health related referrals for the benefit of practitioners and service providers, and that these protocols pay particular attention to protecting consumer privacy, especially disclosure to a third party.
10. That these Information Sheets and protocols form part of the Communication Strategy for Providers, and be used in training to provide guidance to organisations on how to establish simple, user-friendly methods of provider access.
11. That the OHSC informs organisations about the type of data that it will be collecting as part of its monitoring role, and consults consumers about the ways in which the outcomes from the HRA are measured and monitored.
12. That the OHSC work with Office of the Public Advocate to develop guidelines to assist health practitioners to assess capacity to consent, including managing fluctuating capacity, and to clarify the role and procedures for authorised representatives.

Access

A fundamental aspect of the *Health Records Act* is that it sets out, as a matter of law, formal recognition of the right of consumers to access their health information across both the private and public sector. The Act gives individuals an enforceable right of access to their health information and the opportunity to correct and amend this information if necessary. However, while the Act introduces a right of access to information contained within the health record, the record remains the property of the medical practitioner, service provider or organisation.

Access in the Public Sector

Consumer access to personal health information has been a contentious issue in the health sector in Australia. Consumers in Victoria have had the right to access health records created by public health services, such as community health centres or public hospitals, under *Freedom of Information* legislation since 1982. However, there has been opposition from some medical practitioners to the legislative formalisation of these rights, and in particular, opposition to the application of these rights in the private sector. Access to records held in the private sector was

identified by the High Court, in the case of *Breen v. Williams* (1996), as a matter for legislative change, rather than judicial precedent.

Access And Practitioner Discretion

Health service providers have argued that the discretion to refuse access to health records is part of their role in protecting the health of consumers. The *Health Records Act* mediates the practitioner's discretion to refuse access. The law recognises that there will be circumstances where access would pose a serious threat to life or health, or that it could prejudice the privacy of a third person, and so entitles an organisation to refuse access. However, the Act now requires that the reasons for refusing access be made transparent.

Where a practitioner withholds access on the basis of confidentiality, threat to life or health, the consumer (or the practitioner) can nominate a health service provider to assess the grounds for refusal. In circumstances that fall outside of s.36, consumers who have been refused access can make a complaint to the Office of the Health Services Commissioner for mediation or investigation. Any ongoing dispute can ultimately be determined in the Victorian Civil and Administrative Tribunal.

New Consumer Entitlements

The Act also spells out important new entitlements. The Act is technologically neutral, in that it applies to all forms of health information, whether information has been stored in a paper-based, electronic or digital environment. Consumers now have a range of options for accessing their records, depending on when the information was collected.

For information collected in the private sector before 1 July 2002, the practitioner is only required to provide a summary of information, although they have the discretion to provide full access. For information collected after 1 July 2002, consumers are able to choose the preferred form of access to their health information.

Access can take the form of inspection, provision of a copy, provision of a summary, the opportunity to view the record, to receive an explanation, to have the record forwarded to another health practitioner or to receive an explanation from an agreed third party health service provider. It is important that consumers have a clear understanding of these new entitlements so as to ensure that they are protected from opportunistic, reactive and/or misinformed applications of the Act.

Access In The Private Sector

The introduction of the HRA brings the private sector into line with the access arrangements operating in the public sector, and expands on the public sector access provisions. It would be helpful to consumers' understanding of the new Act to explain that it introduces general uniformity between the two sectors. In addition, the new provisions represent a significant shift in thinking about responsibility for determining whether consumer access is appropriate or not, and it is reasonable to expect some guidance will be required in this area. There are likely to be some inconsistencies amongst all service providers about their understanding of obligations under the Act, and there may be some reluctance amongst practitioners to comply.

Closure of Services

Finally, one of the barriers to consumer access to health records arises when a practitioner has retired, or closed a practice for some other reason. The Act includes provisions that will assist consumers to negotiate access with such providers or their successors if they can be found. The Consumer Reference Group considered that the establishment of a central body that keeps track of where records are stored once a health service is closed would assist consumers to locate and access their records.

Recommendations

13. That the OHSC clearly explains the rights of consumers to access their health information, even while the record remains the property of the practitioner or organisation that created it, and the exemptions to this right.
14. That this information includes the forms that access can take, the necessary steps for accessing health records and the obligations of health service providers in regard to access, as set out in the *Health Records Act* and the Health Privacy Principles.
15. That the OHSC support research to evaluate the extent to which the Act has improved consumer access to personal health information.
16. That the OHSC advise DHS on the need to investigate the establishment of a central body to keep a record of notices of closure or sale of health services, and where the services health records will be stored once a provider has retired.

The Deterrent Impact of Fees

Charging fees for consumers to access their own health information has also been a contentious issue. Health service providers have insisted on the need to charge fees to recover the costs of providing consumers with access to their health records. The Consumer Reference Group was unanimous in arguing that fees will deter many people from exercising their access entitlements.

It is interesting to note the experience in New Zealand, that has had almost 10 years of privacy legislation. The *Privacy Act* was introduced in 1993, with a Health Code issued shortly after the Act came into effect. Previously, consumers had the right to access health information held in the public sphere free of charge. The new Code retained the fee-free environment for the public sector, and extended provisions allowing access to records in the private sector. Discussions with the NZ Privacy Commissioner indicate that cost issues can arise in relation to large files (about consumers with a mental illness for example) but these are mostly held in the public sector, where consumers will not be charged fees for access.

The Office of the NZ Privacy Commissioner has reported that although consumers can be charged by private sector agencies for accessing their own health records, the practice of charging fees is discouraged. Practitioners are encouraged to view access as integral to providing good quality health care — that the trivial costs of photocopying, for example, means that it is not worth charging, especially in terms of negative 'PR'. Similarly, the business sector rarely charge fees for access to information, and access entitlements are considered part of the general overheads of a health service provider.

In Victoria, the *Health Records Act* spells out that there is no requirement to charge a fee for access (Section 32.1). In addition, the *Health Records Regulations 2002* (Regulations 5,6 & 7) state that where fees are charged they must not exceed a prescribed maximum amount and that fees cannot be charged for processing a request for access. Poor health status is strongly associated with low income. It is consumers on lower incomes who are likely to have more extensive health records and for whom a requirement to pay for access will prove a most significant deterrent. For these reasons, it is common for public sector health agencies such as hospitals and community health centres to waive any right to charge fees under the Freedom of Information provisions.

The Consumer Reference Group felt that the OHSC has a key role in promoting provider awareness of the importance of consumer access to their records. The role of access in promoting trust and good quality care should be highlighted to service providers. The Communication Strategy needs to encourage organisations to consider the ways in which access to health records can facilitate better consumer understanding of their health and treatment, and promote improved communication between practitioners and their patients.

The OHSC should point out the potential for access fees to undermine these benefits. This approach would remind organisations that it is not necessary to charge consumers for access to their health records and encourage practitioners to consider the circumstances in which it might be appropriate to waive any fee. Information about their willingness to provide access free of charge or to waive the fee in appropriate circumstances could be part of the information policies developed by practitioners. This would demonstrate their sensitivity to issues of financial hardship amongst the people who use their services and that they understand how access promotes good quality care.

Recommendations

17. That the OHSC web site create a link to facilitate public access to the fee schedule and that, in order to minimise the deterrent effect of fees on consumers seeking access to their records, the following points be reiterated in all the information that providers and consumers receive about the Health Records Act:
 - that there is no obligation on organisations to charge a fee for access to health information;
 - that the Health Records Regulations set out the maximum fees that a service provider can charge for access.
18. That the OHSC Communication Strategy:
 - emphasise to service providers the benefits of consumer access to their records as part of good quality care through enhanced trust and communication; and
 - encourage service providers to incorporate in their information policies information about their willingness to provide access free of charge or to waive the fee in appropriate circumstances.
19. That the OHSC advise DHS of the need to monitor and evaluate the impact of compliance with fee structures and its impact on consumers, with particular attention to marginalised groups in Victoria, and that this evaluation be undertaken in conjunction with consumers.

Family History and Other Third Party Information

Victorian Government Regulations, prescribing the ways that third party information can be collected under the HRA, have been made to complement the HPPs. In order to treat an individual it is often necessary to collect information about the consumer's family and social history. In the case of infectious diseases or in counselling settings this will often include the collection of information about third parties such as friends, partners or employers, for example. This usually occurs without the consent of, or any necessary notification to, the third parties concerned.

The *Health Records Regulations 2002* set out prescribed circumstances for the collection of health information. Regulation 8 allows an exception to the general rule that personal information should only be collected from the person concerned and that where it is collected from someone else, the person to whom it relates should be notified as soon as possible. The Regulations allow a consumer to provide information about a third party so long as it is restricted to what is necessary for the provision of safe and effective treatment or services.

This reinforces the broader principle regulating information collection under the *Health Records Act*, by reiterating that information is collected on a 'need to know' basis. The Regulations make no distinction between the collection of health information about the family or social history of a consumer, and the health service provider is not obliged to inform the third party of the information that is recorded.

This approach is consistent with the preferred approach of the Consumer Reference Group in its response to DHS on this issue. The views of the Consumer Reference Group were also forwarded to the Commonwealth Privacy Commissioner. Subsequently, the Commissioner has issued a Public Interest Determination consistent with the Victorian approach. If there are any uncertainties, areas of consistency or variation need to be explained to consumers.

Recommendation

20. That the Communication Strategy include an explanation of the Commonwealth Privacy Commissioner's Public Interest Determination and the Victorian Regulations relating to the collection of information about third parties and disclosure of information to third parties, including the implications of any inconsistency between the two instruments.

Compliance with the Spirit of the HRA

The HRA requires health service providers to be more transparent about the information they collect, and more accountable about how they use and share information. Although there are a range of exceptions to this general rule, this is reinforced by a strong emphasis in the HPPs on consumer consent to the collection, use and disclosure of personal health information.

For example, information must generally be collected directly from the consumer, and in general consumers cannot be refused treatment for failure to provide information.

Similarly, there are many circumstances where consumers may wish to seek health care anonymously and HPP 8 indicates that such preferences should be accommodated where possible. Subject to the exception discussed above, where it is necessary to collect personal information from another party, the consumer must generally be notified of the information collected as soon as possible.

Monitoring Cultural Change

The OHSC needs to consider how it will track changes in the culture of organisations so that practice matches the spirit of the new privacy laws. In some cases, monitoring the new privacy regimes will require joint action by the Victorian Privacy Commissioner and the Health Services Commissioner in some instances.

For example, the Consumer Reference Group was alerted to concerns that the forms authorising collection of information, used by some agencies such as the Transport Accident Commission (TAC) and WorkCover, may be couched in intrusively wide terms. As part of the public sector and funders of health care for accident victims, these agencies will fall under the jurisdiction of both the Victorian Privacy Commissioner as well the Health Services Commissioner.

There may be other issues that will require joint attention by the two Commissioners and regular liaison between the two Offices will assist in the early identification of such issues.

Public Health Registers and Electronic Health Records Systems

Particular types of personal health information are subject to specific provisions in other health legislation – such as the *Health Services Act 1988*, the *Mental Health Act 1986* or the *Health Act 1958* – that impact on consumer privacy. These provisions may have the effect of exempting the management of such information from the strict application of some aspects of the HRA and the HPPs.

In addition, the Consumer Reference Group expressed concern about a perceived lack of transparency in the operation of RAPID, an electronic records system established to support the delivery of mental health services to registered clients.

Investigation into this issue has revealed that the HRA introduces provisions to facilitate the development of a system to manage the electronic sharing of patient information between public (and possibly other) hospitals. Though the legislation specifies that the purpose of such systems must be to facilitate consumers' treatment, these provisions would allow sharing of consumers' personal information within such systems without a consumer's express consent. Unless the process of development of these systems is undertaken with considerable public consultation and transparency, such developments may well generate concerns amongst patients and the broader public.

In order to foster public confidence in its development, the process needs to be made transparent. The OHSC Communication Strategy needs to include information about the development of any such electronic systems and include public consultations that will inform the development of appropriate regulations for such a system.

The Consumer Reference Group felt that, even where legislative provisions override the detailed application of the Health Records Act, it was important that all agencies and practitioners handling personal health information institute practices that are nonetheless consistent, so far as possible, with the spirit of the HPPs. It is noted that the National Public Health Partnership has commissioned and received a *Review of Confidentiality and Privacy in Public Health Legislation*. The findings from this Review could assist public health registers in Victoria to comply with the spirit of both the HRA and the Commonwealth Privacy Act.

Commonwealth and state health officers are also working on the development of a Health Privacy Code which it is hoped will ensure that the common themes of Commonwealth and State privacy and/or health records legislation will be implemented consistently across the Australian public sector. It would apply to both public health registers and electronic systems for managing personal health information within and between public health services.

The Consumer Reference Group felt that, in order to promote compliance with the spirit of the HRA, the OHSC should have a role in monitoring electronic health information management systems and registers collecting personal health information. This needs to include registers developed in the private sector, as well as those managed in the public sector with a legislative mandate to collect identified personal information. It should include communicable and other notifiable disease registers established under the Victorian *Health Act*, the RAPID data collection system under the *Mental Health Act* and any similar electronic data management systems being developed to support information exchange within the public hospital sector.

In addition, the OHSC could provide advice to services and practitioners that provide information to, or exchange information via, such registers/systems. This advice could address effective

communication strategies, including circumstances where consumer consent is not necessary, but where best practice standards would include explaining notification obligations to consumers.

Recommendations

21. That discussions be held between the OHSC, OVPC, TAC and WorkCover to ensure uniformity of approach and attention to the spirit of the HRA even where its principles and provisions are overridden by other legislation.
22. That the OHSC liaise regularly with the Office of the Victorian Privacy Commissioner to ensure early identification of those areas where collaborative action or policy development is required.
23. That the OHSC Communication Strategies include an emphasis on the interaction of the HRA with other Acts that may override it, and encourage providers, through their information policies, to explain the impact of this on consumer rights to access and otherwise control the dissemination of their personal health information.
24. That to ensure general consistency with the spirit of the *Health Records and Information Privacy Acts*, the OHSC monitor the operation of:
 - the state's public health registers, such as communicable and notifiable disease registers, and
 - any electronic systems for sharing patient data between health services, including the Mental Health Rapid data collection system.
25. That DHS be encouraged to develop, in co-operation with OHSC, communication strategies to better inform clients and the general public about the operation of RAPID and or any other electronic systems under development in the public sector to manage consumers' personal health information. This needs to include advice to consumers about the Commissioner's role in monitoring such systems and the availability of the Commissioner to investigate and conciliate complaints.

Making Complaints

Under the new privacy regime, consumers are entitled to make a complaint where they are concerned about an organisation's management of their personal health information. Complaints are a powerful mechanism for protecting consumers from opportunistic, reactive and/or misinformed application of the Act. In order for the HRA to be effective in protecting their rights, consumers should be aware that a health service provider's interpretation of the HPPs can be subject to independent scrutiny, and to feel confident that inaccurate health information can be corrected and inappropriate practices be modified.

This means that consumers need to be informed about the Health Services Commissioner's role and powers under the Health Records Act. They also need an explanation of the different options for pursuing a complaint. This is particularly the case in relation to access issues. Options will vary depending on whether or not the consumer seeks access to records created prior to the passage of the legislation. They will also vary according to whether the complaint relates to a public or private health service, and whether it is pursued through the Office of the Commonwealth Privacy Commissioner, the Victorian Health Services Commissioner or the Victorian Civil and Administrative Tribunal.

Recommendation

26. That the OHSC educate consumers about the role of the Health Services Commissioner, the steps to take in order to make a complaint about a health service provider to the Commissioner and the different options available for pursuing redress, particularly in relation to complaints about access.

Interaction of Federal and State Legislation

Both the Commonwealth and Victorian governments have passed legislation that has its origins in OECD guidelines on the protection of privacy. The Commonwealth *Privacy Act*, Victorian *Freedom of Information Act*, *Information Privacy Act* and *Health Records Act* all provide protection in law against arbitrary interference with consumer privacy. There are also four different sets of privacy principles: the NPPs (federal jurisdiction, private sector application), IPPs (federal jurisdiction, public sector), IPPs (Victorian public sector) and HPPs (Victorian public and private sector health information).

The more consumers understand about the interaction of these Acts, their differing jurisdiction, application, and principles, the greater will be their effectiveness. In particular, it would help consumers to negotiate areas of disagreement with health service providers if the Communication Strategy emphasised the consistency of the underlying principles of privacy protection, and explained the similarities in intent across all these consumer protection regimes. Clear messages about the common elements and bottom line of consumer rights would be further reinforced if the three Commissioners could agree on baseline messages to consumers and common processes for complaints.

Recommendations

27. That the underlying philosophy of the Victorian *Health Records Act*, *Freedom of Information* legislation, the *Information Privacy Act* and the Commonwealth *Privacy Act*, their respective privacy principles, and the interaction across different areas of jurisdiction, application and possible overlap be clearly explained in the OHSC Communication Strategy.
28. That the Health Services Commissioner, the Victorian Privacy Commissioner and the Federal Privacy Commissioner agree on baseline messages about the principles and rights to privacy and to redress, and that these messages are reiterated in the communication strategies of all three offices.

PART THREE: COMMUNICATING WITH CONSUMERS

Consumer Communication Strategy

In research undertaken to understand community attitudes towards privacy, the OFPC found that “awareness of privacy laws and knowledge about (consumer’s) privacy rights generally correlated with higher incidences of assertive privacy related behavior”.⁴ The analysis of the findings from this research suggests that people with an understanding of the issues are able to make judgements about what is important and to act on these issues. The benefits of information and education are further reinforced by the finding that consumers with lower levels of knowledge and understanding are less able to discern practices that are harmful and less sure of how to actively protect their privacy.

The Consumer Reference Group considered that the OHSC should adopt a comprehensive Communication Strategy to inform consumers about the *Health Records Act*. An effective Communication Strategy needs to take account of the ways that consumers obtain information, and the importance of timing in effectively communicating with the public.

The Communication Strategy needs to educate consumers about the HRA and then direct people to information as and when they need it. Stressful events, such as admittance to hospital, reduce people’s ability to retain information. Therefore, a good overall approach is to use posters and brochures and the media to draw people’s attention to the Act. This information then needs to direct people to where they can access explanatory documents and advice, where and how they are available, and access to other education processes.

The following recommendations complement those developed in Part Two (see above), which focused on issues for consumers. The Consumer Reference Group provided detailed advice and recommendations about the development and promotion of a Communication Strategy (see Appendix One) that specifically targets consumers, with an emphasis on methods of communication. The following section includes recommendations about how consumer views can inform the ongoing implementation of the Communication Strategy, the information and education needs of consumers and providers, and approaches to working with marginalised groups in the community and using the media.

Recommendations

29. That the OHSC continue to seek consumer input into the development and implementation of the Communication Strategy, and the development of information products.
30. That the Consumer Reference Group be reconvened in February 2003 to evaluate the impact of the HRA on protecting the privacy of consumers.
31. That the OHSC support qualitative research to describe and evaluate the effect of the Act on the protection of consumer privacy and that this be commenced within 12 months of the introduction of the Act.
32. That the OHSC develop a coordinated approach to working with the Office of the Victorian Privacy Commissioner and Office of the Federal Privacy Commissioner, including joint advertising and presentations to community groups and organisations.

Information and Education for Consumers

⁴ OFPC (2001) Privacy and the Community op. cit.

The OHSC has been undertaking workshops with health service providers. The Consumer Reference Group identified the need for community meetings and information presentations to interested consumers and relevant organisations across the state.

The Communication Strategy needs to develop a set of documents that help consumers to understand the application of the legislation. These documents need to be accessible in both language and content, and to use scenarios and examples. Consumers need a guide to the *Health Records Act* — a document that answers frequently asked questions that consumers are likely to have — and a guide to the Health Privacy Principles.

These documents would be complemented by a series of written and visual information in the form of brochures, posters, fact sheets on web sites, links to related web sites that reinforce priority messages. These products would benefit from being trialed to different groups of consumers, such as people who speak English as a second language and people who are sight-impaired.

In addition to information documents, the OHSC needs to develop a two-tiered approach to informing and educating the general public. This targeted approach distinguishes between general information available to the public, and strategies that deliver more detailed explanations to specific groups. Such an approach needs to use the networks available through non-government advocacy and peak body organisations, recognising the role of these services in consumer education and advocacy. The OHSC could take advantage of existing information networks to publish articles or distribute its own newsletter or bulletin containing information and updates about the HRA.

Recommendations

33. That documents that provide a consumer focused explanation of the Health Records Act and Health Privacy Principles be developed. This would include:
 - a Guide to the *Health Records Act*;
 - information sheets addressing Frequently Asked Questions; and
 - an Annotated Guide to the Health Privacy Principles.
34. That these documents be written in plain English and include scenarios and examples to ensure that consumers understand the ways that the new privacy legislation will be applied to their health information. These products need to be widely distributed through consumer networks.
35. That a series of brochures, beginning with a general overview — then specific issues such as access, consent, complaints, confidentiality — be developed with complementary posters, and that these be displayed in waiting rooms in hospitals, GP clinics and other community-based services affected by the *Health Records Act*.
36. That a calendar of workshops and presentations about the HRA be developed. These workshops and presentations would provide broad-based information about the HRA to the general public and targeted information to consumer, volunteer and self-help organisations.
37. That the OHSC write articles and updates about the HRA for publication in consumer focused newsletters, journals and bulletins.
38. That the information documents produced by OHSC be available in alternative formats, including audio and large print, and in community languages.

The Needs of Marginalised Groups in the Community

The Consumer Reference Group provided detailed advice and recommendations for a Communication Strategy, with direct reference to the needs of marginalised groups in the

community (see *Appendix One Communication Strategy Advice and Recommendations* under headings “Diverse Communities” & “Aboriginal Communities”, *Minutes of the Meeting 28 February 2002*). The Group identified the need for particular effort to communicate with people who speak English as a second language (both Indigenous and immigrant), those who have poor literacy skills in English, people in custody, people who are housebound and people with stigmatised illnesses.

The Group also identified the need for a regional and rural component to the Strategy. Information in the Communication Strategy needs to be available in written and oral forms, with multi-media providing many options for innovative communication with these populations, and written information available in the most common community languages. The OHSC Communication Strategy needs to make good use of the networks available through community organisations to access consumers. This needs to be considered in developing information products and in distributing information through the community.

Recommendations

39. That the Communication Strategy include components targeting:
 - people in regional and rural areas of Victoria;
 - people from migrant and refugee communities;
 - people from Indigenous communities, both in Victoria and who have been referred to specialist services based in Victoria; and
 - people from marginalised and vulnerable populations, people in custody, people with chronic illness, young people and people affected by substance misuse
40. That these components of the Communication Strategy be developed through consultation with consumers that includes representatives from the target community.

Using the Media

The Communication Strategy needs to use print media, radio and television across the mainstream, community and alternative spectrum. The Consumer Reference Group recommended an approach that balanced advertising the HRA to the general public with an approach that targeted specific groups in the community. Discussion reinforced the importance of using examples to illustrate complex issues, using positive language in all information and encouraging service provider compliance through giving examples of good practice.

Recommendations

41. That the promotion of the Communication Strategy messages occur across mainstream, community and alternative media.
42. That the language, content and tone of the information in the Communication Strategy documents be positive, encouraging, and give examples of good practice in health services.

Training and Information for Practitioners

In relation to inaccurate and unreliable information, the Consumer Reference Group noted examples of organisations producing documents that contain erroneous and misleading interpretations of the new privacy requirements.

The New Zealand experience provides some important lessons in the most effective processes for delivering training and information to practitioners. Initially, information was delivered through a series of broad education sessions at public meetings that attracted a diverse group of health professionals affected by the Act. These information sessions were not run by the Privacy Commission, and could include information that was sometimes inaccurate or reflective of a personal bias.

The NZ Deputy Privacy Commissioner has advised that broad education workshops had not been sufficient for educating the workforce about its privacy obligations. The Commissioner found that targeting the people in the workplace who are responsible for implementing and managing the new privacy requirements was the best approach to educating the workforce. As a result, the NZ Privacy Commissioner has developed a program of half-day workshops that are self-funding, are limited to 10 – 12 people, can be tailored to a specific focus, or provided onsite for large employers, and, to ensure quality control, are run by the Privacy Commissioner's staff.

Finally, it is interesting to note that following the introduction of the Privacy Act in 1993, the NZ Deputy Privacy Commissioner issued a Health Code with an Explanatory Commentary that included extracts from relevant Acts in addition to the Privacy Act itself. The use of the Explanatory Commentary in workshops revealed alarming levels of ignorance amongst health professionals about the content of relevant health specific Acts.

Recommendations

43. That in addition to conducting generic information sessions about the HRA, the OHSC develop and offer customised workshops to inform and educate health practitioners and services across the spectrum of settings that collect personal health information. These workshops should include a 'train-the-trainer' approach and include a focus on countering misinformation about the HRA and refresher information about other health related Acts that impact on privacy.
44. That health service providers and other organisations collecting personal health information be encouraged to have the OHSC check any privacy information documents they produce to ensure that that they are both accurate and reflect the consumer oriented spirit of the legislation.

PART FOUR: APPENDICES

Appendix One – Communication Strategy Advice and Recommendations

Brainstorming Strategies For Consumer Input into the Development of a Communication Strategy from the 2nd and 3rd meeting of the Consumer Reference Group

OVERALL STRATEGY

- A Communication Strategy needs to consider the importance of timing in effectively communicating with the public; that information needs to be given when and as it is needed by consumers.
- A good overall approach may be to draw people's attention to the new Act through media publicity and then make sure organisations have information from OHSC. This information needs to be easily accessible to consumers (such as a brochure that they can take away) and posters for organisations that give contact details for further information from OHSC. Health service providers have an obligation to promote the HRA.
- A Communication Strategy needs to be developed with timelines and a timetable of different stages for accessing different groups.
- OHSC needs a regional and rural component of its Strategy that includes community consultations in towns, open meetings advertised through the local paper, and coordinating these presentations with information sessions from the Office of Privacy Commissioner.
- (See also comments on including information on access and fees in a brochure, discussed in Item 4, FOI and Interaction with HRA Legislation & Draft Regulations on Fees.)
- The group noted in the discussion of family medical histories that there may be the need for clear protocols on collection to guide the work of practitioners.
- The HRA does not override other Acts, or legislative requirements such as the obligation to report suspected child abuse. Jenny Muir said that there had been cases where DHS was not diligent about ensuring the confidentiality of people making child protection notifications, and that this causes difficulties in some Aboriginal communities and families. DHS staff need more education about confidentiality and working in a culturally safe manner. A protocol to cover child protection notifications could help the process.
- Under the HRA, the Health Privacy Principles apply to the collection and management of information in **both** sectors.
- The meeting suggested that the Communication Strategy, including the brochure, needs to make clear that private health service providers have to act on access requests by a consumer within a maximum of 30 days (see HPP 6.9).
- Health service providers have a duty to act on a request to issue records to another health service provider under HPP11 as soon as practicable (e.g. to a practitioner for a second opinion) and that any reasons for such a request are a matter of confidentiality between the consumer and the third party.
- Information such as brochures need to clarify that provisions in some other Acts will continue to operate and will not be affected by the HPPs (e.g. *Mental Health Act*).

- There was concern at opportunistic fee-charging unless consumers are very clear about the fee arrangements. Information about charging fees needs to be included in the Communication Strategy and in all the information that is given out about the new HRA.
- Health Service Providers need to be encouraged to have a policy that allows discretion in charging for access, including a hardship exemption. The OHSC could help this situation by making a statement and issuing guidelines supporting this principle to health service providers.
- The OHSC will need to monitor and evaluate the impact of compliance with fee structures, and its impact on different consumers. It was noted that the New Zealand Privacy Commissioner has had good compliance with a general principle that fees should not be charged. More information will be sought about the NZ experience.

FORMAT

- Consider that people's retention of information is reduced in stressful events. Develop strategies for directing people to information when they need it, or go looking for it, such as when they want to make a complaint; for example, posters in reception areas with phone numbers for OHSC.
- In preparing information, it is important to emphasise the positive: "Hospital Liaison Officers are here to help", and to encourage and give examples of organisations that do things well.
- The presentation of information in the brochure needs to be positive and eye-catching, the 1/3 text, 1/3 empty space, 1/3 graphic is a design rule that helps with clear layout; illustrative stories are the most effective means of engaging people, OHSC needs to focus test these brochures for information and for target groups – the Consumer Reference Group can help with this.
- Develop a brochure in plain English, with information in a format that meets the needs of people with an intellectual or sight disability

MEDIA

- Putting information out across Radio for the Print Handicapped, Telephone TY, commercial, ABC and community radio across Victoria. Make presentations on talk-back programs, relevant shows like the *Law Report* and *Health Report* on Radio National.
- Provide interviews to print journalists, noting that OHSC can't control how the information is reported.
- Submit articles for council newsletters and local newspapers to provide information and advertise meetings and forums.
- Approach TV networks about introducing a story about Health Records Act into a TV series (day and night programs).

PEAK BODIES FOR GOVERNMENT AND NON-GOVERNMENT SECTOR

- Provide training and workshops to the Municipal Association of Victoria.
- Distribute brochures through consumer, voluntary and self-help organisations, targeting people who often use the health system (i.e. Chronic Illness Alliance). Victorian Council of Social Services (VCOSS) has such a mailing list. Note that self-help groups are sometimes auspiced by other organisations and OHSC may need to think about how to communicate information through these informal networks.
- Write articles for the newsletters, journals, and other publications of consumer, voluntary and self- help groups. The OHSC Communication Strategy may need to assist organisations; for example with funds to do a mail-out of OHSC written information to members.
- Include brochures in introductory packages that are sent to new groups by alliances or networks.
- Set up links through the OHSC web site for people to get information about the HRA, Health Privacy Principles, the Privacy Act etc. Approach VCOSS about using InfoXchange, which has links to 12 000 organisations and a weekly mailout.
- The Victorian Cancer Council has a cancer information service to patients, workers, volunteer groups and specialist practitioner groups (Contact Doreen Ackaman or Susan Fitzpatrick to access these distribution groups).
- Government has several advisory councils that are coordinated by DHS, which need to be given information about the HRA. Louise Glanville will follow up on this and report back to the next meeting.

DIVERSE COMMUNITIES

- There is a need for different strategies to access different groups in the population, including: targeting the non-English speaking communities through ethnic newspapers and SBS Radio, in particular for people with low levels of English literacy. Approach Ethnic Communities Council and/or Multicultural Commission for a guide to ethnic media.
- Develop a brochure with information in key community languages, have proof reading done by representatives from each target group to ensure information is accurately translated, and sensitive to the diversity of cultural values and assumptions about concepts like 'disability' or 'privacy'. ADEC would be happy to help OHSC to focus test a brochure.

ABORIGINAL COMMUNITIES

- Develop a brochure that meets the needs of Aboriginal people from interstate, who may speak only limited English, who are in Victoria accessing specialist services.
- The Chair noted that advice would also be sought from Melanie Fraser, the OHSC Koori Liaison Officer, who will provide an update to the next meetings on briefings to the Aboriginal sector.
- OHSC needs to meet with the Aboriginal and Torres Strait Islander Commissioner, the two ATSIC Regional Councils and the Victorian Aboriginal Community Controlled Health Organisation for advice on distributing information through the Aboriginal community controlled health services, Aboriginal co-ops., the Koori Mail, and for informing and educating Koori Health Workers. It would help this process if Ron James at the Koori

Health Unit (DHS) is briefed on the HRA; he coordinates a meeting of Koori Health Liaison Officers.

HOSPITALS AND OTHER HEALTH SERVICE PROVIDERS

- Find out if hospitals have processes for informing patients and families from overseas of the HRA or Health Privacy Principles.
- Contact Chairs and/or Resource Officers from Community Advisory Committees to metropolitan Health Services and Primary Care Partnerships to be a conduit for information about HRA. Integrate HRA information into the processes for developing Patient's Charters and Quality Reports of Care.
- Educate Hospital Liaison Officers about the new Act and explore opportunities for better support and professional development to these positions. Regular presentations to Privacy Officers are a good idea.
- Under the Privacy Act, it is compulsory for all hospitals to provide Quality of Care Reports. The OHSC will monitor for improvements in the hospital system, including compliance with HRA.
- The OHSC has been making presentations to the Divisions of General Practice around the state; this is ongoing.
- Continue ongoing education of health service providers about who the Act applies to and their obligations under the Act, especially regarding patient confidentiality or management of communication technologies such as email or fax. Beware of staff who may use the HRA as an excuse for not being able to give information to family/third party.

DEPARTMENT OF HUMAN SERVICES (DHS)

- DHS has its own information and education process for staff regarding HRA and collection of information in its program areas. The group repeated concerns from some DHS staff that information collected by the Department may not comply with the HRA requirements.
- Consumers raised concerns about the operation of the RAPID system, specifically the compulsory recording of primary health care contacts with the Mental Health Team, where these contacts are secondary referrals.

GENERAL COMMUNITY

- Integrate HRA into university curriculum and vocational education courses. Make presentations to orientation days at hospitals, professional association conferences and include information in staff newsletters.
- Educate people in prison about their entitlements, continue to make presentations to prisoners and staff.
- Have information available at neighborhood houses, community legal services, community centres, Royal District Nursing Services, breast screen services, child care groups such as Aboriginal Child Care Association, drug and alcohol services, immunisation day at health services, fair days for organisations, a stand at the Royal Melbourne Show, country shows, health related expos.
- Explore opportunities to inform and educate religious leaders about the HRA.

- Look at a coordinated approach with the Federal Privacy Commissioner, such as full page advertisement in newspapers, joint presentations to community/ organisational meetings.

Comment on Draft Communication Strategy (3rd meeting)

A) Draft Communication Strategy

- Michael McDonald introduced Nicole Webster, consultant in Corporate Communications at DHS, who has been asked to advise OHSC on its Consumer Communication Strategy. Nicole advised of the difficulties of broad education through the mass media, that strategies targeting particular population groups are more effective, and that there needs to be prioritising of these activities. She will look at the recommendations from the last meeting and comment, through Michael, to the next meeting.
- Michael tabled a mockup brochure "*Problem with a health service or concerns about your health privacy?*" for comment from the Consumer Reference Group, specifically on content and distribution. The plan is to print the brochure in community languages and plain English. The OHSC will also produce a poster with the same information.
- People thought that the brochure was a good strategy for directing people to the existence of the OHSC, but that it needed to have more emphasis and explanation of consumers' rights under the HRA.
- Meredith Carter reported that the NZ Office of the Privacy Commissioner has found that targeting the people in the workplace who are responsible for implementing and managing the new privacy requirements was the best approach to educating the workforce. NZ's Deputy Privacy Commissioner had said that broad education workshops had not been effective. Instead, the NZ Office has a calendar of half day workshops that are self-funding, are limited to 10 – 12 people, can be tailored to a specific focus, or provided onsite for large employers, and are run by OPC staff to ensure quality control.
- The group discussed the importance of giving consumers concrete examples to help their understanding of the new Health Records Act and Health Privacy Principles, of documents explaining Frequently Asked Questions (FAQs), of practical information targeting particular issues and/or groups. An annotated guide to the HPPs, with scenarios to explain the new rights of consumers and how these will work would be very useful for educating consumers.
- Susan Joseph said that OHSC was working with the AMA to produce a FAQ about the HRA for doctors.
- The discussion identified police as another group needing targeted training, particularly following from issues around access to medications for people in custody.
- Some consumers have many different health service providers involved in their care, and this creates specific complexities around consumer consent to sharing relevant information. DHS has done work around this issue in relation to their Primary Care Partnerships.
- Health Connect, the electronic health records network under development by the Commonwealth, proposes a consent process for every step; this raises the question about how well consumers understand what they are consenting to.
- OHSC reminded the group that organisations, for example travel or other insurance agents, can only collect necessary health information and that consumers can put a complaint to the Office for mediation or investigation where there is a disagreement between the consumer and the organisation about the definition of "necessary".

Decision

The group recommended that:

1. The brochure be strengthened to emphasise consumers' rights to question organisations on their collection and access policies, and that there is a complaints process through the OHSC.
 2. The brochure includes information directing people with complaints to their local contact in the health service provider as a first step.
 3. OHSC deliver targeted workshops for consumers, with practical information that can be modified to specific groups.
 4. An annotated guide to the Health Privacy Principles be produced as part of the Communication Strategy. This guide could be distributed through community organisations such as those represented on the reference group to help ensure that they have a detailed understanding of the Act, since many will be the first point of contact for advice by individual consumers.
- These recommendations will be included in the report that the Health Issues Centre is preparing for the OHSC on the needs of consumers following the introduction of the HRA.

ACTION:

- Michael McDonald will invite a DHS representative to the next meeting to report on DHS's approach in the Primary Care Partnerships to sharing consumers' health information, ensuring informed consent and addressing other aspects of the HPPs.
- Michael McDonald will comment at the next meeting on Nicole Webster's response and recommendations to the proposals for targeted information strategies, as developed by the Consumer Reference Group, to inform the development of the Communication Strategy.
- Consumer Reference Group members need to advise Michael by Thursday 28 March of any further comments on the draft brochure.

Draft Communication Strategy (continued):

The group discussed ways that the new legislation promotes a culture of transparency and accountability about consumers' health information in health services. Consumers need to be educated about these changes, what they mean, consumer rights and processes for addressing grievances. OHSC needs to make alliances with other information processes, such as InfoXchange and DHS' Better Health Channel.

Decision:

- Michael McDonald will develop a Communication Strategy Action Plan. He will send it out prior to the meeting so that members of the Consumer Reference Group can seek comment from their constituencies on content and process.
- Michael will work with DHS on developing the brochure in line with the advice from the Consumer Reference Group.

Development of the Annotated HPPs

The Consumer Reference Group has recommended to OHSC that an annotated guide to the Health Privacy Principles is needed for consumers to have a clear understanding of each of the

HPPs, and that this needs to include anecdotes and scenarios that explain the issues and changes from a consumer perspective. There was discussion about how this guide could be developed and whether there needs to be a group of consumers advising OHSC on its content and distribution, and to help with trialing it.

Decision:

- The meeting agreed to establish a working party, with membership from the Consumer Reference Group, to work with OHSC to develop the annotated HPPs.

Health Issues Centre Report to OHSC

Health Issues Centre is writing a report to the OHSC on the needs of consumers following the introduction of the HRA, based on issues raised by the Consumer Reference group. The report will address:

- the issues that the HRA raises for consumers and how these can be best addressed,
- the information consumers consider most relevant,
- the most appropriate methods for communicating that information, including
- how best to provide that information to groups with particular needs such as culturally and linguistically diverse communities, Aboriginal people, people with disabilities and those with limited literacy skills etc.
- Health Issues Centre would like the Consumer Reference Groups to endorse the content of the report and have input into developing the recommendations to OHSC. OHSC would like the report prior to 1 July 2002, when the Act comes into full effect.
- the group asked that it be minuted that that they had found the meetings and discussion very educative and effective, that people had had good opportunities for input into guiding the response of OHSC to the new HRA.

Decision:

- Health Issues Centre will draft a report and distribute it for comment to the Consumer Reference Group. The recommendations of this report will be endorsed by the CRG.

Appendix Two - Consumer Reference Group Membership List

Beth Wilson	Chair: Office of the Health Services Commissioner
Andrea Wallace	Australian Plaintiff Lawyers Association
Aurora Panozza	Aboriginal Liaison Officer - Wimmera Health Care Group
Cas O'Neill	CAC Resource Officer - Royal Children's Hospital
Helen Farrugia	Cancer Council of Victoria
Jan Donovan	Member - Health Issues Centre
Jan Whitaker	Electronic Service Delivery Consumer Network
Jason Mifsud	Aboriginal Liaison Officer - South West Health Care
Jenny Muir	Aboriginal Liaison Officer - Ballarat Health Services
Jill Thompson	Council on the Ageing (Victoria)
Joanne Moss	CAC Resource Officer - Peter McCallum Cancer Institute
Josh Meadows	Office of the Victorian Privacy Commissioner
Judy Hogg	CAC Member - Royal Women's Hospital
Licia Kokicinski	Action on Disability Within Ethnic Communities
Louise Glanville	Office of the Public Advocate
Lyn Chaplin	CAC Member - Sisters of Charity
Maree Fenech	CAC Member - Austin and Repatriation Medical Centre
Margaret Davies	Country Women's Association
Mike Kennedy	Victorian AIDS Council
Rob Nicholls	Victorian Council Of Social Services
Sue Healey	Older Person's Action Centre
Anna Boulton	Office of the Health Services Commissioner
Fahna Ammett	OHSC
Michael McDonald	OHSC
Piotr Nyczek	OHSC
Susan Joseph	OHSC
Meredith Carter	Health Issues Centre
Helena Maher	Health Issues Centre