

Submission on the National Health Privacy Code

Health Issues Centre

April 2003

EXECUTIVE SUMMARY

This submission responds to the *National Health Privacy Code* (draft) prepared by the Australian Health Minister's Advisory Council National Health Privacy Working Group and released for public comment in December 2002.

Health Issues Centre believes that privacy and health information needs to be subject to a specific regulatory framework. We commend the Australian health ministers on developing a draft *National Health Privacy Code* and then submitting it for public comment. The proposed *Code* will build consumer's confidence in the commitment of the health and related sectors to protecting consumer privacy. We believe that the introduction of a national approach will have positive outcomes for the quality and safety of health care in Australia. These benefits depend on the *Code* applying to all organisations that collect health information and that it is mandatory for everyone who collects health information to comply with the *Code*. There also needs to be forms of redress for consumers when the code is violated and they suffer harm because their privacy has been infringed upon. It would be beneficial for consumers and professionals if the process for resolving complaints was integrated into a quality assurance framework.

The collection, use and disclosure of health information by practitioners involves issues of great sensitivity to consumers. Consumers are vulnerable to, and dependent on, the skills, expertise and goodwill of their health practitioner and, by extension, the agency in which they practice. The need for frank and open sharing of information between consumers and their practitioner is fundamental to the building of trust in these relationships. While practitioners have a range of professional, ethical and statutory obligations relating to health information, this information is increasingly handled by people with little or no specific training in responding professionally to these particular sensitivities. So, for example, while consumers may trust their practitioner, they may not have the same level of trust for the hospital or corporation that employs that practitioner or the government that monitors that service. Information given with confidence in a practitioner can move quickly beyond that practitioner's control. Therefore, the *Code* and the National Health Privacy Principles provide a framework for health information to be collected, used and disclosed in consistent and principled ways that reduces uncertainty for everyone. 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.

Health Issues Centre makes the following recommendations with a view to strengthening the consumer protections under the *Code* and ensuring that it is consistent and comprehensive in its promotion of privacy.

Recommendations

- 1 That further work on developing HealthConnect be delayed until the community has debated the risks and benefits of electronically linking health information.
- 2.1(a) That consumer input be sought on the development and implementation of a Communication Strategy, and the development of information products, to educate consumers about the *National Health Privacy Code*.
- 2.1(b) That qualitative research to describe and evaluate the effect of the *National Health Privacy Code* on the protection of consumer privacy be undertaken within three years of the introduction of the *Code*.
- 2.2(c) That documents be developed that provide a consumer focused explanation of the *National Health Privacy Code* and the National Health Privacy Principles. This would include:
 - A Guide to the National Health Privacy Code;
 - Information Sheets addressing Frequently Asked Questions; and
 - An Annotated Guide to the Health Privacy Principles.
- 2.2(b) That these documents be written in plain language and include scenarios and examples to ensure that consumers understand the ways that the new privacy *Code* will be applied to their health information. These products need to be widely distributed through consumer networks.
- 2.2(c) That a series of brochures — beginning with a general overview then responding to specific issues such as access and correction, use and disclosure, consent and complaints, confidentiality and privacy — be developed. These brochures would have complementary posters and be available in waiting rooms in hospitals, GP clinics and other services affected by the *National Health Privacy Code*.
- 2.2(d) That these information and education documents be available in alternative formats, including audio and large print, and in community languages.
- 2.2(e) That the Federal Privacy Commissioner write articles and updates about the *National Health Privacy Code* for publication in consumer-focused newsletters, journals and bulletins.
- 2.2(f) That a calendar of workshops and presentations about the *Code* be developed. These workshops and presentations would provide broad-based information about the code to the general public and targeted information to consumer, volunteer and self-help organisations.
- 2.3(a) That the Communication Strategy include components targeting:
 - people in regional and rural areas;
 - people from migrant and refugee communities;
 - people from Indigenous communities, and
 - people from marginalised and vulnerable populations, people in custody, people with chronic illness, young people and people affected by substance misuse.
- 2.3(b) That these components be developed through consultation with consumers that includes representatives from the target community.
- 2.4(a) That messages promoting consumer protections provided by the *National Health Privacy Code* occur across mainstream, community and alternative media.

- 2.4(b) That the language, content and tone of the information in the documents be positive, encouraging, and give examples of good practice in protecting the privacy of consumer's health information.
- 2.5 That the Communication Strategy
- emphasise to service providers the benefits for enhanced trust and communication of providing consumers with access to their records, as part of good quality care; and
 - encourage service providers to incorporate information about their willingness to provide access free of charge or to waive the fee in appropriate circumstances into their information policies.
- 2.6(a) That in addition to conducting generic information sessions about the *Code*, the Federal Privacy Commissioner develop and offer customised workshops to inform and educate practitioners and services across the spectrum of settings that collect personal health information.
- 2.6(b) Workshops targeting health service providers should include refresher information about other health related Acts that impact on privacy.
- 2.6(c) That all organisations collecting personal health information be encouraged to have the Federal Privacy Commissioner check any privacy information documents they produce to ensure that they are both accurate and reflect the consumer-oriented spirit of the Code.
3. That the *National Health Privacy Code* be made mandatory.
4. That the *Code* apply to the handling of all health information no matter where it is collected, used and held.
- 5.1 That consumers be given a right of access to health information regardless of the collection date, and that practitioners have the discretion to provide this in the form of either a summary of the health record, or of access to the original.
- 5.2 That the introduction of the *National Health Privacy Code* be supported by the production of Information Sheets that explain informed consent in the context of the National Health Privacy Principles.
- 5.3 That a central body be established that keeps a record of where patient information has been transferred to when a service closes or moves.
6. That the *Code* include a complaints resolution process that responds to complaints in a consistent way, is accessible to consumers, that identifies individual fault but can also identify systemic problems in the way that health information is managed.

INTRODUCTORY COMMENTS

Privacy rights provide protection under the law from arbitrary interference in an individual's personal interests. If health information is being collected, the individual should be told what is being collected, what it will be used for and who else will have access to this information. The protection of privacy rights depends on the individual being able to access this information, to check it, correct it if it is wrong and to remove it if necessary. These rights provide consumers with fundamental protections of personal interest from the intrusion of organisations, government and business, except where there is a clear public interest that outweighs privacy considerations. While there is an acknowledged need for governments, health services and other interested parties to collect personal data, everyone has aspects of their lives that they want to keep private. Where health information is collected, people want to know that it is used appropriately and with respect for their privacy. People also want to be reassured that information is stored safely.

Concerns about privacy and the misuse of information fall into four categories. People are concerned that information will be used:

- By the media and members of the wider community to discriminate and vilify different groups in the community;
- To compromise an individual's reputation;
- To discriminate against particular individuals and groups in the provisions of services; and
- By people in a position to exploit it for personal gain.

1. ELECTRONIC HEALTH RECORDS

Health Issues Centre believes that the proposal for electronic health records is proceeding without sufficient community understanding and debate. We see the potential for grave and irreparable breaches of privacy that could follow from the electronic linking of health information. Health Issues Centre believes that electronic health records present the potential for violations of privacy that could threaten consumer confidence in the health system. We therefore do not believe that the National Health Privacy Principles are sufficient for electronic records, or that the specific aspects of the electronic record could be made safe through additional standards.

The Consultation Paper proposes that the introduction of electronic health record systems will have significant benefits, including that it will improve patient care and give consumers more control over decisions affecting their health care. The Paper submits that the benefits are "clearly enormous", but doesn't provide the data to support this conclusion. Health Issues Centre believes that the risks of privacy infringements accompanying the introduction of electronic health records are substantial. We would like to see the evidence that demonstrates that electronic health records increase consumer control over decisions affecting their health care. We would also like to see the results from a cost-benefit analysis of introducing electronic health records compared with consumer held records. Handing records over to consumers would give practitioners rapid access to vital information in the case of an accident of emergency, and more time for direct care. It would appear to have the potential to facilitate better information exchange between practitioners. It is also more appropriate for the increasingly mobile population. We suspect that it would also be much cheaper than HealthConnect and would provide much higher guarantees of privacy protection than what technology can deliver.

In the Consultation Paper, the argument for electronic health records is promoted on the basis of benefits to consumers. In fact, the point of electronic health records is to facilitate the exchange of information between practitioners, and between different parts of the health sector. The potential benefits to researchers, government and business of electronically linked health records are apparent and huge, and it is the issues related to these benefits that need to be articulated. There is an alarming disjunction between the

stated reasons being given for electronically linking health data about individuals and the obvious attractions to government of state control of medical information, for example. The experience in the UK, New Zealand and Canada should be enough to deter governments from investing public funds in e-health information systems without engaging the community in debate about the cost benefits and the protections on consumer privacy¹.

Recommendation

1. That further work on developing HealthConnect be delayed until the community has debated the risks and benefits of electronically linking health information.
2. **IMPLEMENTATION OF THE NATIONAL HEALTH PRIVACY CODE**

The following section discusses the issues relating to implementation that should be considered, and makes recommendations related to the information and education needs of consumers and service providers following the introduction of the *Code*.

In research undertaken to understand community attitudes towards privacy, the Office of the Federal Privacy Commissioner found that "awareness of privacy laws and knowledge about (consumer's) privacy rights generally correlated with higher incidences of assertive privacy related behaviour".² 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.

Following the introduction of the *National Health Privacy Code*, consumers will need to be informed and educated about the new privacy protections governing health information. A comprehensive Communication Strategy is needed to explain privacy to consumers, how it relates to health information, the National Health Privacy Principles, the different exemptions, how to access health information and how to seek redress for breaches of privacy.

In 2002, the Office of the Health Services Commissioner funded Health Issues Centre to convene a Consumer Reference Group on the *Health Records Act* (2001). This Reference Group provided advice and recommendations to the Health Services Commissioner on a Communication Strategy to explain the new *Health Records Act (2001)* to consumers. The following findings and recommendations are based on this Report, which is available on the Health Issues Centre website³.

2.1 A Communication Strategy

Health Issues Centre recommend a comprehensive Communication Strategy to inform consumers about the *National Health Privacy Code*. 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. Australia is well placed to learn from the experience in New Zealand, which has had privacy legislation since 1993 and a Health Information Privacy Code since 1994.

¹ Meredith Carter *Integrated Electronic Health Records And Patient Privacy: Possible Benefits But Real Dangers* MJA Vol 172 3 January 2000, pp 28-30.

Amanda Cornwall *Connecting Health A Review Of Health Record Projects In Australia Europe and Canada* Public Interest Advocacy Centre, November 2002.

² Office of the Federal Privacy Commissioner (2001) *Privacy and the Community* Executive Summary www.privacy.gov.au/community/research/index.html accessed 27/08/02

³ <http://home.vicnet.net.au/~hissues/newresources.htm> - *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.

The Communication Strategy needs to educate consumers about the *National Health Privacy Code* 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 code. 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 specifically target consumers, including recommendations about how consumer views can inform the ongoing implementation of the Communication Strategy, the information and education needs of consumers, and approaches to working with marginalised groups in the community and using the media. It also includes recommendation on training and information for all practitioners and organisation that collect health information.

Recommendations

2.1(a) That consumer input be sought on the development and implementation of a Communication Strategy, and the development of information products, to educate consumers about the *National Health Privacy Code*.

2.1(b) That qualitative research to describe and evaluate the effect of the *National Health Privacy Code* on the protection of consumer privacy be undertaken within three years of the introduction of the *Code*.

2.2 Information and Education for Consumers

The Communication Strategy needs to develop a set of documents that help consumers to understand the application of the *Code*. These documents need to be accessible in both language and content, and to use scenarios and examples. Consumers need a guide to the *National Health Privacy Code* — 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 tools in the form of brochures, posters, fact sheets on web sites, links to related web sites, etc that reinforce priority messages. These products would benefit from being trialed to different groups of consumers, for example to people who speak English as a second language and people who are sight-impaired.

In addition to information documents, the Federal Privacy Commissioner 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. Consumers also identified the need for community meetings and information presentations to interested consumers and relevant organisations across the state.

The Commissioner could take advantage of existing information networks to publish articles or distribute its own newsletter or bulletin containing information and updates about the *National Health Privacy Code*.

Recommendations

2.2(a) That documents be developed that provide a consumer focused explanation of the *National Health Privacy Code* and the *National Health Privacy Principles*. This would include:

- A Guide to the *National Health Privacy Code*;
- Information Sheets addressing Frequently Asked Questions; and
- An Annotated Guide to the National Health Privacy Principles.

- 2.2(b)** That these documents be written in plain language 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.
- 2.2(c)** That a series of brochures — beginning with a general overview then responding to 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 services affected by the *National Health Privacy Code*.
- 2.2(d)** That these information and education documents be available in alternative formats, including audio and large print, and in community languages.
- 2.2(e)** That the Federal Privacy Commissioner write articles and updates about the *National Health Privacy Code* for publication in consumer-focused newsletters, journals and bulletins.
- 2.2(f)** That a calendar of workshops and presentations about the *Code* be developed. These workshops and presentations would provide broad-based information about the code to the general public and targeted information to consumer, volunteer and self-help organisations.

2.3 The Needs of Marginalised Groups in the Community

Consumers have 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. A Communication Strategy also need to target the particular needs and circumstances of people in rural and regional areas.

Information in the Communication Strategy needs to be available in written and oral forms, with multi-media technology providing many options for innovative communication with these populations. Written information needs to be available in the most common community languages. The 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.

The findings and recommendations contained in the report commissioned by the Office of the Victorian Privacy Commissioner *Privacy in Diverse Victoria* (2002) will assist in the appropriate and effective communication with people from culturally and linguistically diverse communities⁴.

Recommendations

- 2.3(a)** That the Communication Strategy include components targeting:
- people in regional and rural areas;
 - people from migrant and refugee communities;
 - people from Indigenous communities, and
 - people from marginalised and vulnerable populations, people in custody, people with chronic illness, young people and people affected by substance misuse

⁴ Office of the Victorian Privacy Commissioner (2002) *Privacy in Diverse Victoria Attitudes Towards Information Privacy Among Selected Non-English Speaking Background and Indigenous Groups in Victoria* Report 02.02

2.3(b) That these components be developed through consultation with consumers that includes representatives from the target community.

2.4 Using the Media

The Communication Strategy needs to use print media, radio and television across the mainstream, community and alternative spectrum. Our discussions with consumers has reinforced the importance of using examples to illustrate complex issues, using positive language in all information and encouraging service provider compliance with the Code through giving examples of good practice.

Recommendations

2.4(a) That messages promoting consumer protections provided by the *National Health Privacy Code* occur across mainstream, community and alternative media.

2.4(b) That the language, content and tone of the information in the documents be positive, encouraging, and give examples of good practice in protecting the privacy of consumer's health information.

2.5 The Deterrent Impact of Fees

Charging fees for consumers to access their own health information is 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. However it is clear that charging fees will also deter many people from exercising their access entitlements. It is interesting to note the experience in New Zealand, which 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 provider⁵.

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 practitioners and organisations that hold health information need to understand the importance of consumer access to their records. The role of access in promoting trust and good quality care should be highlighted. The Communication Strategy needs to encourage organisations to consider the ways in which access to health records can

⁵ Blair Stewart, Personal communication, Friday 8 March 2002

facilitate better consumer understanding of their health and treatment, and promote improved communication between practitioners and their patients. Charging fees for access has the potential to undermine these benefits. We recommend an approach that would encourage practitioners to not charge a fee for access or to at least consider the circumstances in which it might be appropriate to waive any fee.

Recommendation

2.5 That the Communication Strategy:

- emphasise to service providers the benefits for enhanced trust and communication of providing consumers with access to their records, as part of good quality care through; and
- encourage service providers to incorporate information about their willingness to provide access free of charge or to waive the fee in appropriate circumstances in their information policies.

2.6 Training and Information for Practitioners

Once the *Code* has been introduced, the changes in how health information must be collected, used, disclosed and stored will need to be explained to health practitioners. In addition, there are a range of other agencies and service providers who have not been subject to the professional codes that have protected the privacy of health information. Beauticians, schools, gyms, insurance companies etc collect health information. These sectors need to be specifically targeted in a Communication Strategy that educates service providers about the need to protect the privacy of consumer's health information.

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 staff⁶.

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

2.6(a) That in addition to conducting generic information sessions about the *Code*, the Federal Privacy Commissioner develop and offer customised workshops to inform and educate practitioners and services across the spectrum of settings that collect personal health information.

⁶ Blair Stewart, Personal communication, Friday 8 March 2002

- 2.6(b)** Workshops targeting health service providers should include refresher information about other health related Acts that impact on privacy.
- 2.6(c)** That all organisations collecting personal health information be encouraged to have the Federal Privacy Commissioner check any privacy information documents they produce to ensure that that they are both accurate and reflect the consumer-oriented spirit of the Code.

3. A MANDATORY NATIONAL HEALTH PRIVACY CODE

Health Issues Centre believes that the purpose and objects of the *National Health Privacy Code* can only be achieved if it is made mandatory.

Currently, there is great variation in the way that services respond to consumer concerns about privacy. Some sectors have thought carefully through the privacy and trust issues that impact on service delivery. Domestic violence services, sexual assault services, HIV/AIDS services, and health services for young people, for example, often have much higher standards of security and protection for health information and take greater care in how information is collected and shared.

Some areas of the health sector have developed policy and practices based on the doctrine of confidentiality. Under this doctrine, confidentiality is an obligation owed to the person who provides the information, whether they are a consumer, practitioner or organisation. There are two main concerns with this approach. Whereas privacy principles give control of the flow of information to the subject of that information, confidentiality leaves decisions about disclosure, for example, in the hands of the practitioner. Secondly, the doctrine of confidentiality does not address the quality of the information collected, or regulate its accuracy or security.

Finally, health information is increasingly collected by organisations outside of the health sector and handled by individuals with no explicit professional obligation to respect confidentiality. The potential for harm to an individual's privacy is retained whether health information is collected by a gym, an insurance company, a TAFE or a health service.

A mandatory *Code* makes explicit what everyone can expect in relation to the handling of health information. It removes uncertainty by establishing minimum standards that everyone must comply with.

Recommendation

3. That the National Health Privacy Code be made mandatory

4. THE SCOPE OF THE NATIONAL HEALTH PRIVACY CODE

The *Code* needs to apply to the handling of all health information no matter where it is collected, used and held.

The reality is that the *Code* will chiefly apply to the health sector, but increasingly, health information is collected, used, shared and stored across a range of sectors. The *Code* will only be effective if it establishes standard procedures that regulate the handling of this information regardless of the nature of the service that handles it. As pointed out earlier, consumers may trust individual practitioners more than they trust the organisations that employ the practitioner, or the government that funds the service. In fact, trust and confidence is likely to diminish as the information moves further from the control of the consumer. The *Code* needs to make explicit the standards and procedures that everyone who handles health information must comply with. This is an important steps for establishing, not just assuming, trust between the individual and the myriad of government agencies, community organisations, research facilities and private

businesses that may have an interest in that information. Consistency across sectors, jurisdictions, professions and organisations is vital to ensuring that standards of quality and safety are met.

Recommendation

4. That the *Code* apply to the handling of all health information no matter where it is collected, used and held.

5. NATIONAL HEALTH PRIVACY PRINCIPLES

The proposed National Health Privacy Principles promote a culture of respect for, and protection of, consumer privacy relating to health information. As suggested above, in the recommendations on implementation, Health Issues Centre believes that a document that explains the Principles in plain language would assist both service providers and consumers. As Bruce Slane argued in a presentation to the Royal New Zealand College of General Practitioners, "Patient expectations of information handling are crucial. Surprise is not a positive thing in a surgery or hospital"⁷.

Services and organisations need to be encouraged to think through their information handling practices. An Explanatory Guide would help services to develop policies and procedures that reduce the element of surprise for consumers. Consumers are entitled to know what information is being collected and why, who in an organisation can access that information how the information is used and to whom it may be disclosed. Privacy policies need to use the Principles as the framework for ensuring that consumers have appropriate levels of information to provide informed consent about how their health information is managed.

5.1 Collection, Use and Disclosure

Health Issues Centre believes that Principles 1 and 2 needs to apply to all information, regardless of when it was collected, or that consumers be given a right of access to a summary of information that has been collected before the *Code* comes into effect. This would ensure consistency with the point of the *Code*, which is to give consumers the right to access information being held about them. As it stands, the proposed application of the National Health Privacy Principles makes no allowance for the transition to having access to health records. Many practitioners will have information in these records that could be damaging to their relationship with the consumer if it was released. Allowing practitioners to release a summary of information collected prior to the introduction of the *Code* protects practitioners while supporting consumer's right of access. This transitional arrangement should also apply to the use and disclosure of health information.

Recommendation

- 5.1 That consumers be given a right of access to health information regardless of the collection date, and that practitioners have the discretion to provide this in the form of either a summary of the health record, or of access to the original.

5.2 Informed 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

⁷ Bruce Slane [Vital Signs Of Privacy: Old Verities In The New World](http://www.privacy.org.au/media/GP.html) Notes for an Address by the Privacy Commissioner, Bruce Slane, to the Royal New Zealand College of General Practitioner's Conference 2002 Rotorua 25 - 29 September 2002, Office of the Privacy Commissioner <http://www.privacy.org.au/media/GP.html> accessed 8/04/03

these practitioners, while wanting other aspects to be shared only between specified practitioners. Application of the *Code* 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 is clear from discussions with consumers, 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 development of appropriate information policies and their implementation will challenge some health service providers and a culture of paternalism in some organisations. *Information Sheets* on best practice information management under the new *Code* will assist the process of cultural change amongst health service providers. These *Information Sheets* need to emphasise the importance of communication to underpin informed consent and provide an understanding of notification obligations where informed consent is not required. Examples and scenarios are also useful for helping consumers and practitioners to understand the new privacy regime.

Recommendation

5.2 That the introduction of the National Health Privacy Code be supported by the production of Information Sheets that explain informed consent in the context of the National Health Privacy Principles

5.3 Data Security and Data Retention

In relation to the requirement that an organisation keep a register of records destroyed or transferred to another health service, Health Issues Centre suggests that a central body be established that keeps a record of where patient information has been transferred to when a service closes or moves.

For example, when a GP retires and her patient records are put into storage, a former patient can contact the central body and find out if his records were kept or destroyed and if kept where they can be located. The reality is that consumers have often used many different health services and that practitioners are as mobile as consumers. This will facilitate consumer access to their own health records, and overcome problems arising from the lapse in time between use and the access request and the mobility of consumers and practitioners.

Recommendation

5.3 That a central body be established that keeps a record of where patient information has been transferred to when a service closes or moves

6. RESPONDING TO COMPLAINTS

The Code needs to include a process that responds to complaints in a consistent way, is accessible to consumers, that identifies individual fault but can also identify systemic problems in the way that health information is managed.

Health Issues Centre believes that an effective complaint process is an essential component to achieving the purpose and objects of the *National Health Privacy Code*. The *National Health Privacy Code* and the national Health Privacy principles are important instruments for reorienting and refining the way that services negotiate issues of privacy with consumers. The complaints process needs to provide redress to consumers when there have been breaches of the Code. Secondly, it needs to be recognised that complaints provide one of the most useful sources of clinical data regarding consumer experiences of health care, and therefore is of great value to services and the agencies responsible for monitoring and evaluating safety and quality.

Recommendation

6. That the *Code* include a complaints resolution process that responds to complaints in a consistent way, is accessible to consumers, that identifies individual fault but can also identify systemic problems in the way that health information is managed.