

# Report of the NCOSS forum on *Electronic health records and new health privacy laws*

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2 May, 2002  
Masonic Centre, Sydney



The Council of Social Service of NSW (NCOSS) is a community organisation working to achieve social justice for disadvantaged individuals and communities. NCOSS provides an independent voice on welfare policy issues and social and economic reforms, and is the major coordinator for non-government organisations working on social justice issues in NSW.

NCOSS receives funding from NSW Health for a Health Policy project, which promotes consumer/community participation in the NSW health system, advocates for disadvantaged communities and assists non-government organisations to play a more active role in health care delivery.

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This report is available on the NCOSS website at:  
[www.ncoss.org.au/bookshelf/index.html](http://www.ncoss.org.au/bookshelf/index.html)

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# 1. Introduction

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## Background

Over the past year NCOSS has discussed with a range of community and consumer organisations the proposed NSW health privacy legislation and the development of linked Electronic Health Records ('the EHR'). Discussions consistently raised a number of issues of concern including the need for: effective protection of privacy, particularly for vulnerable groups; maximising the potential health outcomes; and the full participation of non-government organisations (NGOs) and health consumers in any implementation processes.

There is a great deal of interest within the community sector concerning recent developments in health privacy and electronic health information. In November 2001, NSW Health released an exposure draft of the *Health Records and Information Privacy Bill* ('the Bill'). The draft Bill proposes a set of privacy principles that would govern the collection and use of health information in both the public and private sectors. Health privacy principles in the Bill would govern the implementation and administration of the EHR, which will bring together information held about a person by different parts of the state's health system. NSW Health is currently developing an outline of the EHR and planning pilot projects to test the design.

Both the Bill and the EHR have significant implications for the community, particularly in relation to vulnerable people and health consumers with chronic and complex needs. They have the potential to enhance both the health consumer's privacy and the transparency of the health system. Implemented appropriately, the EHR could contribute towards addressing some current problems in the delivery of health and community care. At the same time they raise many concerns for health consumers.

Therefore NCOSS held the view that there should be an opportunity for informed community input to NSW Health regarding the legislation and its practical application in the health system, and regarding the EHR. In January 2002 NCOSS proposed a Forum for health consumers and community organisations on privacy and health records, and in March NSW Health agreed to provide funding. The Forum was designed as an opportunity for a range of consumers and community groups across NSW to receive information about the EHR and its proposed legislative framework, and to contribute to NSW Health's implementation strategies. The Forum aimed to involve particular groups including people from rural and remote NSW, young people, people from culturally and linguistically diverse backgrounds, people with disabilities, indigenous communities, health consumers with chronic and complex needs, and vulnerable people such as those who have a mental illness. Given questions of information handling and continuity of care, it was important that both health and non-health NGOs were included in consultations.

## The Forum

Over 100 people attended the Forum, including representatives from self-help and chronic illness groups, health peak bodies, community-based health organisations, NSW Health participation structures, organisations representing older people and mental health consumers, community care organisations and individual health consumers. Regional representatives attended from the Hunter, Illawarra, Far West, Mid West, Northern Rivers, Southern NSW and Western Sydney.

A series of presentations by representatives of NSW Health and Privacy NSW outlined the provisions in the exposure draft of the *Health Records and Information Privacy Bill* and the steps being taken to implement the EHR. Participants were given the opportunity in plenary to raise questions arising from the presentations.

In the afternoon a series of nine workshops explored specific aspects of the implementation of the EHR. The first group of workshops examined issues relating to the EHR from the perspectives of particular population groups. The topics were:

1. Rural and regional health consumers
2. Chronic illness
3. Older people
4. People from culturally and linguistically diverse backgrounds
5. People with mental illness.

The first three workshop topics were chosen to ensure that issues relating to relatively high service users were aired, and also to ensure an adequate balance of issues across the state. Forum participants nominated the fourth and fifth workshop topics as priorities for discussion.

The second group of workshops considered issues relating to NGOs and health consumers generally. The topics were:

6. Health NGOs
7. Non-health NGOs
8. Consumers and their carers (two workshops).

## 2. Common issues

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While the plenary sessions and the workshops considered different aspects of the proposed *Health Records and Information Privacy Bill* and the implementation of the EHR, a number of common themes emerged from the Forum. As expected, there was a degree of overlap in discussion of the Bill and the EHR, given the legislation will govern the collection and use of information on an EHR and specific provisions in the Bill relate to consent to participate in the EHR system.

- **Benefits**

Many participants recognised the benefits they expected the EHR would deliver to the consumer and the health system, including improvement in the coordination of care and accurate and timely access to information regarding past treatment and medication. The rights provided by the new laws should also enhance a consumer's access to their own health information. The EHR should provide consumers with reliable information about who has had access to their records and how the information has been used.

Participants emphasised the need to take this opportunity to address *current* problems with health records rather than entrenching them in new technology, for example, the use of respectful language in records, inclusion of both clinical and community care information and addressing paternalistic attitudes to mental illness. In many respects the health privacy laws and the EHR will require a significant culture change, both for health service providers in gaining the consumer's consent and providing access to records, and for consumers in having the choice about whether to have their health information held in an EHR.

Workshop participants raised many concerns regarding the EHR that they felt must be addressed in the implementation process. Some of the key concerns included issues relating to: consent, the information kept on an EHR, access to records, complaints processes, concerns of NGOs and the need for consumer involvement in the EHR process.

- **Consent**

There was significant concern that consumers have the information to provide fully informed consent to have their health records linked in an EHR. The consumer would need to be fully informed about the system and its safeguards, understand what is being asked of them (including the consequences of participating or choosing not to) and be free to be free from pressure when making their decision. These highlight the need for a process of consumer education, including providing plain English information in different formats and in appropriate community languages. There is a corresponding need for providers to be educated about the

EHR and the nature of informed consent, to equip them to discuss it appropriately with health consumers.

Participants were concerned about potential discrimination against an individual if they chose not to opt in to the EHR or if they wished to block access to certain parts of their electronic record. It was argued that health privacy legislation and the rules governing the EHR should explicitly forbid participation in the EHR being used as a condition for providing treatment. The implementation of the EHR should include mechanisms to prevent discrimination against a health consumer on the basis of the person's decision not to participate.

- **Information recorded on the EHR**

Many of the potential benefits of the EHR could only be delivered if there is scope to include the full range of pertinent health and non-health information on a record. This would include information generated by – and accessible by – allied health professionals, community care organisations and NGO service providers.

There is a need for consistent data standards defining what is considered 'health information' and how it is recorded on an EHR, as well as determining what should be excluded from electronic records.

It was agreed that consumers should have control over the information that is added to their record, including the option that certain information, or services delivered by certain providers, should not be added at all.

- **Access - by providers**

Many consumers will be influenced in their decision regarding whether or not to participate in the EHR, by how much control they could expect to have over the information kept on the record. The Forum argued that consumers should have a high degree of control over who has access to their record. In principle, access should be provided on a need-to-know basis only, and access to certain information should be restricted. It was suggested that for some providers, access to a record should be limited to a particular period of time or for the duration of a specific course of treatment. The consumer should retain the option to remove particular information from their EHR at a later date.

Consumer control over access was seen as particularly important in relation to information the consumer might consider to be, or others might perceive as, highly sensitive.

There were concerns that both the legislation and the administrative systems for the EHR should prevent unauthorised access to records as well as unauthorised use of information.

There needs to be a guarantee of complete transparency for the consumer and systems in place to monitor irregular access to records. It was suggested that any printing of electronic information be prohibited as a means of controlling unauthorised access. At the very least, the system should log what information is printed, by whom and for what purpose.

- **Access - by consumers**

The Forum welcomed provisions in the draft Bill setting out the consumer's right of access to health information, although there was some scepticism as to whether the legislation would fully address current problems with access to information. Participants assumed the legislation would ensure their access to records created before its commencement.

It was noted that some consumers will require assistance when accessing health information about them, including the provision of an available computer, assistance with jargon and appropriate support where required, for example when accessing information relating to mental health episodes or trauma. It was stressed repeatedly that access to records should not be provided only a computer-based system, given that many people are not comfortable with or skilled in using information technology. Additional means of access should be provided.

Participants raised a number of concerns relating to potential refusal of access to information or barriers to effective access. In the event that an individual is denied access on the grounds of detriment to their health, it was questioned how this would be assessed appropriately, especially in cases of the records of mental health consumers. Some consumers at the Forum were concerned that providers may still use the legal ownership of a record as a means to deny the consumer access to information. This was particularly of concern for consumers with experience of current problems securing the release of information on health records.

If charges are levied for providing access to information (as envisaged under the draft Bill) it was agreed that fees must not serve as a barrier to accessing information, particularly for consumers with limited financial means.

- **Complaints and breaches of privacy**

It was agreed that effective and credible complaints processes are essential to encourage trust in the EHR and provide means of addressing breaches of privacy. The Forum raised repeated concerns about the inadequacy of the complaints regime under the draft health privacy Bill, particularly for vulnerable people.

As set out in the draft Bill, a complaint could only be initiated by a person who knows their privacy has been breached and who was willing to make a complaint. Given the technology involved in the EHR, a consumer may not know their health privacy had been breached. A consumer may not be in a position to complain, due

to issues of language, mental illness, cultural difference, a fear of retribution or a lack of knowledge of the complaints system. In these instances, there would be no mechanism to ensure compliance with the legislation or to provide a remedy where privacy principles had been breached.

There should therefore be an audit process established by legislation to monitor compliance with health privacy laws. Such audits would be an essential safeguard in the administration of the EHR.

- **Implications for NGOs**

Participants representing both health NGOs and non-health NGOs questioned the planned relationship between the EHR and services provided in the community sector. NGOs sought information regarding whether they would be included in the EHR system, as sources of information for electronic records and as service providers requiring appropriate access to information. In any case, the EHR may place on NGOs additional demands for information, advice and support for clients in negotiating electronic health records in the health system.

Health NGOs discussed whether they would have the choice to become involved with the EHR system or remain independent of it. Non-health NGOs questioned whether the system would acknowledge their role (and the importance of relevant non-health information to the provision of health services) or perpetuate current relationships through new technology. It was agreed that the implementation of the EHR should assist in building trust and continuity between the health system and the community care system. It was agreed that NGOs should be recognised as having a legitimate role in the development and implementation of the EHR.

- **Consumer involvement**

A consistent theme through the Forum was the need for ongoing involvement by consumers and community organisations in the EHR process. It was agreed that participation is required in the design and implementation of the EHR, and to build the consumer understanding and trust necessary for people to participate in the EHR.

Consumers want to be involved at every step and many participants were concerned they had not been involved at an earlier stage in discussions about the legislation or the EHR. The development of the EHR must engage with a range of groups and key stakeholders, at both state-wide and local levels, providing information and seeking input before key decisions are taken. Regional participants stressed the need for information and consultation across NSW.

## 3. Agenda

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### **NCOSS Forum on the Electronic Health Record and new health privacy laws** Thursday, 2 May 2002, Masonic Centre, Sydney

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- 8:45            **Registrations**
- 9:15            **Welcome to country**  
*Allen Madden, Metropolitan Local Aboriginal Land Council*
- 9:20            **Introduction and welcome to the Forum**  
*Alan Kirkland, Director, NCOSS*
- 9:30            **The Health Records and Information Privacy Bill:**
- Overview of the exposure draft
  - Discussion and questions  
*Leanne O'Shannessy, Deputy Director, Legal and Legislative Services, NSW Health*
  - Complaints processes  
*Anna Johnston, Deputy Privacy Commissioner NSW*
- 10:30          **Morning tea**
- 11:00          **The Electronic Health Record (EHR): What does it mean for consumers and community organisations?**  
*Peter Williams, Director, Information & Business Solutions, NSW Health*
- 12:00          **Lunch**
- 1:00            **Concurrent workshops: Workshop 1**  
**Aspects of the EHR and its implementation by NSW Health**
- 5 workshops – population groups – eg. chronic illness, rural and remote health consumers, older people, mental health, carers
- 2:15            **Concurrent workshops: Workshop 2**
- 4 workshops – health NGOs, non-health NGOs, health consumers and the EHR (2)
- 3:15            **Afternoon tea**
- 3:45            **Report back from the workshops**
- 4:45            **Close**

Supported by:



## **4. Guide to the Health Records and Information Privacy Exposure Draft Bill**

Presentation by Leanne O'Shannessy, Deputy Director,  
Legal & Legislative Services, NSW Health

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### **Background**

In June 2000 the Minister for Health appointed the NSW Privacy Commissioner, Mr Chris Puplick, to chair an independent NSW Ministerial Advisory Committee on Privacy and Health Information. The Minister requested the Committee investigate and advise on privacy issues relating to health information, particularly those raised by proposals for the development of a linked electronic health record.

The Committee reported to the Minister in December 2000, after conducting extensive consultation with key stakeholder groups and the public, including two public forums on health privacy issues, and a workshop conducted as part of the Consumers Health Forum national consultation process on electronic health. A copy of the Committee's report to the Minister is available at [www.health.nsw.gov.au](http://www.health.nsw.gov.au)

While many of the Committee's findings were directed at the concept of electronic health records, one of the key recommendations was the enactment of a Health Records and Information Privacy Act to regulate the collection, use, storage and disclosure of health information in NSW. The Committee considered that a strong regulatory regime protecting health information and applying irrespective of the format in which the information is kept, was essential to address community concerns about the privacy risks associated with electronic records.

### **Why an Exposure Draft Bill?**

Given the high level of public interest in privacy issues, the Government has determined to release these legislative proposals as an exposure draft Bill, to enable those affected by the proposals to have the opportunity to consider and comment on the content of the Bill.

The Government wishes to ensure that the community has sufficient opportunity to properly consider and comment on the Bill prior to its introduction in Parliament which is proposed to occur in the Parliamentary Session commencing March 2002. This consultation process is directed at ensuring issues raised by stakeholders are considered and addressed before the Bill's passage through Parliament.

### **How does the Bill relate to existing privacy laws?**

NSW already has privacy legislation regulating the way in which NSW public sector agencies deal with information. In addition, amendments to the Commonwealth Privacy Act, due to commence in December 2001, will expand privacy obligations established under federal law into the private sector (although that legislation will not apply to the NSW public sector).

One of the founding principles of the Health Records and Information Privacy Bill is to build on what has already been achieved at the state and federal level, rather than duplicate it. As such, the Bill has been designed to maintain consistency with the Commonwealth National Privacy Principles, so that action undertaken in order to ensure an agency, organisation or individual is ready to comply with the Commonwealth Principles will ensure compliance with the principles established under this Bill. Most of the terms, definitions and principles created under the Bill reflect those used in the Commonwealth legislation.

The aim of the Health Records and Information Privacy Bill is to provide a single state-based scheme for the management of *health* privacy obligations, imposing the same set of Privacy Principles on information holders in both the public and private sector. The Bill will also provide a readily accessible complaints process and recognise the special issues which arise in the handling of health information. Similar legislative approaches have already been adopted in both the ACT and Victoria.

## **MAIN FEATURES OF THE BILL**

### **Who does the legislation cover?**

The Health Records and Information Privacy Bill covers any public or private sector organisation that holds “health information” as well as individual health service providers.

### **What is “health information”?**

The Health Records and Information Privacy Bill will cover “health information” rather than defining and regulating specific categories of health service providers. “Health information” is defined in clause 6 to include information or opinions about a person’s physical or mental health and information collected in relation to organ donation or genetic information. It also includes information about a “health service” provided to a person. “Health service” is defined to cover a broad range of services including medical, hospital, nursing and ambulance services, as well as services provided by both registered and unregistered health practitioners.

The Bill has exemptions to ensure that it does not cover personal, family and household communications nor interfere with the activities of courts and tribunals, and that it recognises the role of the news media.

### **Does the Bill cover electronically stored information?**

Yes. All the obligations imposed in the legislation on use and disclosure will apply equally to the use, disclosure (and consequently linkage) of electronically stored records.

The Bill also includes a special provision in HPP15 to ensure patient information is not linked into a statewide health record unless they have expressly consented to participate in such a scheme.

## **What obligations are imposed on holders of health information?**

The Bill requires holders of health information to comply with 15 Health Privacy Principles. These principles, which are consistent with the Commonwealth National Privacy Principles, establish obligations in relation to the collection, retention, storage, use and disclosure of health information. They also establish a right for an individual to access health information which applies to them. The Health Privacy Principles (HPP's) cover:

### **Collection**

HPP1 requires that information must not be collected unless it is for a lawful purpose directly related to a function or activity of the organisation or individual.

HPP2 the collection of information should not intrude unreasonably on the personal affairs of an individual, and should be relevant and accurate.

HPP3 states that information should, unless it is unreasonable and impracticable, be collected from the individual to whom it relates.

HPP4 requires those collecting information to inform the person about certain things, including who is collecting the information, the purpose of the collection and the consequences if the information is not provided.

### **Retention and Security**

HPP5 requires information be kept for a reasonable period of time and stored securely.

Part 4 of the Bill also contains additional provision in relation to retention.

### **Access and Alteration**

HPP6 requires holders of health information to allow people to find out if they hold information about them.

HPP7 allows people the right to access health information held about them.

HPP8 allows people to ensure the accuracy of information by providing them with a right to apply to have information amended.

Part 4 of the Bill sets out additional provisions on access and amendment.

### **Accuracy**

HPP9 requires holders of health information to ensure health information they propose to use is accurate, complete and up to date.

### **Use and Disclosure**

HPP10 sets out the list of purposes for which holders of health information can use health information.

HPP 11 sets out the list of purposes for which holders of health information can disclose health information.

### **Identifiers**

HPP12 establishes limits on the use of identifiers.

### **Anonymity**

HPP13 allows people to access health services anonymously.

### **Transborder data flows**

HPP14 sets out specific circumstances and requirements for the cross-border flow of data.

### **Linkage of health records**

HPP15 prevents the creation of linked electronic health records without the express consent of the individual to whom the information relates.

### **How will organisations be required to retain records?**

Public sector agencies are already subject to regulation in relation to retention and storage of records under the State Records Act.

Part 4 of the Bill will require health service providers to retain health records for 7 years after the last incidence of service, and to make a written note of when information is destroyed or transferred. Individuals will not be required to comply with these requirements if they are already bound by existing regulatory schemes for the retention and disposal of records (such as, for example, the Medical Practice Regulation 2000).

Other organisations (who are not health service providers), will be required to destroy or permanently de-identify information if it is no longer needed for the purpose for which it was collected.

The Privacy Commissioner of NSW will be able to issue guidelines to assist organisations in complying with these provisions.

### **How will individuals be able to access health information?**

Public sector agencies are already obliged to provide access to information under the Freedom of Information Act. Under that Act, a public sector agency must make a determination on applications to access information within 21 days of receipt of the application.

Part 4 of the Bill sets out provisions for applications to be made to private sector organisations. The main features of the private sector access scheme are:

- access is limited to health information about the person who has made the application;
- a response must be made to an application within 45 days of receipt;
- access must be given by inspecting the information or providing a copy;
- fees can be charged for granting access;
- organisations will be able to refuse access in certain specified circumstances;
- where access is sought to information collected before the Bill comes into effect, the organisation can comply with the provisions by providing a summary of the information.

The Privacy Commissioner of NSW will be able to issue guidelines to assist organisations in complying with these provisions.

## **How will individuals be able to have health information amended?**

Individuals are already entitled to request public sector agencies to amend information under the Freedom of Information Act. Under that Act, a public sector agency must make a determination on applications to amend information within 21 days of receipt of the application.

Part 4 of the Bill sets out provisions for applications to be made to private sector organisations to amend information. These are similar to those outlined above in relation to access.

The Privacy Commissioner of NSW will be able to issue guidelines to assist organisations in complying with these provisions.

## **How will complaints about breaches of the Health Privacy Principles be handled?**

Complaints about public sector agencies will be dealt with under the existing Privacy and Personal Information Protection Act. Under that Act, agencies are required to have processes in place to conduct internal reviews of the conduct complained of within set time frames. For example, if a public sector agency refuses access to health information, the person who made the request is entitled to request an internal review, and seek to have the agency reconsider its decision. Where a complainant is unhappy with the result of the internal review, they are entitled to take their complaint to the Administrative Decisions Tribunal, where the agency may be ordered to correct their conduct or pay compensation of up to \$40,000.

The complaints process for private sector organisations and individual service providers is set out in Part 6 of the Bill, and will operate through the Office of the NSW Privacy Commissioner. The Privacy Commissioner will have the power to review, investigate and attempt to conciliate the complaint. The Privacy Commissioner will also be able, where appropriate, to refer complaints to the Federal Privacy Commissioner.

While complainants will also have access to the Administrative Decisions Tribunal, this access will be limited to matters which have been investigated by the Privacy Commissioner. Where a person considers a breach of the Privacy Principles has occurred, and makes an application to the Tribunal, it will be empowered to make the same range of orders as those available against public sector agencies.

## **Will people who lack legal capacity be able to use the Act?**

Yes. The Bill contains provisions to ensure that where a person lacks capacity to make a decision or consent or exercise a right under the Act, a guardian, or person authorised to act on their behalf will be able to act for them.

**DEPARTMENT OF HEALTH**  
NOVEMBER 2001

## **5. The complaints and investigation processes under the Health Records and Information Privacy Bill 2002**

Presentation by Anna Johnston, Deputy Privacy Commissioner

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### **Privacy NSW**

## **The complaints and investigation processes under the Health Records & Information Privacy Bill 2002**

### **The existing situation - the PPIP Act**

While the PPIP Act only allows legal remedies in relation to breaches of the Act by public sector agencies, it also gives the Privacy Commissioner power to investigate and conciliate complaints about “violations of, or interferences with, privacy” by any organisation or individual.

When our office receives a complaint, we have to decide how it can or should be dealt with.

If it is a complaint that can be made under Part 5 of the PPIP Act (that is, by seeking internal review by a public sector agency), we usually recommend that course of action to the complainant.

Otherwise we will investigate, unless we decline on one of the grounds specified in s.46 of the Act (such as if the subject matter of the complaint is required by law).

#### Internal Reviews

Under Part 5 of the PPIP Act, individuals have the right to seek a review by a public sector agency in cases where the individual believes the agency has breached one or more of the following:

- one of the 12 Information Protection Principles
- the public register provisions in the Act
- a Privacy Code of Practice

The responsibility for dealing with internal reviews lies with the agencies, although the Privacy Commissioner can make submissions to the agency during the course of the review. The agency must keep our Office notified of the progress of each Internal Review.

If an individual is not satisfied with the outcome of an internal review or the way in which the internal review was conducted, then they may take the matter to the Administrative Decisions Tribunal (ADT).

## Remedies under the PPIP Act

After reviewing a matter under the PPIP Act, the ADT may make orders requiring an agency to undertake certain remedies/action, including:

- to refrain from conduct or action which breaches an IPP or Code
- to correct information disclosed by an agency
- to take steps to remedy loss or damage

The ADT may also make an order requiring an agency to pay damages up to \$40,000 for loss or damage suffered where the applicant has suffered financial loss or psychological or physical harm as a result of the conduct, but only where the conduct occurred on or after 1 July 2001.

## The alternative: a Privacy Commissioner investigation

Our powers under the PPIP Act are limited. We can only make a report on our investigation, and can make findings and/or recommendations. Any such recommendations are not binding on any party. Thus we can only seek to achieve a conciliated outcome.

There is no appeal from our investigation / conciliation processes.

## **The future situation - the HRIP Bill**

If the HRIP Bill passes Parliament without amendment, the complaints / investigation process will be as follows:

**Complaints against public sector agencies** - same as now.

That is:

- breaches of an HPP or a Health Code => internal review => ADT
- other allegations of 'a violation of or interference with privacy' => conciliation by our Office

## **Complaints against private sector individuals or organisations ...**

### Stage One Preliminary assessment

Complaint may be declined on one of the following grounds:

- frivolous or vexatious
- trivial
- lawfully permitted
- alternate means of redress
- referred to another body

### Stage Two Assessment

- is there a prima facie case that a breach occurred?

### Stage Three Dealing with the Complaint

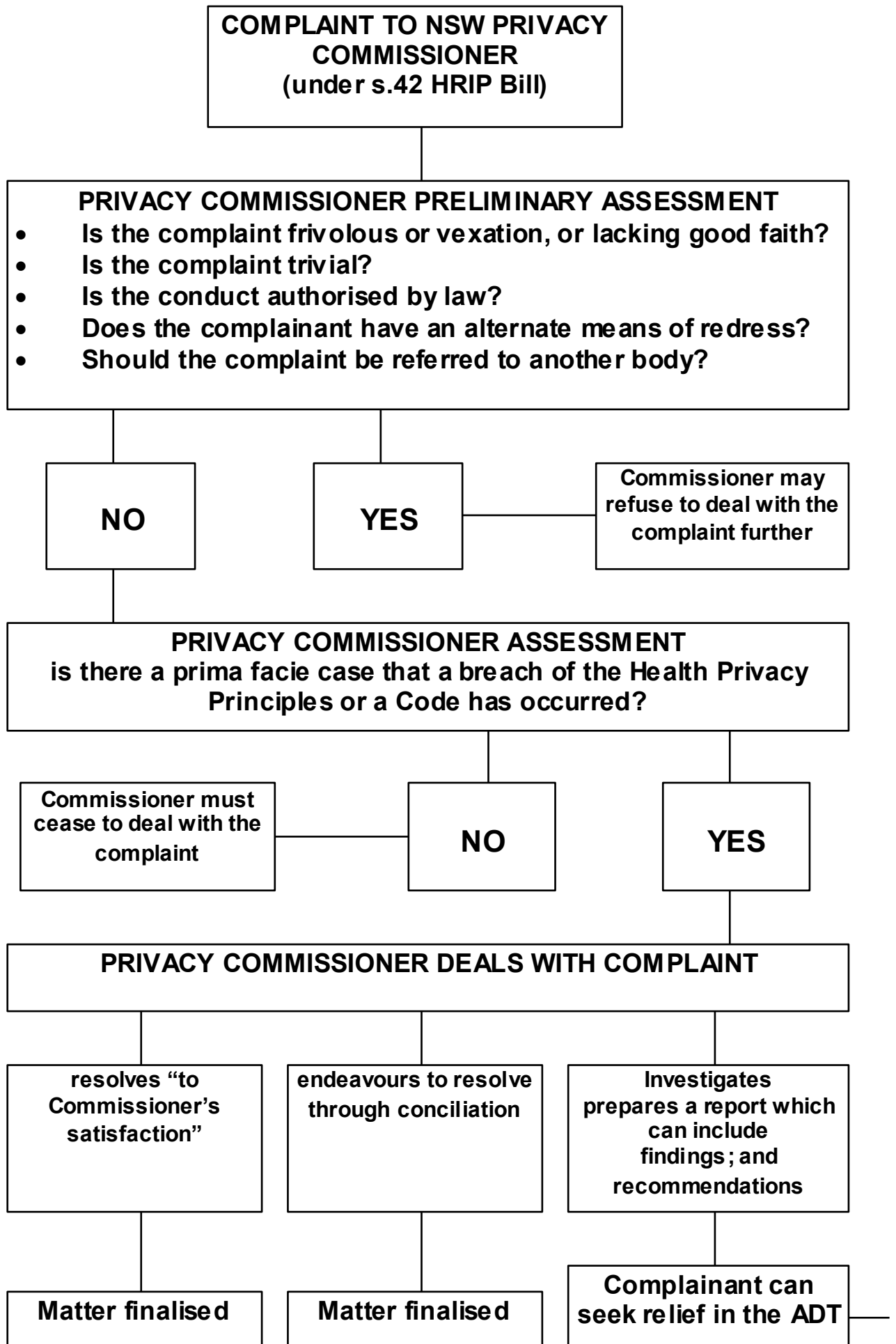
- resolve by conciliation
- resolve to Commissioner's satisfaction
- investigate and report

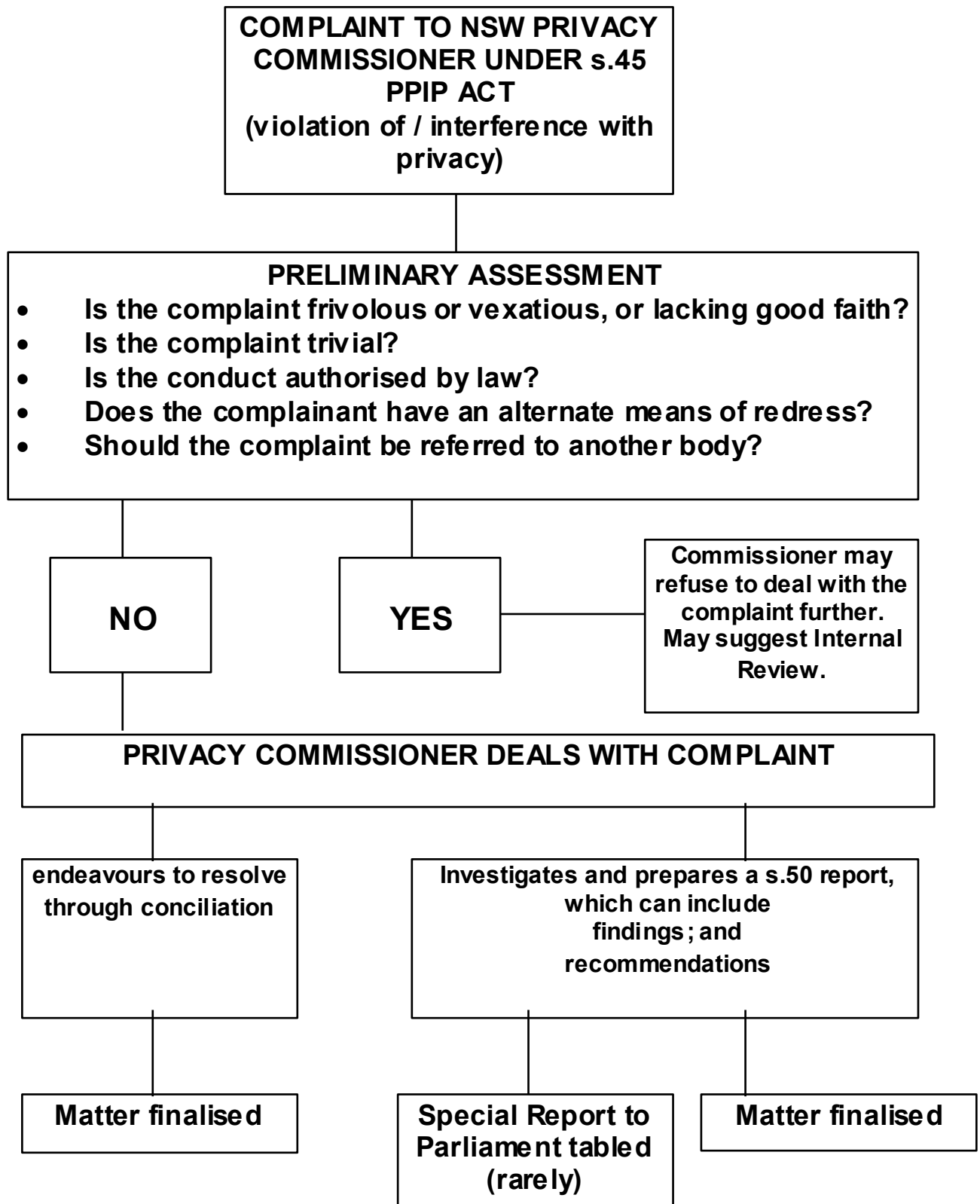
### Stage Four Investigate and Report

- may make a finding
- may make a recommendation

### Stage Five The Administrative Decisions Tribunal

- Only matters which reach Stage Four can be taken to the Tribunal
- Only the complainant (not the Privacy Commissioner, not the respondent) can initiate an action
- Investigation Report is admissible in the proceedings
- ADT has same remedies available as under the PPIP Act





## 6. The Electronic Health Record – What does it mean for consumers?

Presentation by Peter Williams, Director, Information and Business Solutions, NSW Health

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### National Electronic Health Records Taskforce

The purpose of the National Electronic Health Records Taskforce was to bring a coordinated approach to electronic health record systems and to avoid the potential for incompatible systems and duplication

Better Health

NSWHEALTH



### Defining the Electronic Health Record

"An electronic longitudinal collection of personal health information, usually based on the individual, entered or accepted by health care providers, which can be distributed over a number of sites or aggregated at a particular source. The information is organised primarily to support continuing efficient and quality health care. The record is under the control of the consumer and stored securely"

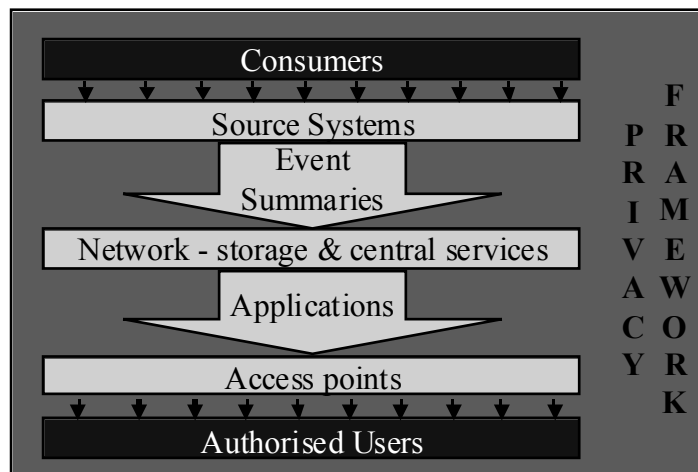
Better Health

NSWHEALTH

## Key Elements of the Definition

- Entered or accepted by clinicians
- May be distributed or aggregated
- Stored securely
- Primarily to support quality health care
- Under the control of the consumer

## HealthConnect - A Health Information Network for Australia



## Benefits of EHRs

- Empowering consumers
- Quality and safety
- Privacy
- Clinical decision making
- Policy making

## The Building Blocks

- Privacy, confidentiality and security
- Person, facility and provider identifiers
- Standards
- Event summaries
- Telecommunications infrastructure
- Use of information and communication technologies by providers

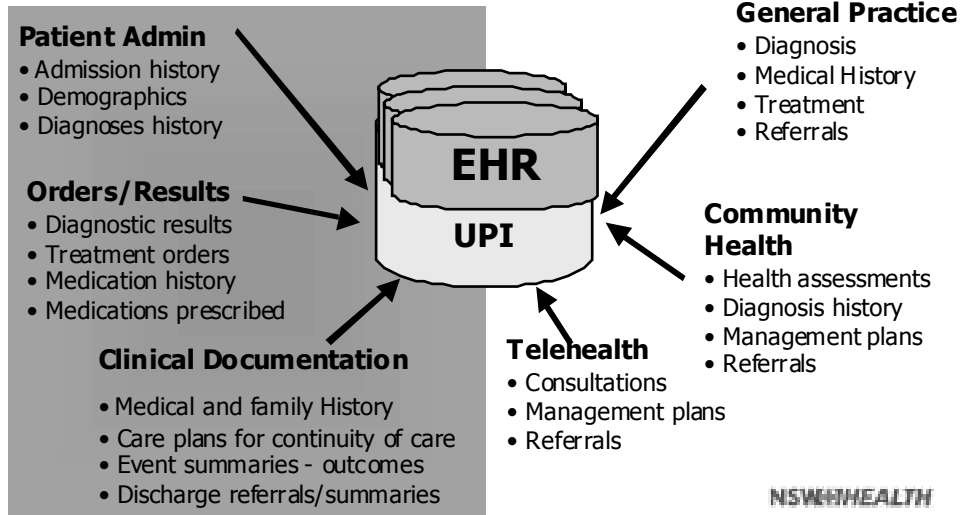
## **Health *Connect* Current Status**

- Report published and endorsed by Health Ministers - to report in July 2002
- National Project Office established
- Business architecture developed
- Lead sites identified including NSW Health

## **Health Council Report**

- Introduction of statewide unique patient identifier subject to privacy considerations
- Development of EHR across the State by 2010
- Substantial progress in two Areas within two to three years
- GAP response
  - Established Ministerial Advisory Committee on Privacy and Health Information
  - Established Information Management Implementation and Coordination Group

## Electronic Health Record (EHR\*Net) Information Sources



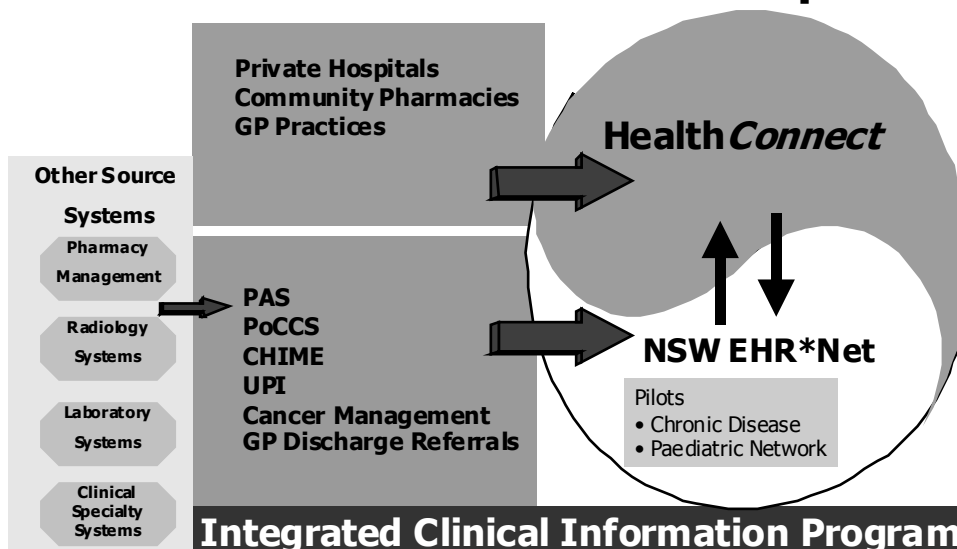
## EHR\*Net Strategy

- Strategy endorsed and published
- Recommends incremental approach
- Initial implementation based around clinical service need e.g. Chronic Disease Management (Hunter) and Child Health Information (Western Sydney)
- Systems architecture under development - hybrid of repository and registry models likely
- Complementary to HealthConnect

## Linkage with Federal Projects

- NSW Health EHR\*Net will be compatible with national initiatives under *HealthConnect*
- NSW Health is taking a lead role .... in developing national standards and EHR architecture, and in implementing *HealthConnect*

## Electronic Health Record Development



## Where are we now with EHR\*Net?

- Governance structure and project teams in place
- Health *Connect* Business Architecture developed and comments sought
- High level design completed
- Tender for detail design
- Prototype by Q3 2002

## Issues and implications

- Requires clinical focus and close involvement in change management
- Privacy and security frameworks must be established with wide consultation
- Consumer involvement in all aspects of the program and, in particular, evaluation
- Need to upgrade the IM skills of both clinicians and information professionals

## Issues and implications

- Agreement on content of event summaries
- Establishing and implementing rules for consumer control over access
- Information storage, archive and retrieval
- The EHR\*Net gives important benefits but is not a substitute for Point Of Care Systems.
- There is an urgent need to establish the agreed architectures and standards

## Current year activity

- EHR Strategy published
- Security policy published
- Telecommunications tender to be issued
- Health *Connect* lead site established
- PAS and CHIME deployed in Hunter
- Statewide UPI facility established
- NSW health privacy legislation drafted
- EHR\*Net architecture determined
- Statewide provider directory established
- Electronic discharge summary deployed

## Strategic timelines

- EHR\*Net for Chronic Disease 2002/03
- Statewide deployment of UPI 2002/03
- EHR\*Net for Child Health 2002/03
- Statewide "supernet" 2002/03
- Statewide discharge summary 2002/03
- Point-of-care clinicals in two Areas 2003/04
- EHR evaluation and rollout 2004/05
- Statewide PAS and Community Systems 2005/06
- Statewide point-of-care 2006/07
- General deployment of EHR 2007/08

## What's next?

- Communicate the strategies
- Consumer involvement at all levels
- Establish the architectures for the EHR
  - Business process
  - Data
  - Applications
  - Technology

## **7. Workshop outcomes**

### **7.1 Population groups**

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#### **Workshop 1: People from rural and regional communities**

Facilitated by Maz Thomson, Council of Social Service of NSW (NCOSS)

Participants canvassed a number of benefits they expected the EHR would provide. These included improved access by consumers to health information held about them as well as improved access by their health service providers. Access to information would be particularly valuable in the event of an emergency. It should streamline the consumer's movement through the health system, removing the need for them to repeat many details, and streamline the transfer of information such as specialists' reports between multiple providers. Participants believed the EHR could reinforce the health care provided on a given occasion of service by allowing the consumer to obtain access to their record to 'check back on' advice given regarding recommendations and options for treatment. Some participants expected that the linkage and exchange of information across the health system could help lessen the sense of isolation felt by many rural and regional health consumers.

#### **Communication**

In order for these benefits to be realised, the EHR needs to be developed and implemented with both consultation and education processes, including open and pro-active communication by NSW Health. There will need to be a high level of participation by consumers – including by people from regional areas – in the development of the EHR.

It was recognised that people need to be given the opportunity to develop an understanding of, and trust in, the EHR. This requires the provision of adequate information, particularly regarding access and security issues. Information should be provided in plain English and in different formats (for example, videos), taking account of different levels of language and literacy skills. There should also be provision for information sessions in regional areas.

Both consumers and health service providers will also need education regarding their specific rights and responsibilities, in addition to broader education about the EHR and its information technology.

#### **Technology and the EHR**

The workshop discussed several issues relating to information technology, which must be addressed in the implementation of the EHR. There needs to be consumer input to the development of standardised fields and forms used for the capture of health information. Consumers will need information about the nature of the EHR

system, the security of the system and the technological safeguards that would prevent the system from crashing. It should be recognised in this process that people have greatly varying understandings of technology. Certain population groups are wary of computer technology and this will have significant implications for their perception of electronic records.

Participants were concerned that at present some rural areas do not have the broadbanding required to participate satisfactorily in the EHR system. The administration of the EHR should recognise the wide variation in levels of access to information technology and skills in using it. How would people who did not own computers, for example, obtain access to their health information? People in regional areas also have major constraints imposed by the distance they may live from the nearest computer or public access point to the Internet.

### **Privacy, consent and participation**

The issue of confidentiality of information was a significant concern for participants in this workshop, who felt that information about the EHR provided to consumers must dispel concerns regarding unauthorised access to a person's information. Many consumers would hold fears about who could access their records and how much effective control the consumer could have over that access. Similarly, consumers must be informed about measures to prevent unauthorised changes being made to their recorded health information.

Consent was clearly identified as a very important and complex issue for the EHR. Participants questioned the possible consequences of a consumer deciding they did not wish to have their information linked in an EHR. There was also discussion regarding what would happen when a consumer who had consented to join the EHR later decided they no longer wished to be part of the system. Could they actually opt out? There was also a great deal of discussion regarding whether researchers would be able to gain access to information held on records without the explicit consent of the consumer.

Participants wanted to know the full range of implications of participating in the EHR. It was queried whether there would be implications for Medicare services arising from the information stored on electronic records.

Some consumers feared possible retribution from their health service provider if they were found, through information stored on their electronic record, to have consulted another provider. Consumers were also concerned that the information held on an EHR may bias subsequent health service providers, which would be of particular concern if the consumer sought a second opinion. Should another health provider read notes from the initial consultation on an EHR, the second opinion may be biased (or the consumer's confidence in the opinion undermined) by the access to the first provider's notes.

Health service providers from regional areas were concerned that they may incur additional costs which need to be covered, including time spent on record-keeping and explaining systems to consumers. Describing systems to consumers and seeking consent may also impose additional stress on staff.

### **Confidence in the EHR**

Finally, the workshop considered the measures that would increase participants' confidence in the EHR. It should be able to fully describe the systems in place for ensuring the confidentiality of records and which health service providers are registered to use the system. Some participants sought guarantees about confidentiality in regard to cultural concerns raised by access to information (especially for indigenous communities) and questions relating to the use of information in research.

The system should be able to demonstrate its advantages and successes. At the same time, consumers need to be informed about its safeguards, in terms of the legislative framework and what the technology provides, in terms of 'locking' entries and generating audit trails. Consumers need to see the proven independence of complaints mechanisms and the ease of access to them if the consumer wishes to make a complaint. Above all, consumers must be confident that all relevant aspects of the EHR are fully transparent.

## **Workshop 2: People with a chronic illness**

Facilitated by Stephen Gallagher, AIDS Council of NSW (ACON)

The workshop considered that, for people with a chronic illness, an EHR could potentially provide significant benefits in terms of the quality of care they receive and in negotiating different parts of the health system. A linked record could provide a 'map' of a particular condition's progress, allowing appropriate interventions to be more easily identified at appropriate times. It would also diminish duplication in treatment and decrease the current level of reliance on a patient's memory of their previous practitioners, conditions, medications and other treatments. The EHR has the potential to encourage a more holistic approach to health care if allied and other health services are included in the system.

The integration of medical records was seen as a benefit for people with chronic illness, providing for seamless recording of an individual's interactions with health services and assisting with better management of their transitions between services. However, it was agreed that a key issue for the EHR would be to ensure that consistent data standards governed the information collected on electronic records. These standards should address both the level of information required and the collection of information by a range of health disciplines.

### **Potential disadvantages**

While the group was of the view that the EHR could usefully encourage consistency of practice throughout the health system, participants were concerned that information recorded by prior practitioners could prejudice, or otherwise unduly influence, the opinions and diagnoses of future practitioners.

The EHR represents a potential disadvantage for both consumers and practitioners, in the data entry that may be required in addition to the information currently recorded in a practitioner's medical notes. This would impose extra costs in time and other resources. If as a result of these pressures the data was entered during the consultation, the workshop was concerned the EHR would change the nature of the interaction between the practitioner and the client.

For health service providers there would also be additional hardware costs in order to participate in the EHR, which would represent a particular burden for allied health professionals. If funds were offered to assist providers to participate in the EHR, there must be transparency and equity of funding arrangements, especially in relation to allied health care practitioners.

### **Security and access**

The workshop discussed concerns relating to security and access to information held on electronic records. The security of the EHR system was raised as a concern, including the potential fear by consumers that hackers could obtain highly sensitive

information by 'breaking into' the information technology system used to store records. Participants were also concerned about the future control of health information about a person if (or when) a government out-sourced the administration of the EHR system.

There may be issues relating to a patient's responsibility to provide consent for access to their records, for example when the patient is unconscious, experiencing dementia or (if the system is based on PIN numbers to control access) unwilling or unable to divulge a PIN number. In terms of consumer access to their records, the system would need to guarantee ease of access over the long term, including in an environment of changing technology and statutory limits.

Participants were particularly concerned that a person could be subject to prejudicial treatment within the health system on the grounds of their medical history, if that history was made known by its inclusion on an EHR. Examples given included a history of alcohol and other drug issues or treatment for mental health.

### **Concerns for people with chronic illness**

The workshop noted the EHR raises particular concerns for people with a chronic illness that need to be addressed in the implementation process. These concerns relate to the potential for prejudicial treatment by private health organisations and insurance companies, if an individual's health information was disclosed. Participants also raised the concern that a health consumer could receive prejudicial treatment from health service providers and staff as a result of the consumer's decision to refuse to divulge electronically-held health information. At the same time it was recognised that opting in and out of recording information on an EHR could jeopardise the quality of future treatment provided.

The group agreed that the implementation process must provide training across all disciplines, including for allied health care professionals, to ensure all health service providers have an equal capacity to participate in the system. The implementation must raise awareness of health privacy and the EHR among consumers. Above all, the introduction of the EHR was seen as a major cultural change in the health system, a change that will need to be effectively communicated to consumers.

### **Workshop 3: Older people**

Facilitated by Brenda Bailey, Council on the Aging (COTA)

Participants in the workshop questioned whether the development of an EHR should be a priority for the health system and whether the money could be better spent elsewhere. In particular, they raised the potential opportunity cost of spending on the EHR rather than on health service delivery, and whether this spending would compromise direct care. A few participants even questioned whether it was worth the workshop group discussing its concerns, as the system would not be in place in 10 years due to a shortage of money or a change of government.

#### **Benefits**

Most participants were sceptical about the EHR's practical benefits for the client. They noted that if it is to succeed, it must be demonstrated that participation in the system will deliver benefits to the individual and improve their quality of care.

Notwithstanding these views, the workshop acknowledged the potential benefits an EHR may provide for health consumers. It may reduce the current burden on individual health consumers to provide personal information at each event and it will represent an improvement on the paper records carried by the individual or health facility. The linking of information should encourage more effective case management if comprehensive information is available to case managers. In emergencies, the availability of more comprehensive health information might provide for better clinical decisions and better care. This could be of particular benefit for frail older people who are currently required to remember details, in some cases involving many medications over many years.

The group raised concerns relating to how an individual's health record is correctly located in the system and whether DNA matching could be used as an accurate identifier. The EHR must also facilitate other systems of patient identification, such as the 'bracelet ID' used in hospitals.

#### **Information recorded**

Participants discussed the need for a range of health and non-health information to be included on the record. It will be essential that information, such as that generated by GPs and allied health professionals, be integrated with the EHR. The system should include scope for the inclusion of alternatives such as traditional Chinese medicine. The group questioned how aged care services would be linked with the EHR, a particular concern for this workshop. It was also recognised that vulnerable people may have a particular need to include information in addition to details of hospital visits. For older people, an EHR may record whether the individual has elected a guardian or has a written statement indicating their wishes in case of incapacity. In this regard, the EHR may be an opportunity to address

current gaps in NSW by linking advance care directives with electronic records, giving the consumer greater control at the point of entry into the hospital system over the treatment they subsequently receive.

It will be necessary to clearly define what is health information for the purposes of the record, and address issues such as how conflicting information generated by different providers will be reflected on an EHR. Similarly, it will be important for the system to reflect whether records are up to date.

Importantly, the group agreed consumers want control over the information that is added to their record and when it is added.

Participants were of the view that the record could include family history, but they recognised that this can create a dilemma for older people. Some older people want family history information available to other family members as it may assist their grandchildren with management of their health. Other older people would want to retain control over how long their information is stored on the system and strictly limit access to it.

### **Privacy and access**

A number of requirements must be met for the potential benefits of the EHR to be realised, especially in relation to issues of access to records and the confidentiality of information. Consumers want to have a high level of control over who can access their record. The workshop supported a system of pre-determined levels of confidentiality, with the consumer controlling who has access to information of a particular level of sensitivity. This would require legislation to ensure that access is adequately controlled, and the development of models to implement control over access.

The group argued for proactive and ongoing evaluation of privacy in electronic records. The system should be based on a regime that ensures compliance with privacy standards, rather than the system relying on individual complaints in order for concerns to be identified and addressed. Participants also raised privacy concerns if people who access health information could take copies. How would privacy be protected if copies of information could be made, and would the consumer be informed that it had happened?

In relation to consumer access to records, the workshop questioned whether the consumer would incur costs if they wanted to obtain access to information held about them. It should also be recognised that a higher proportion of older people lack computer literacy.

## **Concerns for older people**

One concern identified for older people related to the consumer's exercise of consent in therapeutic settings. Some consumers view professionals as authority figures and may therefore give consent against their wishes but in order to comply with perceived pressure. There should be safeguards to ensure that consent is both informed and freely obtained, without any element of coercion by GPs or service providers.

The group raised other concerns including:

- That the client may become a 'record' in the health system (the system thus losing sight of the individual);
- That the information recorded on electronic records may be used in making decisions on restricting treatment, especially for those over 70 years of age; and
- Whether the information on electronic records will be used for research purposes, a particular concern for people from smaller communities.

The group noted that certain information, which might be considered of minor or simply demographic importance, would have a high degree of sensitivity for some older people. This should be reflected in standards governing access to, and disclosure of, information on a record. For example, whether a person is living alone would be highly sensitive for a consumer who felt the information, if known, might put at risk their personal security.

The implementation of the EHR must inform older people about the system and the consequences of opting in or out. It should inform them that participation is optional and that a consumer can opt in at a later date. It should clearly set out the status of those who do not opt in, including whether their services will be affected by that decision. Finally it needs to set out whether people can opt out at a later date (and how they would do so), as well as the likely consequences.

Information should be age-specific, that is, appropriately researched and targeted to reach its audience. Information should also be directed to adult middle-aged children of the very old, who may be decision makers on their parents' behalf. The particular needs of clients in residential care and retirement villages should also be taken into account.

Participants noted that many consumers who have experience of authoritarian governments will be more resistant to initiatives to link their health information in one record.

## **Participation and the EHR**

There was a strong call for continued consultation with older people and their representative organisations in the development of the EHR.

## **Workshop 4: People from culturally and linguistically diverse backgrounds**

Facilitated by Tim Goodwin, Council of Social Service of NSW (NCOSS)

Forum participants identified the impact of the EHR on people from culturally and linguistically diverse backgrounds as a priority issue for discussion. The workshop group considered a range of broader issues relating to the EHR as well as specific concerns of language, culture and access to health services that apply to people from diverse backgrounds.

The workshop expected that the benefits of an EHR would include improvements in continuity and integration between health services, which could lead to improved quality of care.

### **Health records and information**

Participants were concerned that the successful implementation of the EHR will require a culture shift in the health system with regard to how records are viewed by providers. This is particularly the case in the language used to describe patients in records, and in terms of 'access' and 'disclosure' of health information being different to 'ownership' of the record.

Consumers with prior experience of clinicians refusing to provide information when requested, or inappropriately providing information, are seeking guarantees that the EHR system and the new health privacy legislation will prevent these difficulties from occurring in future.

### **Confidence in the EHR**

Consumers will need to have adequate information about the EHR system if they are to have confidence in it and, ultimately, if they are to provide informed consent to participate. They will need to be informed about who will have access to their record, who has authority to add to records, the safeguards regulating access and the security measures in place to protect their privacy. In particular, consumers should have information about who *else* can authorise access to their record and to whom access can be granted.

The workshop recognised that the transparency of the system should be a key strength, providing details on who has had access to information and when, and guaranteeing a greater level of transparency than is currently the case. The group endorsed the idea that a consumer could be provided with a regular report of who has obtained access to their health information.

It must be recognised that a higher proportion of people from diverse backgrounds have negative experiences of repressive governments prior to migration to Australia. This is particularly the case for traumatised people from refugee backgrounds, who

also have a high degree of sensitivity in relation to certain information, such as their mental health information, being known.

## **Consent**

Some participants were not confident that doctors and nurses would take the necessary time to fully explain to the consumer issues relating to the EHR. This was particularly the case for participants who had experience of perfunctory use of current consent forms, presented as either a simple formality or an implied condition for treatment to be provided.

This underlines the need to inform and educate health service providers about the EHR and about informed consent to participate, in order to equip them to discuss it with patients.

## **Language issues**

Language represents a major barrier to access to health services by people from diverse backgrounds. If it is not addressed in the implementation of the EHR it will represent a serious problem for this population group when consumers interact with the system of electronic records. The workshop stressed the link between the provision of information in appropriate languages and a consumer's understanding of the EHR (and hence their ability to provide informed consent to participate). Participants were concerned that where language is an issue, it must be recognised that it may take additional time and resources to fully explain the nature of the EHR. It cannot be assumed that, because language barriers make the situation more complex or difficult, the consumer does not require the same level of information that would be provided to others in order to give their consent.

Therefore information will need to be provided in community languages, including written information with the parallel English text beside the appropriate translation. Participants pointed to the lessons that could be learnt from the Home and Community Care (HACC) Reform Workers in relation to this process.

Because it cannot be assumed that people have adequate levels of literacy in their primary language, the model will also require budgetary allocation and appropriate points of access for interpreter services. The workshop was particularly concerned that adequate funding be made available for interpreters in all sectors of the health system. In regional areas, where there are often no interpreters available for many languages, there will need to be other models for provision of interpreter services. It was also raised that the interpreters themselves may require additional training to equip them with the vocabulary to adequately explain health and information technology issues raised by the EHR.

It was agreed that the language of health and information technology will represent a barrier for some people from diverse backgrounds who have sufficient English

language skills that they do not usually require an interpreter but who nonetheless lack the specialised vocabulary to understand the EHR system.

In addition to information provided to individuals in their interactions with the health system, the workshop recommended that NSW Health provide broader information on the EHR to non-English speaking communities. This would require a multicultural strategy that provides information to people in a language they understand and opportunities to ask questions about the system. One participant suggested the training of bilingual cultural educators, who could raise awareness of the EHR in communities and answer community questions and concerns.

### **Women from diverse backgrounds**

There are particular concerns in relation to women from culturally and linguistically diverse backgrounds. At present, women may access several different health services for different aspects of their health, with varying degrees of sensitivity attached to different information. This may range from general health concerns with a lower level of sensitivity, to matters such as obstetric and gynaecological services, which they may have a particular wish to keep private, and serious and well-founded concerns if that information was more broadly accessible. Some women attend Women's Health Centres for certain health issues because they receive a guarantee of complete confidentiality for information collected.

For these women to participate in the EHR, they would require the system to allow them to choose which information and which health service providers are added to their EHR. In addition, they would seek a high degree of control over who has access to their EHR, and to which parts of their record. Such a system should provide for:

- Certain health service providers to be left off a consumer's record;
- Certain information not to be included;
- Some information recorded, but access to it strictly limited (such that the existence of blocked information would not be seen by others on the system); and
- Some information available to anyone accessing their record.

### **Information included**

Above all, the EHR system needs to accommodate flexibility in terms of which information and which health service providers a consumer wishes to include on their record.

It should also be recognised that some health conditions or one-off episodes may be so sensitive that they should not be recorded at all. If they were recorded, consumers would fear adverse conclusions being drawn on the basis of that information. Examples given in the workshop included:

- Sexuality issues;
- Terminations of pregnancy;
- Episodes of self-harm;
- Attempted suicide that didn't require hospitalisation; and
- One-off psychotic episodes.

Other information, such as a person's HIV status, would be so sensitive that the individual must genuinely have the power to decide whether or not it should be recorded on their EHR.

## **Complaints**

Workshop participants were concerned that under the draft privacy legislation, the scrutiny of a person's health information privacy is left to the individual. In cases where a person does not know their privacy has been breached, where they do not know the complaints system or where they are not confident in the mainstream language, they might not complain and therefore a breach of their health privacy would not be addressed. This underlines the need for a mechanism to monitor compliance with the legislation.

The complaints regime under the EHR will require interpreters and advisors to enable people to effectively exercise their right to complain.

## **Other concerns**

Participants were concerned that individuals who do not consent to participate in the EHR may suffer some disadvantage in the health system. They may suffer future discrimination on the grounds that they are not part of the EHR. They may be seen as a 'difficult' patient or as someone who has 'something to hide' and therefore be handled differently in the health system. The workshop agreed that the implementation of the EHR should prevent this discrimination from occurring.

It was questioned whether the EHR will have implications for practitioners with increasing fears of litigation. Participants questioned whether potential litigation would have implications for the information included on an EHR and for allowing access to health records in general.

In relation to access, it was stressed that not everyone can access or use computers.

## **Workshop 5: People with a mental illness**

Facilitated by Ros Bragg, Council of Social Service of NSW (NCOSS)

The EHR and people with a mental illness was the second topic identified by Forum participants as a priority issue for discussion.

The workshop discussed the benefits of the EHR including the possibility that a consumer would only be required to tell their story once. There would be advantages to locating key elements of their health information in the one place. It would enable improvements in the consumer's condition to be tracked, and information to be recorded such as particular 'triggers' or adverse reactions, for example, to particular medications. Centrally held and accessible records might also facilitate moves towards collaborative care.

In order for the benefits to be realised, the workshop considered there must be a process of education for consumers and providers. The workshop was also concerned that the practice of the EHR not differ from the full letter and intent of new health privacy legislation. This will require the development of appropriate processes to give full effect to the provisions in the Bill. In particular, the nature of *informed* consent must be clearly defined for mental health consumers and their carers, and appropriate implementation processes developed. There will need to be processes to ensure better access to records than are currently in place.

### **Information recorded**

Participants emphasised the need to address current problems in health records and mental illness, in relation to what information is collected, how the consumer is described in records and how individuals are labelled in the health system on the basis of information on their record.

In order for there to be confidence in the information on an EHR, standards should govern what information is recorded and how it is represented, and opportunities provided to amend incorrect information. Participants were concerned that the EHR must record only facts about a person's health, rather than speculation or interpretation. They were also concerned in the event that a misdiagnosis is captured on a person's record, especially if their access to future services is blocked on the basis of that misdiagnosis.

### **Privacy and access**

Participants agreed that the EHR system must strictly regulate access to health records and guarantee the security of information held on them. Levels of access should be defined (as distinct from general access to all parts of a consumer's record) and the health consumer should provide or withhold consent for different levels of information to be accessed. Participants also questioned who else in the health system would have authority to grant access to a record. There must be clear

systems in place describing how a consumer can obtain access to their health records and how access is approved. The workshop raised the question of whether the legal ownership of the information would affect the granting of access to it.

The workshop discussed particular concerns for mental health consumers obtaining access to health information on their record. Many participants expressed strong views that consumers not be denied access to their records out of concern for the effect on the consumer. Some consumers will require support and assistance when accessing information about traumatic incidents or acute episodes. Some participants expressed concerns about medico-legal issues arising from the full release of information to patients.

There must be fully transparent reporting processes detailing who has had access to which parts of a consumer's record. There should be measures in place to prevent people who access a record from printing or otherwise reproducing the information contained in it.

### **Participation and the EHR**

Participants were concerned that the change to electronic health records must not be driven by the technology but by the health care needs of individual consumers. Therefore consumers and their advocates will need to be involved throughout the policy development and implementation of the EHR. This should include involvement of consumer advocates, carer groups and the networks of peak bodies. Organisations such as the Mental Health Coordinating Council and Carers NSW were specifically mentioned.

Participants suggested focus groups document people's concerns to inform the implementation process. Particular attention should be given to issues affecting vulnerable groups such as people living in boarding houses.

## **7.2 NGOs, health consumers & carers**

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### **Workshop 6: Health NGOs**

Facilitated by Ros Bragg, Council of Social Service of NSW (NCOSS)

This workshop discussed issues relating to the EHR from the perspective of non-government organisations (NGOs) that provide health services.

The EHR has the potential to improve the quality of information held in health records and to address current problems of discrimination in the health system caused by the recording of value-laden information. It should enable a better coordinated approach to health care, improve health outcomes for individual consumers and save the health system money through decreasing duplication.

With information recorded in a single accessible record, there should be improved outcomes for consumers being treated out of their local area and for people referred from rural and remote communities. The record may also allow for automated follow-up of treatment, for example in relation to medications and tests.

The workshop noted that if non-government organisations (NGOs) were included in the EHR, it would enhance equity in the health system and strengthen the recognition of NGOs as legitimate and key players in health service provision.

Some participants expressed a fundamental disagreement with the notion of the EHR and they were concerned that it would be imposed to the detriment of already marginalised groups in the community and the health system.

### **The EHR system**

The substantial costs of the EHR were discussed and whether the costs are justified by the anticipated benefits for health consumers. The implementation of the EHR will require resources, computers and education, and providers participating in the system will incur ongoing compliance costs. Some participants argued the EHR would impose additional work and time demands on health service providers, with marginal benefits for clients. It was raised that centralised and standard information may encourage the 'medicalisation' of non-medical aspects of health care.

The workshop queried the measures against which the performance of the EHR will be evaluated, particularly given the large cost and widespread impact that electronic records will have on the health system. Participants wanted further information regarding the evaluation process and how the evaluation outcomes would inform future administration of the system. There was some interest from NGOs in being involved in determining how the evaluation should be conducted.

Participants also raised questions about the provision of staff training related to the EHR and whether liability could attach to information recorded on an EHR.

### **Information recorded**

The workshop discussed how broadly 'health information' would be defined for the EHR. It was agreed there should be the potential to record information from all health service providers, including allied health professionals. Some participants argued that the agreed standards and criteria for determining the information included on an EHR should be defined in legislation rather than in guidelines or regulations.

Concerns were expressed at the potential infringement of a health consumer's privacy if second opinions were tracked on their EHR. Participants also raised concerns regarding damaging or inaccurate information which may be recorded on an EHR and later subpoenaed in legal proceedings.

From the perspective of the individual health consumer, questions of access to and security of information on an EHR must be clearly addressed. In particular the consumer should exercise a high degree of control over who has access to information about them.

### **Use of information**

There were very strong concerns raised regarding the use of aggregated or notionally 'de-identified' data, particularly regarding information about people from Aboriginal communities or from rural areas. Participants raised distressing examples of the use of information that had been considered de-identified but from which specific individuals could nonetheless be identified.

Representatives of Aboriginal organisations raised particular concerns regarding the use of 'de-identified' data in research. There were concerns that, under the proposed legislation, information about Aboriginal people on electronic and other health records could be used for research purposes without the consent or oversight of appropriate ethics committees. The standard for what may be considered 'de-identified information' also may not be appropriate for information about individuals from Aboriginal communities.

### **Concerns for NGOs**

Workshop participants questioned whether it is planned to include NGOs as participants in the EHR system, and discussed both the advantages and disadvantages of participating or remaining independent of it. The key question

was whether NGOs would be a source of information for electronic records, with the power to access and add to information to an EHR. If NGOs are anticipated to join the EHR system, would their participation be voluntary and would they be funded to participate? There may also be a potential conflict that would need to be addressed, especially for Aboriginal health NGOs, between the EHR system and current memoranda of understanding (MOUs) with NSW Health.

It was noted that the administration associated with the EHR would impose additional burdens on NGOs and affect the service delivery by organisations such as Women's Health Centres. Participants were concerned that there may be implications for its future funding if an organisation decided to remain independent of the EHR.

Conversely, the workshop recognised that there would be costs associated with a form of electronic integration with the mainstream health system, including the possibility of clients losing confidence in the confidentiality of the information they provided to an NGO service provider.

### **NGOs and implementation**

Some participants were concerned that little information had been disseminated to date regarding the EHR and it was agreed that this lack of information needed to be addressed. There were also concerns that NGOs had not yet been consulted in the development of plans for the implementation, administration and evaluation of the EHR. This was a strong concern for some NGOs from the areas where the planned pilot projects for the EHR would be taking place.

It was agreed that from this point on, there needed to be consultation both at the statewide level with peak organisations and at the local level across the state. Consultation should include both consumers and providers. In particular peak Aboriginal organisations must be involved in this process.

## **Workshop 7: Non-health NGOs**

Facilitated by Brenda Bailey, Council on the Aging (COTA)

This workshop considered the EHR from the perspective of NGOs that provide non-health services, including community care and other community sector organisations. Due to the nature of the services these NGOs provide, they have significant interest in issues relating to continuity of care with the mainstream health system, and in the handling of health information. Many organisations also provide advocacy services to individual clients.

### **Non-health NGOs and the EHR**

It was agreed that NSW Health must acknowledge and recognise in practical ways that non-health NGOs have a role to play in the implementation of the EHR. Importantly, the EHR should promote continuity between health and community care services, including providing scope for relevant non-health information to be added to records. Participants noted this will require the development of trust and respect between health and community services, which may require a cultural change within the health sector.

There were a number of outstanding questions relating to the interaction of non-health NGOs and the EHR. It was unclear to participants whether non-health NGOs will have any interaction with the EHR system and, if so, what the nature of that interaction will be. Participants questioned how health information will be defined and whether the definition will include information held by NGOs. Will non-health NGOs have the authority to access electronic records? Should they have such authority? If they are granted access, will they be able to add pertinent information to the record or will they have access only to view information?

### **Information recorded**

As noted above, the workshop agreed the EHR should include relevant non-health information. In the event that the EHR allows the recording of details of community services and care provided by non-health NGOs, the workshop agreed it could improve the relationship between the two sectors. At the same time some participants were concerned that, given the current relationship, if an EHR indicates the source of recorded non-health information, it may be discounted or accorded a lesser status by a staff in the health system.

To some degree the information that is relevant to health services, and therefore that should be recorded, will depend on the needs of the client. Some participants, however, felt that their services would not be appropriate for inclusion on electronic records, irrespective of client needs.

Consistent standards for language and terminology must be developed to ensure compatibility across the human service and information technology sectors. For

example, 'network' has a different meaning in each discipline. The system will require protocols for resolving inconsistencies in information recorded, such as the inclusion of conflicting diagnoses on the one record. Clear procedures will also be required detailing how, and under what circumstances, information on records can be amended.

### **Access and privacy**

The workshop agreed that information recorded on an EHR should be categorised into different levels, with access to information graded according to the information required by particular users. This would apply to all users of the system, including non-health NGOs with access to electronic records. Participants believed it was not appropriate for non-health NGO services to have access to all information on a record. They should have access only to information relevant to their service and that the client agrees should be accessed.

Protocols must be established to obtain the client's consent before accessing their record. This consent to access should also cover the nature of the information to which it applies. The record therefore must have the capacity to block access to other categories of information.

It was agreed the consumer's access to information held about them on an EHR may encourage improvements in communication between provider and consumer, through the process of clarifying and checking information as it is recorded.

The issue of sub-contracting of services was also raised, and the likely implications of a third party providing a service and accessing records.

### **Client support and complaints**

There were concerns that non-health NGOs may receive requests from clients of the health system for information, advice and support regarding the EHR and access to their health information. NGOs may also face demands to provide information and support regarding complaints processes under health privacy legislation and the EHR. These demands would place additional strain on the current limited resources of these organisations, and may require the allocation of specific resources to enable NGOs to perform an effective role in relation to the EHR. The workshop agreed that information services and systemic advocacy services should be funded to assist clients in their negotiation of the system.

Irrespective of how support services are provided, it should be determined where the responsibility lies for supporting health consumers wanting to make complaints and resources should be allocated to provide this support. Participants noted consumers should be permitted to lodge a verbal complaint about the handling of their record and other privacy issues and not be limited to making complaints in writing.

## **Information about the EHR**

The successful implementation of the EHR will require clear and accessible information in a range of formats to enable individuals and organisations to develop an understanding of the system. Consumers must be informed about issues relating to the EHR including its ownership, maintenance and security, as well as the consumer's right not to opt in to the record.

The communication strategy should provide:

- Plain English materials;
- Information in community languages;
- Information for people with little or no computer literacy;
- Frequently asked questions (FAQs) relevant to each service type; and
- Material appropriate for specific audiences, such as regional & Aboriginal and Torres Strait Islander populations.

It was stressed that communication about the EHR must be an ongoing process and not a one-off or short-term event. Information should be provided using a range of media and not restricted to publication on the Internet.

## **Implementation issues**

The implementation process should provide opportunities for consultation with, and dialogue among, several groups including health and HACC service providers, professional groups and consumers. Major decisions during the process will require consultation at State, regional and local levels, which in turn will require realistic timeframes to enable effective input to decision-making. NGOs should be represented on specific EHR committees.

It was stressed that the system should be subject to a process of ongoing review to ensure it is working as designed.

The workshop raised the question of how the EHR would relate to other government programs to develop the electronic referral of client information, such as the Better Service Delivery Program (BSDP).

## **Workshops 8 & 9: Consumers and their carers**

Facilitated by Stephen Gallagher, AIDS Council of NSW (ACON)

Facilitated by Tim Goodwin, Council of Social Service of NSW (NCOSS)

Two parallel workshops discussed the EHR from the perspective of individual consumers of health services and their carers.

It was recognised that electronic records would be less likely to be lost or tampered with than paper records, which would represent a benefit to consumers in the health system. Audit trails investigating how information had been accessed would be easier to conduct if required. Some participants argued that electronic records would be easier to secure than current paper-based record systems, and sensitive information protected with a higher degree of confidentiality. However some participants believed that no information held on a computer is ever completely secure.

One participant argued the EHR may save the health system money by providing a disincentive for 'doctor-shopping' when a range of providers are visible on one record. Other participants would be concerned if details of consumers' usage of health service providers, as recorded on their EHRs, were used in this way for management of the health system.

### **Concerns regarding consent**

It is essential that health consumers are able to effectively exercise their right of consent to participate in the EHR, and consent to grant a particular level of access to a record, in the full knowledge of what they are consenting to. This includes information about the EHR system, the nature of the access they would be granting to their record and the period of time for which their consent would remain in force. Participants questioned how long an indication of consent would remain valid and when consent may need to be revisited.

For consent to be free and informed, it would be important that the consumer not feel they are under pressure to participate in the EHR. There were concerns that a provider could require participation in the EHR as a condition of offering treatment, with the consumer 'free' to consent or choose to seek treatment elsewhere. Both the legislation and the rules governing the EHR should include a non-discrimination clause to prevent participation being used in this way.

The workshops raised concerns in relation to parents and children granting consent. Participants sought clarity about the age at which an individual would be considered competent to provide consent to participate in the EHR system or to allow access to their record. It was noted there are different measures of competence for different issues, including the age at which a young person is entitled to see a doctor without a parent or guardian present, the age of sexual consent and the age of legal majority. The age of competence to consent that is used in the administration

of the EHR will raise particular issues that need to be clarified, such as the rights of (and limits on) parental access to information held about their children.

It was also questioned what procedures would govern consent in the case of mental health consumers, and the likely implications for their carers.

### **Information recorded**

One workshop explored differing views about the information to be recorded on the EHR, and whether a consumer should be permitted to choose which information is recorded and which excluded. A small number of participants argued that the EHR should function on the principle of 'all information on or none on'. But the majority believed the consumer should nominate which pieces of information and which service providers are added to their record. The consumer should have the right to remove information from their record at a later date for reasons including a change in their personal circumstances. The other workshop considered whether the fact that information had been revoked would itself be included on a record, as well as the potential implications for ongoing clinical care of a consumer removing information.

It was noted that some consumers would *choose* to have as much of their health information as possible included on their EHR, so they and their health service providers would have access to all relevant health information in the one place.

The EHR should provide scope for the inclusion of information by allied health practitioners. Participants believed that relevant oral health information should also be included on the EHR. They were concerned that the current split between a consumer's 'health' and their oral/dental health not be perpetuated through the EHR.

The system needs to clarify that speculation should not be recorded on an EHR, but only confirmed diagnoses.

### **Access to records**

Different degrees of sensitivity attach to different types of health information. The EHR should therefore provide for levels of authorised access, ranging from consent to access general or less sensitive information, to restricted access to highly sensitive information. It could also provide forms of one-off access to a record on a particular occasion. It was agreed that the existence of restricted information should only be known to those people authorised to view it and other users of a record should not even be aware that something has been blocked.

In addition to recording who has had access to an electronic record, the system should record whether any information was printed off. Participants noted that printed information would not be protected by the same security measures in place to protect electronic data on the EHR.

Both workshops agreed that consumers obtaining access to sensitive or potentially harmful information on their EHR may require support or supervision. They may require assistance interpreting terminology or the information may be distressing, especially when it relates to psychiatric health or drug and alcohol issues.

It was questioned whether consumers should have access to information on a family member's record, for the purposes of diagnosing or predicting inherited or genetic conditions.

One workshop queried the security of consumer access to the EHR system if access is controlled by a system of PIN numbers. There is the potential for other parties, such as ex-spouses, to misuse a PIN number to access an individual's record.

### **Information about the EHR**

The implementation of the EHR will require a public awareness campaign to inform both consumers and health service providers about the system. The campaign should set out the individual benefits of the EHR, the security guarantees of the EHR system and, importantly, how it differs from the current system of record-keeping. Information should be written in plain language, that is, free of information technology and medical jargon. One workshop agreed consumers must be provided with information setting out:

- What information is to go on the EHR?
- Who will have access to it?
- What good will it do me to participate?

Information should be provided in different formats and appropriate for different groups of people, such as older people or people in regional and rural areas. Information should be translated into community languages. It was stressed that there is a particular need for material appropriate to people who do not understand information technology or the Internet.

Consumers should be informed about whether they could withdraw from participation in the EHR at a later date, and whether information could be deleted from their record in the event of a change of mind or circumstances. Consumers should be informed who owns the data held on their EHR.

One workshop agreed that the consumer education strategy should be based on providing information about the EHR for consumers to consider in their own time, rather than expecting them to absorb information and make a decision when they have an immediate need for health services. It was suggested that information could be made available through outlets such as Post Offices. A parallel was drawn with information about organ donation, where people are encouraged to thoroughly

consider the issues, discuss it with carers and others if they need to, and seek further information before making a decision.

### **Complaints processes**

Effective complaints processes will be required to build consumers' confidence in the EHR. This requires a simple process, which is easy to use and as brief as possible. Consumers should be empowered to use avenues for complaint when appropriate, and informed where and how to lodge complaints.

### **Electronic records and research**

One consumer workshop discussed concerns relating to the use of information when research and clinical care are conducted together. Apart from disclosure of any potential conflict of interest, there must be full disclosure when information being entered on a consumer's EHR is likely to be used for other purposes such as a research study. The consumer should be informed which parts of their record a clinician or research team would access and for what purposes.

The consent to the collection and use of their health information should be clearly separate from their consent to participate in a research study, or their consent to a particular course of treatment.

### **Consumer involvement**

There was some degree of scepticism as to the effectiveness of consumer participation in the EHR project. Participants questioned whether the major decisions had in fact already been taken. Decisions may also be effectively circumscribed by constraints that consumer input has little likelihood of influencing, such as international standards, cost, or technological limitations imposing particular options on the structure of the EHR's computer system.

Despite the scepticism, it was agreed that consumer participation is an essential element in the development and implementation of the EHR. More consumer representatives should be appointed to working groups. It should be recognised that, despite having limited time and resources available to them, consumers sit on these groups as part of the decision-making process and not simply as observers.

The implementation of the EHR should provide regular opportunities to bring consumer input together and feed it into the decision-making process. There should be a process of consultations (similar to this Forum) with individuals and organisations, including holding events in regional areas.

## 8. NCOSS Briefing on the Health Records and Information Privacy Bill 2002

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### Council of Social Service of NSW (NCOSS) Comments on NSW *Health Records and Information Privacy Bill 2002*

NCOSS welcomes the *Health Records and Information Privacy Bill* ('HRIP Bill') as an opportunity to implement a single, consistent set of health privacy principles that apply to both public and private sector health service providers.

NCOSS is concerned that privacy frameworks must effectively protect the privacy of health consumers and also support a system which effectively promotes continuity of care, especially between hospitals and the community. Our key concerns relate to the position of disadvantaged health consumers, including people with chronic illness or complex needs, and multiple service users. Disadvantaged groups such as people with mental illness, people with disabilities, younger people and people from Aboriginal and Torres Strait Islander backgrounds face major barriers to health services and often suffer from poorer health status than the general community.

We are pleased that the HRIP Bill regulates the collection, use and disclosure of health information and defines the rights of health consumers to have access to, and request amendments to, health information held about them. NCOSS also welcomes Health Privacy Principle 15, which proscribes the inclusion of a person's health information in linked electronic health records without the express consent of the individual concerned.<sup>1</sup>

### Health records and information privacy

NCOSS held a *Forum on the Electronic Health Record and new health privacy laws* on 2 May 2002, bringing together more than 100 health consumers, health NGOs and non-health NGOs from across NSW. The Forum, held with the support of NSW Health, discussed the exposure draft of the legislation and its implications for health privacy and health records, and provided input to the Department regarding the draft Bill.

Participants in the Forum outlined the benefits they expected from the new legislation, including:

- Encouraging the use of respectful language in records;
- Enhanced access by the consumer to their health records;
- Improved protection of health information; and
- Audit trails recording access, use and disclosure of health information

In this regard, many health consumers saw the new legislation and its implementation as a chance to address the deficiencies in the current system of health privacy.

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<sup>1</sup> HRIP Bill, Schedule 1 Health Privacy Principles, Clause 15 *Linkage of health records*.

## Access to health records

NCOSS welcomes the provision in the HRIP Bill for an individual to have access to health information held about them, including receiving "an accurate summary" of information collected before the commencement of the legislation.<sup>2</sup> There have been strong calls from consumers for full access to records created before the legislation commences. *NCOSS therefore views the present access provisions as an absolute minimum, and would strongly oppose any attempt to weaken this requirement.*

Participants in the NCOSS Forum noted that consumers will require assistance with accessing records, including the provision of an available computer, assistance with technical jargon and appropriate support for people where required (access to information on mental health, trauma, etc.) Participants repeatedly raised concerns that access not be based solely on access to or skills in using information technology, and that there needs to be additional means of seeing one's record.

NCOSS is pleased that the HRIP Bill allows an individual to request that access to their health information be provided in a particular form.<sup>3</sup>

## Unauthorised access to health information

The HRIP Bill contains sanctions for corrupt disclosure, use or supply of health information<sup>4</sup> but has no sanctions for unauthorised access to information.

NCOSS notes several NSW and Commonwealth Acts prohibit access without lawful authority to certain categories of information. These include the NSW *Crimes Act 1900*, the NSW *Road Transport (General) Act 1999*, the NSW *Births, Deaths and Marriages Registration Act 1995*, the Cth *Taxation Administration Act 1953*, the Cth *New Tax System (Family Assistance) (Administration) Act 1999*, the Cth *Privacy Act 1988* (relating to credit reports), the *Child Care Payments Act 1997* and the *Social Security (Administration) Act 1999*. We can provide these provisions in NSW and Commonwealth legislation upon request.

**Amendment:** *NCOSS recommends that the Bill be amended to prohibit unauthorised access to health information and include penalties for obtaining such access. A proposed amendment is included below.* The proposed penalty for unauthorised access is identical to those for Clause 68 (Corrupt disclosure or use of health information by public sector officials) and Clause 69 (Offering to supply health information that has been disclosed unlawfully) in the HRIP Bill.

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<sup>2</sup> HRIP Bill, Clause 28 (4).

<sup>3</sup> HRIP Bill, Clause 28.

<sup>4</sup> HRIP Bill, Clauses 68 & 69.

## **Proposed amendment**

### **Part 8 Miscellaneous Clause 69A**

#### **Unauthorised access to health information**

(1) A person must not obtain access to health information held by a health service provider unless the access is authorised by this Act.

Maximum penalty: 100 penalty units or imprisonment for 2 years or both.

(2) For the purposes of an offence under this Clause, a person causes any such unauthorised access if the person's conduct substantially contributes to the unauthorised access.

Maximum penalty: 100 penalty units or imprisonment for 2 years or both.

#### **Auditing breaches of privacy**

NCOSS is concerned that the complaints-based regime in the HRIP Bill is inadequate to ensure compliance with the provisions of the HRIP and to provide remedies against breaches of the legislation. The regime established by the Bill requires an individual health consumer to *know* that their privacy has been breached and to lodge a complaint that such a breach has occurred.

NCOSS is particularly concerned that many disadvantaged people will not be in a position to complain due to factors such as language, mental illness, cultural issues, and their knowledge of and confidence in using the complaints system. Participants in the NCOSS Forum believed that an audit or oversight process should be embedded in the legislation.

While NCOSS is disappointed that an audit process has not been established in the HRIP Bill, it is pleased that the Bill provides for a regulation to be made for "the auditing of compliance by organisations with the provisions of this Act, including the types of activities or conduct that may be subject to audit, the persons or bodies by whom an audit may be conducted and the frequency or timing of audits".<sup>5</sup>

*NCOSS recommends that the Government provide a formal undertaking to establish mechanisms auditing compliance with the HRIP Bill no more than six months from passage of the legislation. We stress that the development of regulations would require full consumer and community participation.*

#### **Electronic health records as a condition of treatment**

Health consumers attending the NCOSS Forum raised concerns that some health service providers could require participation in the electronic health record (EHR) as a precondition for the provision of treatment. NCOSS is concerned that the HRIP Bill does not forbid discrimination on the grounds that a person has not consented to participate in a system of linked health records.

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<sup>5</sup> HRIP Bill, Clause 75 (2) (f).

This provision is required to guarantee a consumer can effectively exercise their right to grant or withhold consent to have their information linked (as specified in Health Privacy Principle 15). In its current form, the Bill prohibits a person from using threats or intimidation to obtain consent to a linked health record, but this may not cover all instances where granting consent to a linked record (or having granted consent in the past) is a stated condition before treatment will be provided. It is particularly necessary for disadvantaged health consumers and consumers in areas where there are fewer providers. In many rural areas, there are significant power imbalances created between health service consumers and providers as a result of the limited opportunities for treatment and the distances between providers.

A similar provision regarding conditions on treatment exists in s.71 of the *NSW Health Services Act 1997*, which reads: "A person without means must not be refused care or treatment for sickness or injury at any public hospital by reason only of the person's inability to pay for the care or treatment."

***Amendment:*** *NCOSS recommends that the legislation make it unlawful to refuse treatment on the grounds that a person has not consented to participate in linked health records.*

### **Proposed amendment**

#### **Schedule 1: Health Privacy Principles 15 Linkage of health records**

##### **Clause 2A**

An organisation must not refuse to provide health care to an individual by reason only that the individual has not consented to have health information about himself or herself included in a health records linkage system.

### **Health privacy legislation and the community sector**

NGOs that provide health services or handle health information are subject to an increasingly complex range of privacy standards through State and Commonwealth legislation. While there is a broad level of consistency between the *Commonwealth Privacy Act 1988* and the *HRIP Bill*, the majority of NGOs have limited capacity to ensure they are compliant with relevant health privacy legislation.

NCOSS has proposed to NSW Health that it fund a small project to develop privacy management tools for use by community sector organisations. Community sector health organisations generally deal more often with members of disadvantaged groups. Such a project would significantly improve the position of disadvantaged individuals in terms of the health services they receive from community organisations and the support they require to negotiate their health privacy rights in relation to other providers.

*NCOSS recommends that such a project be funded in conjunction with the EHR initiative.*

NCOSS also notes the HRIP Bill sets out the functions of the Privacy Commissioner under the Bill, including to promote the adoption of and compliance with the Act, to prepare guidelines under the act and "to provide assistance to organisations in adopting and complying with the Health Privacy Principles".<sup>6</sup>

*NCOSS recommends that the Privacy Commissioner devote adequate funding and other resources to assist the community sector to adopt the required privacy management practices, including development of compliance tools, training and information appropriate to the sector. If this requires additional resources, we seek a commitment from the Government that it provide those resources as part of the implementation of the legislation.*

## **Participation in implementation of HRIP**

Participants in NCOSS forums relating to health privacy have consistently called for consumer and community participation in all stages in the implementation of health privacy legislation and a system of linked Electronic Health Records. NCOSS would be gravely concerned if the legislation and its provision for the EHR were implemented without consumer and community participation.

NSW Health must ensure full and appropriate involvement of consumer and community representatives in processes to implement the HRIP Bill in both the public and private sectors. Consumer and community participation should also be a key component in development of regulations addressing fees for providing access to records and audit mechanisms for compliance.

*NCOSS recommends, at a minimum, that NSW Health establish regular stakeholder forums for reporting on progress and seeking input on ongoing implementation of new initiatives.* It is not sufficient for such a significant system-wide change in practice to rely solely on local-level participation structures as part of regionally-based pilots.

## **About NCOSS**

NCOSS is the peak body for social and community services in NSW. NCOSS works with its members on behalf of disadvantaged people and communities towards achieving social justice in NSW.

The NCOSS Health Policy Project is funded by NSW Health to promote community participation, advocate for disadvantaged communities and assist non-government organisations (NGOs) to play a more active role in health care delivery.

An NCOSS Senior Policy Officer is the Consumer Representative on the NSW Department of Health Privacy of Information Steering Committee.

For further information, contact Tim Goodwin, Senior Policy Officer, NCOSS on (02) 9211 2599 ext 116, or email <tim@ncoss.org.au>.

June 2002

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<sup>6</sup> HRIP Bill, Clause 58, paragraphs (a), (b) and (c).