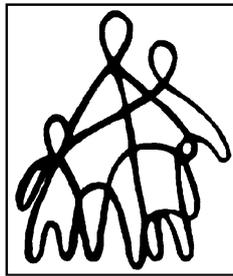


**SUBMISSION TO THE
NSW DEPARTMENT OF HEALTH - 'REPORT TO THE NSW MINISTER FOR HEALTH:
PANACEA OR PLACEBO?, LINKED ELECTRONIC
HEALTH RECORDS (EHR)
AND IMPROVEMENTS IN HEALTH OUTCOMES'**



NCOSS

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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 (NGO) to play a more active role in health care delivery.

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

Background

Earlier proposals to introduce an Electronic Health Record (EHR) include the Australian Health Information Agreement 1997. The NSW Health Information Management Technology and Telecommunications Strategy is currently under review and sets out a statewide strategy to develop an EHR for every individual in NSW, while at the same time supporting improved service delivery and health outcomes. Public discussion regarding the introduction of an EHR has to date been very limited. Since the introduction of these documents, there have been few discussions about the ethics and cost effectiveness of technology within NSW Health. As yet, NSW Health has not involved a broad range of community interests in discussion.

NCOSS held a forum on the 12th March 2001, to consider the development of a networked, Electronic Health Record (EHR) system within NSW Health. This submission is based on discussions that were held at this forum. 24 forum participants included organisations such as the NSW Association for Mental Health, The Spastic Centre of NSW, University of NSW Centre for General Practice Integration Studies, Wollongong Crisis Centre (Detoxification and Rehabilitation), Sisters of Charity Outreach, Medical Consumers Association Inc., Royal Blind Society, the Hepatitis C Council of NSW and the Thalassaemia Centre of NSW. The groups who attended the forum appreciated the presentation by Peter Williams and the opportunity to gain more information about the EHR and engage in worthy discussion.

Given the speed with which NSW Health intends to implement the EHR system, the changes in the way that health information is managed will require:

- Real consultation;
- Failure-avoidance strategies that create community confidence;
- Effective protection of privacy, especially for vulnerable people;

- Effective continuity of care; and
- Inclusion of all related service providers.

NCOSS is concerned that NGOs have been excluded from the EHR implementation process within NSW Health. Many NGO's provide a range of human services within the one organisation that relate directly to individual and population health status.

Recommendations

1. NSW Health proceed with the development of a system of linked electronic health records across the state which protects personal privacy and maximises public health outcomes.

NCOSS supports the development of a linked EHR across the state however, there is a need for effective community participation in its development.

Personal privacy

NCOSS strongly urges that NSW Health ensure personal privacy is protected for consumers, especially for those who are vulnerable, such as people with mental illness who are subject to the Mental Health Act, people with disabilities, people of non English speaking background and indigenous communities who have a limited understanding of English, people who are in acute crisis and are unable to provide consent and people who are intoxicated with substances.

Strategies that ensure community confidence regarding personal privacy protection include, further consultation about what will appear on the health record. Discussion should include; how the EHR will work, how will consumers know what is being included in the EHR, how will consumers be able to put a block on information, will there be indicators that information has been suppressed?

On page 24 of the NSW Health Council Report, it states that the introduction of an EHR should be 'subject to informed community debate'. Prior to this report very few people in the community were aware of government intentions to link the EHR. NCOSS believes that there needs to be an examination of what is wide community consultation in the minds of decision-makers before plans to proceed with a linked EHR go ahead.

Maximises public health outcomes

NCOSS strongly believes that public health outcomes will be maximised when there is an improvement in continuity of care and quality of care for consumers. EHR also needs to be based on principles of consumer control of their health information. This needs to be based on an 'opt-in' not 'opt-out' basis.

It is also important to take this opportunity to improve consumer access to their health record. At present, legal issues of ownership are impeding consumers to basic information about their health and treatment.

2. The system be based on the following principles -

2(a). Measurable benefit of individual health consumers and improvement of public health outcomes as a primary goal.

NCOSS strongly supports that the EHR provide measurable benefit to individual health and improvement of public health outcomes as primary goals and not as side benefits.

Measurable benefit to individual health

NCOSS strongly urges that NSW Health measure the benefit to individual health accurately and comprehensively by creating an option for consumers to view their EHRs in multi-lingual format, in at least the fifteen most commonly spoken languages in NSW.

NCOSS supports the provision of clear rationales and guidelines regarding the collection of measurable consumer health data and the benefits to consumers.

NCOSS strongly urges that consumers of health services have practical opportunities to access their EHR. This could include access points in community health services, hospitals and other health services.

NCOSS strongly supports that EHRs be accessible to all consumers, especially for people who access Non Government, community services. Under current proposals, the health benefits measured by an EHR will represent only a proportion of the population. NCOSS believes that closer community links between the Non Government community sector and NSW Health will maximise improvements in public health outcomes.

Improvement of public health outcomes

NCOSS is concerned that community care, in the discussion of continuity of care between hospital and home, has been left out of the EHR implementation process.

NCOSS is aware that the inclusion of NGO's in the EHR system will increase costs to NSW Health however, understands that ultimately, public money that is directed to only a proportion of the population may not justify an expensive information technology roll-out. The implementation of an EHR should include all community sectors if it is to be implemented at all.

NCOSS strongly supports that NSW Health provide estimates of total costs associated with the introduction of an EHR system, as well as cost benefit analyses of the opportunity costs.

2(b). Protection for the privacy of individuals and communities

NCOSS has fundamental concerns about EHRs being available to a wide range of public and private service providers, and particularly that::

- The EHR may also be used for other purposes such as the investigation of individual consumers by law enforcement agencies, health and life insurance companies, banks, employers and businesses.
- The speed with which the implementation of the EHR has occurred. This appears to have decreased community confidence in NSW Health and the community's perception of privacy protection.

NCOSS strongly urges that legislation about privacy and security issues are rigorously enforced by correct legal processes.

NCOSS strongly recommends that NSW Health demonstrate transparency regarding the introduction of an EHR.

2 (c). Consumers have the right to ensure that particular information on any health record is excluded from automatic transfer to other authorised recipients of such information except with the consumer's express consent.

NCOSS agrees that consumers must give consent to the transfer of information between authorised recipients, as well as what information will be transferred.

There are fears amongst some consumers that an EHR is the beginning of an equivalent "Australia Card".

2 (d). Physical security and integrity

NCOSS is concerned that a top-down, centralised model of information technology will potentially allow for the corruption of local EHR systems. This is a major concern for the community.

NCOSS recommends that information technology consultants are readily available to continually monitor the EHR system across the health system and are accountable to the Privacy Commissioner and the Health Care Complaints Commission.

NCOSS strongly urges that NSW Health specify quality control frameworks within the privacy legislation and an incident response plan, in the event of security integrity breakdown.

2 (e). Data is complete, accurate and up to date

NCOSS strongly supports that the data in the system be as complete, accurate and up to date as can be achieved.

NCOSS suggests the following strategies:

- A revision of current data collection methods within NSW Health services (Occasion of service system).
- An explanation of who receives what services and from whom, at what cost and with what effect.
- NSW Health scrutinise health service providers at a level that has never been experienced before, for purposes of ensuring that accuracy and completeness are maintained.
- Specifications about what should be measured, how data should be measured, how routine outcome assessment should be integrated into standard clinical care.
- NSW Health design outcome measurement tools that are objective, responsive to inter-rater reliability, validity, sensitivity, repeatability and confounding factors.

2 (f). Transparent audit trails

NCOSS strongly supports the recommendation to provide transparent audit trails.

NCOSS is concerned that 'people in white coats' have ready and unchallenged access to health records at present. Audit trails are a positive aspect of a shift to EHR.

3. Governed by state legislation - Health Records and Information Privacy Act

NCOSS strongly urges that legislation relating to public health service providers also encompasses private health service providers equally.

NCOSS strongly supports health specific privacy legislation. NCOSS strongly recommends that this legislation cover health information and not just targetting health services to ensure effective coverage of continuity of care.

NCOSS is concerned that the Commonwealth and state governments do not currently have a consistent framework regarding a networked system.

NCOSS strongly supports that NSW Health provide clear strategies regarding how collaboration between the Commonwealth and State governments will operate in practice and how the NSW and Commonwealth EHR initiatives will co-exist. Also, while NCOSS appreciates that the NSW Health Information Management Implementation Coordination Management Group is responsible for implementing these reforms, there are concerns that the Privacy Act is not adequately detailed or comprehensive.

4. That the Health Records and Information Privacy Act -

4 (a). Apply to all health records in the public and private system

NCOSS strongly supports the incorporation of public and private systems of health care within the Health Records and Information Privacy Act, as well as NGO's.

NCOSS strongly supports the need for health information to ensure that continuity of care for consumers is maintained across all related settings and that consumers are not lost in the human services system.

4 (b). Purposes for which health records may be linked and transferred

NCOSS strongly recommends that further community consultation be conducted.

Some key concerns include:

- There has been minimal community consultation regarding the EHR.
- Individual consent processes are currently unclear about the type of information made available to whom and the transfer of what type of information between which provider.
- Some people who are vulnerable, such as people with mental illness, people from culturally and linguistically diverse backgrounds, people with disabilities and people from indigenous communities are unable to provide informed consent.
- Current legislation appears to be vague regarding third parties who can access health records without the knowledge of the subject.

NCOSS recommends that NSW Health provide a detailed outline of how linking and transferring of information will occur and create opportunities for community debate about this proposal.

NCOSS strongly urges that NSW Health considers vulnerable groups in the design and accessibility of the EHR, by providing paper-based informed consent procedures and multi-lingual / translated information.

NCOSS strongly supports consumers decision-making about who has access to their health record.

NCOSS recommends that the mechanisms for review and proper enforcement are directly applicable to transfers which occur without specific legislative authority.

4 (c). Incorporate the Information Protection Principles (Part 2 of the Privacy and Personal Information Protection Act 1998)

NCOSS supports this recommendation.

4 (d). Protocols and mechanisms for EMR transfers between parties

NCOSS strongly recommends that the Health Records and Information Privacy Act must clearly state who an 'authorised party' is regarding who will receive transferred information.

NCOSS strongly supports consumer choice regarding who transfers information, when, what information and to whom.

4 (e). Provide for the inspection, access, copy annotation and correction of any health record by subjects of such health records, except where exceptional circumstances apply.

NCOSS agrees that the Act should provide for the inspection, access, copy annotation and correction of any health record by subjects of such health records and the opportunity and the resources to do so.

However, the Act does not specify when "exceptional circumstances" apply. There is great potential to disenfranchise vulnerable people with unclear guidelines such as these.

There are some concerns that on occasions, members of the 'treatment team' will be able to access health records without the consent of the subject. The definition of who is a part of the treatment team is unspecified and could potentially be open to abuse.

NCOSS strongly suggests that further community consultation be conducted regarding the definition of "exceptional circumstances" as well as discussion about a list of who is a member of the 'treatment team'.

4 (f). Privacy Commissioner of NSW has the power to

- **Investigate and determine complaints**
- **Initiate investigations, enquiries and audits under the Act**
- **Report and recommend to the Minister and Parliament about the Act**

NCOSS supports the undertaking of these tasks however, believes that the jurisdiction between the Privacy Commissioner and the Health Care Complaints Commission needs to be resolved.

4 (g). Mechanisms for complaints related to breaches of privacy

NCOSS agrees that mechanisms for complaints related to breaches of privacy should be detailed, clear, in plain English and available in various community languages and recommends the Health Care Complaints Commission as an example model.

4 (h). Civil and criminal penalties for breaches of the Act

NCOSS strongly urges robust penalties for people who are in breach of the Act.

4 (i). Incorporate existing privacy and confidentiality requirements present in existing health related statutes in NSW

NCOSS strongly supports that the EHR improve consumer access and control over their health records. The new legislation should take opportunities to improve consumer access and control and at a minimum provide no lesser provision regarding privacy and confidentiality as exists at present.

4 (j). Recognise problems related to the capacity of children to withhold information from their parent/guardian

NCOSS strongly recommends a clear framework be developed to ensure that young people have confidential access to health services. It is a danger to the health of young people to do otherwise and creates particular risks for disadvantaged young people, such as homeless youths, those taking illicit drugs and those experiencing abuse.

5. Relevant agencies be resourced for the discharge of responsibilities under the Act.

NCOSS recommends that adequate resources are provided to undertake the role of administering the Act.

6. Community consultation in the development of the Act

NCOSS is concerned that the decision to proceed with an EHR system has occurred with minimal public scrutiny and consultation. It appears that consultation is based on the legislation regarding privacy and security issues and not on the principles of the legislation. The legislation will be introduced to parliament without the community having had the opportunity to comment on its entirety.

Suggested strategies for further community consultation include:

- Community meetings with people from rural and remote NSW, young people, people from culturally and linguistically diverse backgrounds, indigenous communities and vulnerable people such as those who have a mental illness and disability and members of the general community.
- Provide bilingual information for people from culturally and linguistically diverse backgrounds and indigenous communities, to ensure correct understanding and consent.

7. Education campaign for the general public and health providers

NCOSS supports education campaigns for the general public and health providers.

Training for the general public should include:

- the risks and benefits of an EHR system;
- available resources for consumer use; and
- wide accessibility of technology for vulnerable groups especially.

Health providers:

- correct use of a computer;
- correct use of an EHR;
- the proper collection and use of data and the understanding that data can not on its own be used as a measure of performance.

8. These campaigns to be monitored and evaluated by the Privacy Commissioner

NCOSS recommends that it is valuable to have external oversight regarding the monitoring and evaluation of the campaign.

9. Opportunity to improve the quality of health records generally, ie: data standards, accuracy, uniformity of nomenclature, standardisation of recording/reporting

NCOSS believes it is important to improve the quality of health records generally and not just to transfer unsatisfactory practices to another medium.

NCOSS also recommends an evolutionary, bottom-up approach to the implementation of the EHR and to improve the quality of health records generally. While a bottom-up approach to the EHR is more costly, it will ensure that data are less open to error by health providers as well as cost savings in the longer term.

10. Unique Personal Identifiers

- **UPI - highest integrity**
- **Generated by the DOH or AHSs**
- **UPI should not be linked to Medicare numbers**

NCOSS stresses the importance of not linking the UPI to individual Medicare cards. The compulsory presentation of a Medicare card for prescription medication (MedicineConnect Scheme) may in fact pose a problem for consumers who wish to opt-out of an EHR system.

11. Those accessing health services on an anonymous basis should not be penalised

NCOSS strongly supports this recommendation.

NCOSS is concerned about vulnerable people avoiding services because of a perception of a breach of privacy. This can be a significant issue even when privacy has absolute protection. It is imperative to ensure that vulnerable people have ready anonymous access to health services.

NCOSS is concerned that issues of funding will remove the anonymous access to services and the requirement to produce a Medicare card for pharmacy medication is a backdoor route to compulsory use of the EHR system, despite assurances by NSW Health that individuals voluntarily agree to participate in the EHR.

12. That the EHR not be accessible for data matching/mining, outside the NSW health care system

NCOSS strongly supports this recommendation as essential for the maintenance of community confidence in the EHR system.

13. Research projects seeking access to EHRs be dealt with under Section 95 and 95A of the Privacy Act 1998

NCOSS considers that all research conducted for the purpose of early intervention and detection is consented to by individual consumers first.

14. NSW Health publish a timetable consistent with the recommendations of the Health Council Report

NCOSS agrees that the EHR needs a timetable which is publicly available.

NCOSS strongly recommends that community consultation be built into the ongoing development of an EHR system satisfactorily, to identify issues as they emerge.

NCOSS believes that the EHR needs to develop greater community acceptance.

15. Recommendations of the Health Council Report be followed. One pilot project should be based in an AHS in remote NSW

NCOSS strongly supports this recommendation and the need for careful investing of remote area issues.