



# **Electronic Health Records – consumer issues and perspectives**

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# CHF membership based

~100 voting member organisations  
representing more than 860,000 people

**Population** - older people, women,  
culturally diverse groups

**Illness, self-help** - diabetes, asthma,  
arthritis, HIV/AIDS

**Health interest** - State, community  
groups



- Provide leadership and a national voice for health consumers, which balances the views of government, industry, service providers and health professionals.



# Consumers and E-health Project 2000-2001

Consumer workshops in each state and territory. The major areas covered were:

- the BMMS (*MediConnect*) and *HealthConnect*;
- the implications of computers in general practice; and
- information needs to make informed decisions about participating.



# Key consumer issues

## Objectives

- Improve health outcomes by empowering consumers.
- Improve access to services, encourage participation and reduce disadvantage.

CHF (2001). *Consumers and E-health Project Principles*.



## **Information and Participation**

- Consumers to be informed and consulted – potential uses of information eg secondary use.
- Decision to participate voluntary, free from coercion and full informed – decision with the individual to ‘opt-in’.

CHF (2001). *Consumers and E-health Project Principles*.



## **Consumers' control over their own information**

- Access to own personal information – able to make contributions to the record.
- Decide who can access personal health information – ability to deny access.

CHF (2001). *Consumers and E-health Project Principles*



## **Operation and oversight**

- Information held and transferred securely.
- Mechanisms to protect privacy - audit and monitoring to protect privacy breaches
- Independent complaints system and strong penalties for misuse of information – consider adverse consequences.
- Governance will be transparent and accountable – consumers included in structures.

CHF (2001). *Consumers and E-health Project Principles*.



# Electronic Health Records Project 2004-2005

- Project page on CHF website – [www.chf.org.au](http://www.chf.org.au)
- E-health resource group – creation of automatic email list
- Consumer Representatives Workshop – best practice principles
- Project information papers and questionnaire
- Member information sessions



# Benefits of electronic health records

- Improved safety - better access to health information
- Access to vital medical data in an emergency
- Assistance to consumers who may have difficulty recalling relevant health information
- Current medication records an early focus
- Medical histories will not have to be repeated with every visit to a medical practitioner



- The record would be available across the country
- Will be useful for people with chronic conditions or with high usage of the health system
- Improved dissemination of information to consumers
- Timely access to health information – this will benefit people in rural and remote areas



## **Electronic health records for health consumers**

- What do consumers want in their record?
- How will consumers use their record?
  - sensitive information
  - classes and/or specified practitioners
  - access and add information
- A voluntary decision to participate



## **Communicating to a range of audiences**

- What strategies will be used to inform the community about electronic health records? Let's ensure consumers are involved.



## **The compliance framework**

- Protecting personal health information – monitoring use; where to go if something goes wrong
  - For the electronic health record
  - For records kept by your health service
- An audit trail with strong penalties that ‘hurt’
- Clarity for all participants, including consumers, on privacy arrangements.



- How will policies and protocols around the use of information for secondary (eg research) uses work for consumers?
- Well communicated what the guidelines will be.



## **Areas for further research**

- Delivering benefits to all health consumers.
- The use and application of a unique identifying number
- Information to ensure informed consent



# Case examples

## **Concern of discrimination from disclosure of information**

- Person with MS – is concerned wider knowledge of condition will affect job and further advancement within this job, and cause discrimination in the workplace.



## **Right to control information disclosure**

- Treatment at a public cancer care centre – psychological consultation services used.
- Entire clinical record of psychological consultations disclosed to all of the team at the centre and others outside (eg GPs, dieticians, physiotherapists, radiation therapists) without knowledge or consent.
- Not informed this was routine practice or that sensitive information would be made available to all in the care team.



- Case went to NSW Administrative Decisions Tribunal – found the health service stop collecting health information without informing the purpose it is being collected for and intended recipients.
- Non-alignment between a doctor and patient on what information each considers necessary to be disclosed or can benefit or harm - acknowledge the privacy concerns health consumers have about information they regard as particularly sensitive.
- Breast Cancer Action Group NSW has taken on issue – provide written information



Need to get all these right for the system to work and for consumers to feel confident in the system and have ownership of their health record.

The outcome should be an improved and better health system for consumers!