

Electronic Health Records - a consumer advocate's perspective

NSW Council of Social Services (NCOSS) and the
Consumers' Health Forum of Australia (CHF)

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Presentation topics

- Prevalence of discrimination in health service provision
- Forms of HIV related discrimination
- Where instances of discrimination occur
- Areas of concern for People Living with HIV/AIDS
- Questions for consideration

Discrimination in Health Service Provision – HIV Futures 3, Survey 2002

- 898 people living with HIV/AIDS (PLWHA) completed survey –largest of its type internationally
- On going study conducted every 2 years
- Conducted by the Australian Research Centre in Sex, Health and Society, La Trobe University in collaboration with National Association of PLWHA, Australian Federation of AIDS Organisations, the Haemophilia Foundation of Australia and their respective state based affiliates

Discrimination in Health Service Provision – HIV Futures 3, Survey 2002

- 37.7% have ever experienced less favourable treatment because of HIV in relation to health services
- 18% experienced health care service discrimination in last 2 years
- 18.4% experienced unwanted/unnecessary disclosure of their health status by health care workers

Forms of HIV related discrimination experienced at medical services

- Confidentiality problems 38.1%
- Avoidance 37.1%
- Being treated last 27.6%
- Additional infection control measures 26.9%
- Refusal of treatment 24.4%
- Being rushed through 24%
- Harassment 11.9%
- Abuse 7.5%

Where instances of discrimination occur

- The majority of instances of discrimination occurred in non-HIV 'specialist' settings
- Two fifths of respondents indicated that they had experienced AIDS related illness
- Two fifths also indicated that they had a major health concern other than HIV/AIDS

Where instances of discrimination occur

- The most common conditions other than HIV were hepatitis C, cardiovascular disease, asthma and hepatitis B

Where instances of discrimination occur

- All respondents highlighted invasive questioning most notably about mode of HIV acquisition which bears no relation to diagnostic need or service provided

Where instances of discrimination occur

- Indicates a need for professional development in relation to HIV/AIDS throughout the health sector !!!!!

Areas of concern for some People Living with HIV/AIDS

- Previous history of illicit drug use and treatment
- Previous criminal record leading to imprisonment
- Previous/current history of mental illness

Areas of concern for some People Living with HIV/AIDS

- Some PLWHA choose not to tell their GP about HIV status when seeking care for non-HIV related medical care for a range of personal reasons

Questions for consideration

- What level of control does the consumer reasonably have the right to expect in relation to health privacy?
- What controls does the consumer have over the 'views' available to the health care provider?
- What level of control does the consumer have over the longevity of health records?
- How does a consumer determine what health care professionals 'need to know' in order to provide appropriate service?

Questions for consideration

- How will consumer education occur?
- Who will ultimately be responsible for providing accurate information about consumer rights?
- What rights do consumers have in refusing to provide blocked 'views' from providers
- How will provider training incorporate 'intrusive' and extraneous questioning?
- How will the quality of service be affected by those who do not participate?
- How do we prevent coercion from occurring?

Conclusion

Questions for consumer organisations

- How do we engage people who may have legitimate concerns about privacy who would benefit from *HealthConnect*?
- How do we provide adequate information to enable consumers to overcome their fears, and to empower them to determine information that may be withheld without deleteriously affecting their health?
- How do we ensure that information obscured from 'views' doesn't affect quality of health service interaction?