

# Patients rarely detect breaches of confidence

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## Abstract

### *Objective:*

*To measure the prevalence of patient reported breaches of confidence emanating from health services in South Australia.*

### *Methods:*

*A community household survey with follow up telephone interviews of those reporting unauthorised disclosures. Recruitment interviews were conducted during October and November 2001 with 3037 South Australian residents over 15 years of age. South Australian households were selected randomly within a representative selection of census collection districts. Follow up telephone interviews were conducted with 18 respondents who reported unauthorised information releases in the twelve months prior to the initial survey.*

### *Results:*

*The one year prevalence of breaches of confidence reported by patients was 0.23 +/- 0.17% (1.96 x SE). This prevalence was significantly lower than a previously published estimate (Mulligan, 2001) of 1.1 +/- 0.4% (difference between proportions  $p = 0.003$ ,  $z = 4.415$ ) which relied upon reports of information disclosed without the patients permission as a proxy for breaches of confidence.*

*An incidental finding was that 0.20 +/- 0.16% (1.96 x SE) of respondents reported exchanges of information amongst members of treating teams which had not been authorised by the patient.*

### *Conclusion:*

*True breaches of confidence arising from health care interactions are rarely detected by patients. Ordinary information sharing within treating teams may be a more important source of misunderstandings between patients and health care providers. This issue can be addressed at the point of care by informing patients what will be done with their health information and who may later gain access to it.*

## Introduction

Confidentiality of health services has important public health impacts. Evidence from empirical research studies indicates that some members of the community, such as adolescents, will not seek care without a guarantee of confidentiality (Marks et al 1983, Cheng et al 1993, Zabin, Stark and Emerson 1991). Persons with HIV infection will delay seeking a diagnosis where anonymous services are not available to them (Bindman et al 1998). Other patients may withhold important information from their treating team in an attempt to shield

themselves from the harmful effects of a breach of confidence (Salinsky 1992). Medical practitioners may avoid collecting sensitive information where they believe that patients may suffer adverse consequences following its disclosure (Rivara et al 2000), and blood donors are less willing to donate, if confidentiality is withdrawn (Banks 1991).

As new technologies become available in health, patients have new concerns about confidentiality. The proliferation of predictive genetic testing has brought in its wake the new prospect of genetic discrimination. Apart from case series identifying instances of genetic discrimination in Europe (Low, King and Wilkie 1998), the USA (Billings et al 1992) and Australia (Barlow-Stewart and Keays 2001), there is little research concerning the harms which follow from inappropriate disclosure of health information.

A patient's legal right to expect confidential care is supported by professional registration boards, the common law action for breach of confidence and by legislation.

Despite the importance of confidentiality and the legal protection it receives, there has been little research into the effectiveness of protection for confidential health information. Claims that confidentiality in health care delivery is being eroded have been difficult to assess in the absence of trend data.

In 2001 Mulligan reported on the results of a South Australian population survey which asked members of the community whether they had experienced unauthorised disclosure of information by a doctor or a health service. This produced a proxy measure for breaches of confidence across the South Australian health system. The reported one year prevalence of 1.1 +/- 0.4 % comprised both legal disclosures and illegal events (that is, disclosures which were made without consent or other lawful basis).

Not every unauthorised disclosure is illegal, indeed some (such as child abuse reports) are mandated by law. In order to differentiate between legal and illegal disclosures, the population survey was repeated. Interviews were then conducted with individuals who reported unauthorised disclosures to identify the subgroup who had experienced illegal disclosures (actionable breaches of confidence).

## Methods

Recruitment interviews were conducted as part of an annual omnibus health survey by the South Australian Health Commission, in which 4,400 homes were selected randomly within census selection districts. Excluding vacant premises and those who declined, 3037 household members over 15 were interviewed, giving a response rate of 71%.

Respondents were asked "in the last twelve months, has any doctor or health service released information about you to another person without getting your permission?" Those giving an affirmative response were asked for consent to participate in a follow up telephone interview. Consenting participants were then interviewed by the first author using a semi structured questionnaire designed to tease out the legal issues distinguishing legal from illegal disclosures (see Box 1). This qualitative data was reviewed by the second author (a legal practitioner) to determine which reported events were illegal.

This protocol was given ethical clearance by the Social and Behavioural Research Ethics Committee of the Flinders University of South Australia.

## Results

Twenty four of 3037 respondents reported experiencing unauthorised release of health information in the previous twelve months. Eighteen agreed to be interviewed, while a further five supplied limited qualitative information about the event at the time of the initial survey.

Six reported events which did not meet the selection criteria. They described events which took place more than 12 months prior to the initial survey, reported that health information had been disclosed by someone who was not a doctor or a health service, or reported an event at the recruitment interview which they did not recollect at the follow up interview.

Eleven individuals reported disclosures which were permitted or mandated by law. Of these, seven described transfers of information between treating practitioners. They included electronic accessing of pathology tests ordered by a different practitioner; discharge summaries being sent from an emergency department, hospital or treating specialist to a general practitioner; discussion of patient's information at multi disciplinary team meetings; conferral by specialists in order to plan appropriate referral; and a hand over from a hospital nurse to a community follow up team.

Four respondents reported actionable releases of health information. In one instance a patient, who sought to keep treatment confidential from his employer, found that a discharge summary of treatment in a private hospital had been sent to the public health service which employed him. In another, a general practitioner disclosed a patient's name in the course of making enquires to a register of drug dependent persons. One respondent discovered that a health practitioner had discussed personal details about him with other clients and another found that her general practitioner had discussed her health with her daughter (who was also a doctor).

A further three respondents reported events which could not be classified because insufficient information was given at first interview to reach a judgment on whether the event was legal, and a follow up interview was declined.

## Discussion

### *Prevalence of unauthorised disclosures*

Twenty-four of 3037 South Australians reported that they had become aware of information being released from a health service without their permission within the previous year. This establishes the one year prevalence in the population at  $0.8 \pm 0.3\%$  ( $1.96 \times \text{std error of the proportion}$  95% confidence interval). In 1999 it was estimated that  $1.1 \pm 0.4\%$  ( $1.96 \times \text{s.e.}$ ) of South Australians had become aware of unauthorised information release from health services in a survey using the same survey and selection methods (Mulligan, 2001). This change in prevalence was not significant ( $p=0.22$ ). A difference in the prevalence rates of at least 0.53% (detectable effect size) would be required to demonstrate significance using samples of this size.

Disclosures which are not authorised by patients are not necessarily illegal. This study sought to identify amongst the unauthorised disclosures reported by patients, those which constituted actionable breaches of confidence.

### *Prevalence of breaches of confidence*

The one year prevalence of persons experiencing illegal disclosures of information from health services in this sample was  $7/3037$ , giving an estimate of the prevalence in the South Australian population of  $0.23 \pm 0.17\%$  ( $1.96 \times \text{standard error of the proportion}$ ), if all of the unclassifiable events were actionable breaches of confidence. This prevalence was significantly lower than the previously published estimate of  $1.1 \pm 0.4\%$  (difference between proportions  $p=0.003$ ,  $z=4.415$ ). The prevalence rate may have been as low as  $4/3037$ , giving a prevalence estimate of  $0.13 \pm 0.13\%$  ( $1.96 \times \text{SEP}$ ), if none of the unclassifiable events were actionable.

This method has identified actionable information releases in health more accurately than the previous estimate, which accepted a proxy measure representing an agglomeration of legal and illegal events amongst patient reports of unauthorised information releases. The rate at which patients become aware of breaches of confidence arising from health services in South Australia is lower than the earlier estimate suggested. This method was not able to identify those breaches of confidence which occur without patients ever becoming aware of them. The rate at which undetected breaches of confidence occur remains unknown.

### *Other patient concerns*

The survey also identified an interesting group of patients who had become aware of transfers of information between health care practitioners which were not authorised by the patients. While information sharing between members of the treating team is not illegal and is routine amongst practitioners, some patients objected to this.

The Commonwealth Privacy Act 1988 requires practitioners to ensure that patients are informed prospectively about why their health information is being collected, who is collecting it, how it will be used, to whom it may be given and that they can access it if they wish (National Privacy Principle 1 and Information Privacy Principle 1 of this Act). If this were done consistently, patients would not be surprised by routine information transfers between treating practitioners. This information may be easily supplied to new patients in pamphlet format. If patients were given such advice prospectively, any patient with special concerns about ordinary disclosure practices would have the opportunity to voice them and to negotiate with their treating practitioner about what information should be disclosed to whom.

### *South Australian Law*

In South Australia, Section 64 of the Health Commission Act requires that 'an officer or employee of the Commission, an incorporated hospital or an incorporated health centre must not divulge personal information, relating to any patient, obtained in the course of employment otherwise than as he or she may be authorised or required to divulge by law or by his or her employer.' South Australia does not have a privacy statute applying to personal information generally, such as the Northern Territory Information Act 2002. Nor does it have legislation applying specifically to health information, such as the ACT Health Records (Privacy and Access) Act 1997, or the Victorian Health Records Act 2001. In the absence of such legislation, complaints concerning breaches of confidence arising from public sector health facilities may be directed to the Ombudsman or the Medical Board of South Australia. Complaints concerning breaches of confidence by private health providers may also be directed to the Medical Board. The scope of the Commonwealth Privacy Act 1988 was expanded to apply to health information held in the private sector in 2000, however these provisions did not become enforceable until December 2001 and did not apply at the time that our survey was conducted. The Privacy Act now provides an additional avenue of complaint to the Federal Privacy Commissioner where breaches of confidence occur in the private sector.

## **Conclusions**

A reduction in the level of confidentiality accorded to health information could be expected to have an adverse impact on public health. Patients in South Australia rarely become aware of breaches of confidence, suggesting that current methods for protecting confidential health information are reasonably effective. Patient reports that information had been released from health services without their permission did not rise over two years and thus the survey provided no evidence that confidentiality is being rapidly eroded.

Apart from wrongful disclosures of health information (breaches of confidence), there are some patients who are surprised or offended when they become aware of information exchanges between treating practitioners. The concerns of these patients could be addressed by providing all patients with prospective information about who else may later gain access to information about them and advising them of the uses which will be made of health records. Following enactment of amendments to the Commonwealth Privacy Act, the provision of such patient education has become a requirement in the private sector in South Australia. It should act to dispel misunderstandings between patients and health care providers over routine communications and information sharing amongst treating practitioners.

## **BOX 1. Questions Distinguishing Legal from Illegal Disclosures of Health Information**

**Opening question** - Can you tell me what happened?

Prompts were used to gather specific information

**Confider** - Who released the information?

**Recipient** - Who was the information released to?

**Source** - Is there any other way that [the recipient] might have discovered that information?

**Nature of the information released** - What information about you did [the confider] release?

**Necessary quality of confidence** - Do other people than [the confider] also have the same information about you?

**Information given for a particular purpose** - When you gave that information to [the confider], what did you understand that it would be used for?

**Explicit Consent** - Do you recollect ever signing a consent to release information about you, perhaps as part of an application for insurance?

**Implied Consent** - Did [the confider] let you know or suggest in any way beforehand that they would be releasing information about you?

**Public Interest** - Was this done to prevent harm to you, or to anyone else?

**Detriment** - What was the consequence for you?

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