

# Why protect confidentiality in health records? A review of research evidence

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## Abstract

We present the main arguments for protecting the confidentiality of health services, along with those for limiting confidentiality. These arguments are then substantiated by reference to research evidence.

There is evidence that access to health care is restricted if confidentiality is not promised to some groups of patients. Fear of disclosure does diminish patients' candour, and this can compromise the quality of care.

While patients are concerned about confidentiality and some are harmed by 'leaks' from health services, most people in Australia still trust health providers to keep their secrets, and patients rarely become aware of a breach of confidence.

It has been claimed that strict protection of confidentiality may obstruct the pursuit of medical research and the use of electronic medical records. There is, as yet, no evidence that gaining full benefit from the use of electronic medical records entails reduced protection for confidentiality. The losses to epidemiological research if patient consent were always required are hotly debated.

Confidentiality should be protected because it protects patients from harm, supports access to health care and produces better health outcomes.

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## What is known about this topic?

Confidentiality of patient information is highly valued and breaches that harm patients are rare. There is evidence that access to care may be restricted or patients may be less candid with their care providers if confidentiality is not guaranteed.

## What does this paper add?

A key element in supporting public confidence and accountability to patients is to ensure patients are aware of the extent and limits of the secrecy which can be offered. In a climate of increasing consumer expectations, some patients will seek a greater degree of control over disclosure of their health information.

## What are the implications?

Confidentiality should continue to be protected for all patients, including young patients, because the provision of confidential health services protects patients from harm, supports access to health care and produces better health outcomes.

**EXISTING BASELINE DATA** gives a good basis for monitoring impacts over time as new initiatives such as electronic linkage of medical records are introduced.

The power of information technology to store, link and network information is increasing. Australian governments have responded with the introduction of new legislation, such as amendments to the Commonwealth *Privacy Act 1988*, the NSW *Health Records and Information Privacy Act 2002*, the ACT *Health Records (Privacy and Access) Act 1997* and the Victorian *Health Records Act 2001*. Debate has also been rekindled over the value of protecting confidential health information and whether rigorous protection for confidential health information is in the public interest or not (Etzioni 1999; Gostin & Hodge 2000).

We seek to draw attention to empirical research evidence concerning the value of confidentiality

in health. Opening with a restatement of arguments for maintaining the confidentiality of health information (and arguments for limiting it) we will present the available research evidence. The claim that confidentiality in health services is valuable can be substantiated by a review of these arguments in the light of research evidence.

A central ethical argument for preserving the confidentiality of health information is that it demonstrates respect for the autonomy of the patient. Practitioners demonstrate respect for patients' autonomy when they acknowledge that patients have the right to make decisions about themselves and their lives. That right includes a right to choose who will be privy to their secrets.

Confidentiality confers a number of practical benefits. It shields patients from harm which might flow from disclosure of health information. It encourages patients to be candid with their health care providers. For people who avoid medical care without a guarantee of confidentiality, it is a prerequisite for access.

The obligation to maintain confidentiality is not absolute. There are competing public interests which justify disclosure in some circumstances. The most powerful arguments in favour of breaching confidentiality turn on the need to prevent harm to others. Disclosures which may prevent child abuse or homicide are salient examples.

Other social benefits are derived from the free flow of information. The offer of confidentiality necessarily restricts information transfers and may work against the public benefit from using information more efficiently through electronic networking. In population research, having to obtain individual consent from patients for record linkage may compromise large epidemiological studies which rely on a high recruitment rate in a defined population to maintain their statistical validity.

These are the core arguments for providing confidential services as well as those for limiting confidentiality in health. But what is the evidence that these benefits and risks are real? Do patients actually avoid health care, or become less candid with their doctors when they are concerned about

confidentiality? Are people actually harmed by breaches of confidence? And, can any losses arising from restricting disclosures of health information be substantiated?

## **Are patients harmed by breaches of confidence?**

There has been surprisingly little research describing the consequences which patients experience following breaches of confidence.

Evidence that harm to patients does flow from breaches of confidence is provided by two population surveys. A randomised telephone survey of 2100 adults in the United States (California HealthCare Foundation 1999) found that one in five adults had experienced improper disclosure of medical information and half of these indicated that this resulted in "harm or embarrassment". There may be a lower rate of harmful disclosures in the Australian health system. A population survey of 3013 South Australians (Mulligan 2001) found that only 1.7% of South Australians reported unauthorised disclosures of information by health services which caused "trouble or problems" for them. Another randomised population survey of 3037 South Australians found that only one in 400 (0.25%) had experienced a breach of confidence arising from health care in the previous year (Mulligan & Paterson 2003).

A specific example of harm which may flow from disclosure of health information is discrimination based on genetic characteristics. The rise in predictive genetic testing has generated new information which may become the basis for discrimination if it is released. Surveys of support groups for people with inherited disorders have identified cases of genetic discrimination in the USA (Billings et al. 1992), the UK (Low, King & Wilkie 1998) and Australia (Barlow-Stewart & Keays 2001).

These studies indicate that harm does arise when confidentiality is compromised. While there are some specific examples, further research will be needed to characterise the consequences for patients.

## **Are patients concerned about confidentiality?**

In a systematic review of research published between 1980 and 1997 on the use of computers in general practice (Mitchell & Sullivan 2001), 8 of 89 well constructed surveys identified patient concerns that computers might compromise confidentiality. In Australia, a national survey of 1524 Australians (Privacy Commissioner 2001) asked respondents whether they trusted doctors and hospitals "to keep and use information in a responsible way". A large majority (84%) considered doctors and hospitals to be trustworthy. This finding was consistent with the views of South Australians surveyed by one of us (Mulligan 2001), most (85%) of whom also considered doctors and hospitals to be trustworthy data custodians.

The finding that doctors and hospitals are generally trusted custodians of personal information is striking. It suggests that, whatever data management practices have been in place, they have been successful in developing a climate of trust among the Australian public. In contrast, American patients may be more cynical. The California HealthCare Foundation (1999) survey found that 15% of the American patients interviewed took measures to protect themselves from disclosure of health information. Some went to a different doctor, paid out of pocket rather than make an insurance claim, avoided care, gave inaccurate information to their doctor, or asked the doctor not to record the problem or to record a less embarrassing or less serious one.

## **Does a loss of candour flow from concerns about confidentiality?**

Fear of consequences may cause patients to withhold information. For example, the fear of discrimination may lead HIV-positive persons to refrain from telling their GP of their HIV status. In a survey of 656 HIV-positive patients in the United Kingdom (Shaw, Tomlinson & Higginson 1996), one quarter had not told their general practitioner. Some (34%) of these patients indicated that they would be happy for all members

of the practice staff to know of their diagnosis if there was "a clearly displayed policy of staff confidentiality", and 41% would be happy for all practice staff to know of their HIV status if there was a policy of "non-discrimination against patients who are black, gay, drug users, or HIV positive" in the surgery.

Further evidence that some patients are less candid in disclosing sensitive information to their doctors when they are concerned about confidentiality has been provided by a survey of patients with epilepsy (Salinsky, Wegener & Sinnema 1992). This survey of 158 seizure clinic patients in Oregon found that compulsory reporting would discourage patients from reporting seizures to their treating practitioner. Nearly half of the patients indicated that they would not inform their doctor of a breakthrough seizure if doctors were required to report driving impairments.

Contamination of blood supplies with HIV infection predated the availability of effective screening tests for the presence of the virus. People who were infected by blood transfusions subsequently sought to take legal action against transfusion services and hospitals. Liability often turned on what the transfusion service knew, or ought to have known, about the donor. There have been cases across the world in which litigants have sought to force transfusion services to reveal the names of donors, or medical information about them (Magnussen 1992). Transfusion services have opposed these applications, arguing that any perception by donors that their identity might be revealed would discourage people from donating blood and lead to a decrease in the blood supply.

In research setting out to provide evidence for this contention, Banks et al (1993) surveyed 361 donors attending US Red Cross blood donation centres. The donors were asked to indicate the extent of their willingness to give accurate medical and personal history when donating, to undertake additional tests, to provide more detailed personal information and to donate blood again within the next twelve months. The questionnaire was then repeated with the preamble: "If the American Red Cross were required to

release your personal history information to lawyers and courts for use in lawsuits including public trials, would you agree or disagree with the following statements?" A significant number of donors changed their attitude in the hypothetical circumstance that information might be released. While nearly a fifth (18%) were less willing to donate, the biggest change was a fall in willingness to provide accurate information about personal and medical history (50%).

Patients' candour in disclosing information to health providers is required for the efficacy of health care, since diagnosis and treatment may be inappropriate or ineffective if the clinician does not have all of the relevant facts. These three studies provide examples of patients who may withhold information from health care providers because they are concerned about adverse consequences if that information is later disclosed to others. The only study which indicates how many patients or what proportion of the population withhold information is from the United States and may not reflect Australian experience.

### **Does fear of disclosure deter people from receiving health care?**

While there has been no measurement of the extent to which access to health care across the whole population is dependent on the promise of confidentiality, several studies have identified groups within the population who are less able to receive health care when they (or their doctors) fear that confidentiality will not be maintained. Trauma patients, teenagers seeking contraception, gay adolescents and people with HIV infection are examples.

In a paper entitled "Screening trauma patients for alcohol problems: are insurance companies barriers?" Rivara et al. (2000) postulated that there was a low rate of screening American trauma patients for alcohol use because this information could result in patients being denied insurance coverage (if their insurer discovered that they had been intoxicated at the time of an accident). This research team surveyed legislation

in each of the United States to determine whether insurers had a legal right to deny coverage for an injury due to alcohol use. They found that insurers do have this right in 26 of 31 states and concluded that physicians' concerns were well founded.

In a survey of 649 New York high school students, Marks et al (1983) found that, while most had ready access to health care, many engaged in risk activities (sexual activity or drug use) and few had sought care for these matters. Nearly half of these teenagers reported that they would seek health care for these problems "only if parents do not know". Similar findings were repeated a decade later in two surveys of American teenagers. In 1991 (Zabin, Stark & Emerson 1991) 1245 teenage girls were asked why they had delayed seeking contraceptive advice after starting sexual activity. Many cited fear that their parents would find out. A similar survey (Cheng et al. 1993) of 1295 high school students in Massachusetts found that a quarter gave a positive response when asked "Would you ever not go for health care because your parents might find out?"

Gay adolescents have been found to be at increased risk for depression and suicide. Effective preventive care would rely upon the health professional becoming aware that their client was gay. Allen et al. (1998) surveyed 102 people between 18 and 23 who were gay, lesbian or bisexual. Fewer than half of them remembered being informed about their right to medical confidentiality, but those who did remember this were three times more likely to have discussed their sexual orientation with their health care provider. Disappointingly, disclosure did not necessarily result in better care. Only half of those who disclosed then received appropriate preventive health advice.

In contrast, another American survey of adolescents found that those who received an assurance of confidentiality from their health provider were more likely to receive advice about contraception, sexually transmitted diseases and drug use. A survey of 2224 Massachusetts high school students (Thrall et al. 2000) found that those who were sexually active were more likely to have had

a pelvic examination if they had received an explicit assurance of confidentiality than if they had not received this assurance. This study demonstrated a clear link between the promise of a confidential service and patients receiving appropriate care.

The clearest evidence that a guarantee of confidentiality can result in improved health outcomes is provided by a study of delays in starting treatment for HIV infection. Bindman et al. (1998) postulated that persons who learn that they are HIV positive through anonymous testing would seek medical care earlier in the course of the disease than they might where anonymous testing was not available. This hypothesis was born out in their survey of 835 people who were newly diagnosed as HIV infected in 8 American states. Those who had utilised anonymous testing entered treatment at an earlier stage of the disease, had higher markers for immunity (CD4+ counts) on commencing treatment, and remained longer in treatment programs before reaching a diagnosis of the full AIDS syndrome.

There is some evidence that patients are harmed by compromised confidentiality. There is also evidence from some patient groups that they will be less candid with their doctors unless confidentiality is guaranteed, and two studies have demonstrated that the promise of a confidential service ensures care for patients who would otherwise avoid or delay seeking health services.

### **Do public interest disclosures reduce harm to patients or to other people?**

Despite the adoption of mandatory reporting of child abuse in many jurisdictions and a duty under Californian law to warn those who are endangered by violent patients, there has been no research into the efficacy of mandated disclosures by health professionals. Instead, research effort has focused on the attitude of health practitioners to mandatory reporting and their willingness to report.

In California, professionals are obliged to warn third parties who are endangered by their clients.

Following the Tarasoff decision in 1976, which established this duty, 1272 Californian psychiatrists and psychologists were surveyed (Wise 1979). Most of these practitioners (80%) treated at least one potentially dangerous patient per year while more than a third had warned a third party within the previous year. In a survey of 296 members of the American Psychological Association (Thelen, Rodriquez & Sprengelmeyer 1994), researchers sought to relate beliefs about the value of absolute confidentiality in the psychotherapeutic relationship to actual reporting behavior. Those who believed in absolute confidentiality were less likely to report high risk of suicide or homicide or evidence of child abuse.

Two American studies have explored the circumstances under which other considerations may outweigh the service providers' duty to maintain the confidentiality of health information. In 1980, Lindenthal & Thomas reported on a survey of 200 psychiatrists, 92 psychologists and 147 internal medicine practitioners who were asked to respond to ten clinical vignettes. These depicted situations where a patient disclosed shoplifting, embezzlement, family abandonment, reckless driving, incest, alcoholism, drug use, pyromania, rape or premeditated murder. Not surprisingly, there was a clear progression from a low likelihood of disclosure for shoplifting to a very high likelihood of disclosing murder.

Farber et al. (1989) presented 70 internal medicine residents in a US hospital with vignettes in which patients revealed a crime which they either had committed recently or planned to commit. These doctors were more likely to disclose information to the police where killing had occurred, where there was threatened violence during the crime or where the patient had a previous record of violent crimes. For all crimes disclosure was more likely if the crime was yet to be carried out than if it were in the past.

These studies indicate that, while some American service providers support absolute confidentiality, many accept that there are some situations which warrant disclosure of information to third parties without the clients' consent, particularly

where there is an opportunity to avert harm to the patient or another person. None of this provides evidence that limiting confidentiality of health information does in fact prevent harm to other people (as it is intended to do) in the case of mandated reporting by health professionals. Two other areas in which it is argued that limitations to confidentiality will yield social benefits are in data gathering for epidemiological research and in the use of electronic patient records.

### **Does a requirement for patient consent compromise research efforts?**

The benefits of medical research may be compromised by the demand for patients to consent to the use of confidential information. Melton (1997) has pointed out that the Mayo Clinics' collection of over 5 million medical records has been used to provide data for tens of thousands of studies and that the Rochester Epidemiology Project, which links these records with those from other treatment centres, has provided data for more than a thousand publications describing the natural history of various diseases. This was all made possible by a Minnesota law which allowed the release of health records for scientific research without specific patient consent. Melton has asserted that all of this research activity would be threatened by a requirement for individual consent to use records for research.

In Australia, Bruinsma, Venn and Skene (2000) have provided illustrations of research projects which would have been frustrated by the requirement for individual patient consent to link health data. Woolf et al. (2000) have supported the assertion that requiring patient consent would introduce sample bias. In this survey, the characteristics of those who agreed to participate in research were compared with those who refused. While 91% of the 15 997 hospital patients surveyed did agree to allow their records to be used for research, elderly women and those with mental health concerns were more likely to refuse.

This evidence points to research findings which would be foregone if patient consent were required for all research. There is vigorous debate among researchers as to the extent of the loss to scientific knowledge which would result (Smith 1997; Doyal 1997; Pfeffer & Alderson 1997). The available research evidence does not measure the relative losses to scientific knowledge of requiring consent (and potentially obstructing certain types of research) versus dispensing with the requirement for patient consent (and potentially producing mistrust and unwillingness to participate among potential research subjects).

### **Do the benefits of electronic patient records outweigh the risks to confidentiality?**

The benefits of electronic patient records are well documented. Any disadvantage arising from compromised confidentiality or loss of patient trust has yet to be measured. A number of surveys of primary care practitioners have shown that computerisation of medical records improves immunisation rates and adherence to best practice standards in the management of chronic diseases (such as diabetes, hypertension and HIV infection) (Mitchell & Sullivan 2001).

There is no research evidence to indicate that any compromise of confidentiality is required in order to achieve these health gains. The mere use of a computer only introduces the possibility of information misuse, it does not mean that it will necessarily occur.

### **What does the research evidence demonstrate?**

The available research evidence is unsatisfactory in the sense that not all of the assertions concerning risks and benefits of providing confidential health services have been investigated rigorously. For example, there is no empirical research directly demonstrating an association between keeping confidences and respect for patient autonomy.

A small section of the literature has explored patient preferences for autonomy more generally. Schneider (1998) reviewed 17 surveys of patient preferences for control of decision making. This review found that many patients want information about their illnesses and treatments, yet a substantial minority of patients are reluctant to make their own decisions. These studies cast some light on how patients think about autonomy. Schneider's conclusion is that respect for patient autonomy is better expressed by allowing patients to choose how much control they will have over decisions about their care than by requiring patients to act as the primary decision maker.

There is also no clear evidence that public interest disclosures, such as mandatory reporting, are necessarily effective in reducing child abuse or violent crime. Despite this research deficit it is widely believed that preventing harm to others does sometimes require disclosure of information without the patients' consent. American surveys indicate that health care providers accept that some situations warrant disclosures, particularly where harm can be averted.

The free flow of information brings with it health benefits. It has been claimed that strict protection of confidentiality may obstruct the pursuit of medical research and the use of electronic medical records. No evidence that the advantages of electronic medical records necessarily entail reducing protection for confidentiality is available, and the possible losses to medical research are hotly debated.

Despite weaknesses in the available research evidence, there are some important conclusions which can be supported. There are groups of patients whose access to health care is reduced if confidentiality is not offered. Some patients will not receive needed care unless confidentiality is promised, and loss of candour does compromise the quality of care which some patients receive.

While people can be harmed by disclosures of health information, and fear of repercussions does restrict access, most people in Australia still trust their health providers to be responsible data custodians and patients rarely become aware of any breach of confidence.

## **Why should confidentiality be protected?**

Confidentiality should be protected because the provision of confidential health services protects patients from harm, supports access to health care and produces better health outcomes.

The Australian health care system is in the privileged position of being trusted by patients to keep their secrets. We have baseline data on the level of public confidence in health services and the frequency with which breaches of confidence occur. These measurements should be repeated over time as new initiatives such as electronic linkage of medical records are introduced. We do not wish to lose the health advantage that we have by creating skeptical patients who avoid health care or obscure information from their care providers.

A key element in supporting public confidence and providing the transparency which is required for accountability is to provide clear information to patients. Health services can express respect for patients' autonomy by explaining to them the extent and limits of the secrecy which can be offered. In a climate of increasing consumer expectations, some patients will seek a greater degree of control over disclosure of their health information.

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