Short Guide to the *Open Disclosure Standard* Review Report

June 2012

AUSTRALIAN COMMISSION ON SAFETY AND QUALITY IN HEALTH CARE

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Contents

What is the purpose of this document?

The Australian Commission on Safety and Quality in Health Care is reviewing the national *Open Disclosure Standard*.

The *Short Guide to the Open Disclosure Standard Review Report* summarises the key points of the review as reported in the *Open Disclosure Standard Review Report*. It is not an executive summary of the *Open Disclosure Standard Review Report*, but rather an easy to read guide to some of the key points identified in the report. For example, the recommendations in the *Open Disclosure Standard Review Report* are not included in the short guide and neither are the references on which the review is based.

The *Open Disclosure Standard Review Report* contains a complete appraisal of the review, its outcomes, the evidence and the final recommendations. The *Open Disclosure Standard Review Report* is recommended to those with a higher level interest in the review and the associated consultation process.

The *Open Disclosure Standard Review Report* and the *Australian Open Disclosure Framework — Consultation Draft* are available www.safetyandquality.gov.au/our-work/open-disclosure/the-open-disclosure-standard

1 Introduction

Every day across Australia, many thousands of patients undergo medical treatments and procedures. These interventions are often complicated, use highly advanced equipment and involve multiple practitioners.

Most often the treatments result in excellent outcomes. However, modern health care also carries some risks. Sometimes things go wrong, and patients are unintentionally harmed during care.

Open disclosure is frank and open discussion with patients, their families and carers following harm from health care.[A] Since the 1980s, doctors, other healthcare professionals and health service organisations have started to accept that open disclosure is the right thing to do.

In 2003, the national *Open Disclosure Standard* (the Standard) was released. It has served as a guide for Australian healthcare practitioners and health service organisations on communicating with patients after health care has resulted in harm.

The Standard says that the open disclosure process should include, at a minimum, an expression of regret, explanation of what has occurred, and description of the action being taken to manage the incident and prevent recurrence.

The Australian Commission on Safety and Quality in Health Care (the Commission) is responsible for maintaining the Standard and for helping healthcare professionals and health service organisations implement open disclosure.

There has been a lot of research and investigation into open disclosure over the past few years, producing new knowledge and evidence of what works and what doesn't work for both patients and healthcare professionals. This is why the Commission is reviewing the Standard.

What is patient harm?

Patient harm is suffering, disability or death caused by health care. It is not a known complication, side effect or discomfort associated with an illness or its medical treatment. For example, hair loss during chemotherapy is a known side effect and therefore not classified as patient harm.

Patient harm is never intentional. It happens because something doesn't go to plan. However, patient harm is always unnecessary and often preventable.

An occurrence of harm in health care is called a harmful incident or adverse event. Research has reported that about one in ten patients experience varying levels of harm during a visit to hospital, the doctor or other healthcare providers.

Most often the effects of a harmful incident are minor. Unfortunately, serious effects happen from time to time. Patient harm can affect family, carer(s) and loved ones.

A In the remainder of this document, the term patient also includes family, carers and other support persons.

Do patient perceptions of harm count?

Patient perceptions are increasingly seen as important measures of the safety and quality of care. Sometimes a harmful incident may not be noticed by busy practitioners. Patients are in a unique position to perceive harm and can enable the health service organisation to identify harmful incidents and learn from them.

Harm does not need to be physical. It can also be distress caused by aspects of the patient's journey through, or contact with, the health service organisation. Because patients value respect and empathy as part of their care, they are likely to feel distressed when these are not provided.

Emotional or psychological harm includes being inadequately prepared for side effects or complications that may happen as a consequence of health care. In these situations, patients are entitled to an explanation and sometimes an apology.

In order to maintain trust and be responsive to patient needs, healthcare professionals are encouraged to listen to patient concerns and to respond to them appropriately.

Why do harmful incidents happen?

There are many reasons why harmful incidents happen. Modern health care is a complex undertaking that involves many individuals and processes, as well as highly technical equipment. Because of this complexity, there are many opportunities for things to go wrong. Sometimes even a small oversight or malfunction can cause serious harm to a patient.

This complexity also means that patient harm is very rarely the fault of any one person or event. This is why health service organisations are encouraged not to blame individuals for harm but, instead, to look for ways to improve the system to prevent patient harm occurring again in the future.

We are learning more about the risk factors of patient harm, and of ways to improve safety and quality. For example, when healthcare professionals don't talk to each other as much as they should there is a bigger chance of harm occurring. There is also some research to suggest that patients who take an active role in their care (for example, by asking lots of questions) tend to experience harm less often.

Why is open disclosure important?

Australian health service organisations have improved patient safety over time in many important ways. For instance, many health service organisations have reduced levels of healthcare-associated infections. The Commission and other organisations are working with Australian healthcare professionals and health service organisations to reduce patient harm further.

Open disclosure is an important part of this work because:

- it helps patients (and healthcare professionals) recover from the effects of harmful incidents

- patients supply valuable information that can be used to improve the safety and quality of health care
- acknowledging that patient harm has occurred is an important first step to thoroughly investigating an incident to prevent recurrence, and help build safer and better healthcare systems.

However, the uptake of good open disclosure practice has been slower than some other safety and quality initiatives. Reviewing the Standard may result in open disclosure happening more often and in ways better suited to patients.

2 Patient needs and expectations

Patients have expectations about their health care and about actions that might follow patient harm. These expectations are not only about the medical care patients receive, but about their entire experience during medical care.

As well as good and safe medical care, patients value the non-medical aspects of care such as:

- effective communication
- empathy and compassion
- being treated respectfully
- being consulted on their care.

Focusing on patient needs and expectations has been shown to improve the quality and safety of health care. In particular, the non-medical aspects of care become even more important after something has gone wrong with health care and resulted in harm.

Why is communication important?

Good communication throughout the whole healthcare journey is valued very highly by patients, families and carers. They also value being included in the decision-making process related to their care.

Good communication is the most important part of open disclosure. We have learned from talking to many patients that the best thing for them after harmful incidents is for healthcare professionals to be open and honest. It is also important that patients are listened to and have the opportunity to talk about what happened and ask questions. This gives patients confidence that the incident and their care are being openly explained and rebuilds their trust in the healthcare professionals and the health service organisation.

Increasingly, health service organisations are focusing on improving the communications skills of healthcare professionals who provide care to patients.

What do patients need immediately after harm?

There is growing evidence indicating that harmed patients expect and appreciate prompt and honest acknowledgement that something has happened. They expect this even if all the facts about the event are not yet known.

Patients also want to know the details of what happened to them as soon as health service organisations have the information. They want to know what is being done to fix the problem that caused the incident.

This is why open disclosure will often happen through a series of discussions after the harmful incident.

What about out-of-pocket expenses due to patient harm?

According to the research, open disclosure is most effective when combined with a prompt offer to reimburse out-of-pocket expenses caused by the harmful incident. These expenses may include child care, transport or meals as well as health care to manage the harm.

It is important to note that that such payments are made in good faith and do not automatically mean that the providers are at fault.

A harmed patient is entitled to seek financial (or other) assistance for loss directly related to the incident. These concerns are addressed separately to the open disclosure.

3 Saying sorry

Research indicates that one of the most important parts of open disclosure for patients is to hear the words 'I am/we are sorry…' from healthcare professionals.

There may not be sufficient information about the harmful incident to provide an explanation until an investigation takes place. However, this should not stop healthcare professionals saying sorry about the incident and reassuring the patient that steps are being taken to find out what happened.

Why is saying sorry so important?

In many nations and cultures, saying sorry is an important part of how people treat each other with respect and dignity, especially after something bad has happened.

In health care, recent research suggests that saying sorry benefits both patients and healthcare professionals. For patients, a sincere and heartfelt apology or expression of regret can help them recover from the harmful incident, both emotionally and physically.

Healthcare professionals are deeply affected by patient harm. Studies have shown that saying sorry is important for healthcare professionals following harmful incidents (see Section 4).

Why can saying sorry be difficult?

Saying sorry can cause anxiety for some healthcare professionals. Some say that they fear that apologising or expressing regret is an admission that they are 'guilty' of something.

All Australian states and territories have laws 'protecting' apologies or expressions of regret. This means that a healthcare professional saying sorry to a patient cannot be used as evidence of admission of liability in court. There are no examples we could find from legal cases where judges or juries used somebody's apology as evidence.

However, the laws are different in each state and territory and they were not created with open disclosure in mind. Differences between the laws create some confusion about what is permitted or protected.

Are there any legal restrictions on what can be said in open disclosure?

No restrictions apply to what can be said during open disclosure. In the majority of cases healthcare professionals should be encouraged to be open, frank and honest about what has occurred, but not to speculate on what is not known.

However, sometimes there are legal restrictions on what healthcare professionals can tell patients about an incident. These restrictions should be explained clearly to patients, families and carers including how open disclosure will occur during the restriction and when the restriction is expected to end.

Why might patients pursue alternative actions?

Research and experience in open disclosure indicate that sometimes patients can get so angry about lack of or poor communication after harmful incidents that they take alternative action to get an explanation for what happened. Alternative actions can include commencing litigation and contacting the media.

Money is only one of many considerations for most patients in deciding whether they will litigate. Harmful incidents can escalate when patients perceive silence and possible cover-ups from their healthcare professionals and health service organisations. They appreciate full and open disclosure after harmful incidents.

Health service organisations are sometimes concerned that openly disclosing harm can alert patients to the fact that they have been harmed, and that this could prompt an increase in litigation. While this may be true, it doesn't change the fact that talking openly with patients about harm is the right thing to do.

The lesson from health service organisations where open disclosure is implemented successfully is that openly communicating and saying sorry following harm is valued by patients and families.

There are examples around the world where 'extreme honesty' as part of a comprehensive patient safety program has led to reduced medico-legal activity.

4 Healthcare professionals need support

Healthcare professionals are committed to caring for patients. They are deeply affected by harmful incidents, even if they only played a small role. Providers involved in harmful incidents are sometimes called the 'second victims' because of the enduring effects the incident can have on them.

It is very important that healthcare professionals are supported by their colleagues and the health service organisation after a harmful incident in order to cope and to ensure their emotional wellbeing.

What do healthcare professionals think about open disclosure?

Healthcare professionals believe open disclosure is the right thing to do for patients. However, they often lack understanding and knowledge about it including:

- not being completely aware of the needs of patients
- feeling insufficiently skilled or experienced to carry out open disclosure in a confident manner.

We know that some healthcare professionals are concerned about openly disclosing harmful incidents. They may also be worried that undertaking open disclosure may make them a target of blame.

Some healthcare professionals only consider physical harm in the context of open disclosure and may undervalue other types of harm, such as emotional or psychological distress. This can sometimes create tension and conflict between patients and their healthcare providers.

The research and examples from around the world show that education and training can reduce these concerns, and help healthcare professionals focus more on the needs of the patient. Evidence suggests that this benefits both the patient and the healthcare professional.

Why are healthcare professionals sometimes not supported?

Healthcare professionals should be supported by their health service organisations following harmful incidents, but sometimes they are not. This can be because of certain values and culture within health service organisations. Culture can refer to 'the way things are done', and can also be described as the atmosphere or tone within a health service organisation or a profession working within the organisation.

Poor culture includes unrealistic expectations (such as errors never occurring) and the blaming of individuals for error (when it is often systems that cause errors). It often involves covering

up mistakes and not informing patients about harm in order to protect individuals or the organisation.

It is important to ensure that health service organisations accept that harmful incidents will sometimes occur and to manage these so that:

- patients recover as well as possible
- healthcare professionals involved are supported
- health service organisations learn from the harmful incident so that it does not happen again.

Why is culture important?

Research and examination have shown that a culture of honesty, transparency, openness and support benefits health service organisations. This type of positive culture ensures that mistakes are not covered up, helping the facility to continually improve. A culture that places the patient at the centre of care also contributes to a safer and high-quality health service organisation.

Transparency, openness and patient-centredness are the basic principles of open disclosure. Supporting healthcare professionals to perform open disclosure may benefit the whole health service organisation.

What can management do?

An important part of having the right culture is leadership. A health service organisation will struggle to provide safe and quality care if its senior management or executives don't actively promote the values of transparency, openness and patient-centredness and lead by example.

Is training and education of staff important?

Research suggests that training and educating staff on how to disclose harmful incidents openly can improve the safety and quality culture of health service organisations. It can also help healthcare professionals understand the context of their individual actions and how they can contribute to improved healthcare systems.

Open disclosure training and education may assist healthcare professionals become better communicators with improved understanding of patient needs in addition to the therapeutic needs of their illness or disease. Improved communication skills will assist healthcare professionals working in teams to treat each other with respect.

These effects combined can improve the safety and quality of care provided to patients and make health service organisations better places to work for healthcare professionals.

Health service organisation leaders and other managers need to support healthcare professionals to be open with patients when things go wrong. Open disclosure education and training, together with management support for being open about harmful incidents, can ensure that harmful incidents are managed and communicated effectively and sympathetically.

5 Confidentiality

Confidentiality is important in health care and in open disclosure. Confidentiality protects both the patient and the healthcare professional from unauthorised access to information. However, there is a need to balance this with openness and transparency.

In the case of healthcare professionals, unauthorised access to information can sometimes lead to unwarranted criticism and harassment.

Are families and carers automatically informed if something goes wrong?

It is important for a patient to formally nominate an official support person who will act on their behalf if they are harmed. This will most often be done during admission to medical care.

Providers should always prompt patients to do this and advise on the legal way in which it is done. While this is perhaps not what patients want to think about when beginning treatment, it can avoid a lot of difficulty should something go wrong.

This nominated support person will be kept informed in the case of patient harm.

What should be provided to patients in writing?

A written summary of open disclosure meetings or discussions, and the plan of action taken by the health service to prevent a similar incident from happening again should be given to patients and their support persons.

Outcomes from open disclosure discussions should be written down and filed appropriately by the health service organisation.

6 Putting open disclosure into action

Research identifies some common barriers to open disclosure in all settings and countries.

The agreed ways of overcoming these barriers include developing a culture within health service organisations that values transparency, openness and patient-centredness. This culture will be the foundation for making sure that harmful incidents are openly disclosed and that the needs of harmed patients are met.

Building a safety and quality culture requires healthcare professional education and development (see Section 4). Ideally, healthcare professional education and development begins with undergraduate education and continues throughout their career.

There are examples from Australia and around the world to draw on for guidance on implementing sound open disclosure practice. These are provided in the *Open Disclosure Standard Review Report*.

Why is open disclosure a priority?

It is sometimes suggested that open disclosure takes resources away from treating patients. Training staff to be good at open disclosure and communicate effectively with patients after harmful incidents costs time and money.

This argument presumes that open disclosure is not part of routine care but an optional extra. But the evidence suggests that caring for patients after harmful incidents, including communicating with them, should be seen as a normal part of high-quality care.

The research is clear that harmed patients benefit greatly from prompt and comprehensive disclosure following harmful incidents. Healthcare professionals also benefit from disclosing harmful incidents.

There are additional benefits from providing healthcare professionals with the skills necessary for good open disclosure. These include good listening skills, better communication with patients and colleagues, and understanding care from the patient's point of view.

The research is also clear that open disclosure helps healthcare organisation to learn from harm and to improve their processes to prevent future harm

There is a strong case that investing in open disclosure provides value for money for health service organisations.

7 The current Standard

Reviewing the latest evidence and research demonstrates that the current Standard would benefit from some changes. The *Open Disclosure Standard Review Report* recommends how this should be done. Many of the recommendations are about increasing the focus on patients in open disclosure and ensuring that open disclosure is a two-way exchange of information between patient and healthcare professional.

The full report and the revised Standard, the *Australian Open Disclosure Framework — Consultation Draft*, can be accessed at www.safetyandquality.gov.au/our-work/open-disclosure/the-open-disclosure-standard

8 How you can contribute

We would like your feedback on the revised Standard, the *Australian Open Disclosure Framework — Consultation Draft,* which can be found at www.safetyandquality.gov.au/our-work/open-disclosure/the-open-disclosure-standard

You can provide feedback by:

- completing a survey at the above website
- writing to us by email or post (see details below).

A submission template is available at www.safetyandquality.gov.au/our-work/open-disclosure/the-open-disclosure-standard

Please forward written submissions to:

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