



**Disclosure of Harm to Patients and Families
Alberta Perspective**

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**Why Develop a Provincial
Disclosure of Harm Framework?**


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Health Quality Network (HQN)

- College & Association of Registered Nurses of Alberta
- Alberta Cancer Board
- Alberta College of Pharmacists
- Alberta Health and Wellness
- Alberta Medical Association
- Alberta Mental Health Board
- College of Physicians & Surgeons of Alberta
- Federation of Regulated Health Professions
- HQCA
- Nine health regions
- Health Boards of Alberta

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HQN, at an externally-facilitated brainstorming session in February 2004:

- Identified relevant topic areas that could be worked on at a provincial level.
- Selected three priorities selected to begin work on immediately: disclosure, quality matrix and complaint management.
- Struck sub-committees to follow through with the disclosure initiative and resource binder developed.

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The decision to proceed with a provincial disclosure framework was reinforced by the HQCA survey findings.

(HQCA Alberta Patient Safety Survey, 2005)

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The survey revealed:

95.3% of Albertans felt physicians should be required to tell patients or family members if a preventable medical error is made in the patient's care.

37 % indicated that they or a family member had experienced a preventable medical error (anytime throughout their lives).

Of this 37% - - **63%** did not receive an apology.

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Development Process

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- Literature review.
- Review of policies and practices in other jurisdictions across Canada and around the world.
- Consultation regarding legal issues and Alberta legislation.
 - Legal counsel from various health regions
 - Legal counsel from various professions
 - Faculty of Law, University of Calgary
 - Health Law Institute, University of Alberta
 - Office of the Information and Privacy Commissioner

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Benefits Identified and confirmed:

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- Open and timely disclosure promotes the development of trust within the patient-physician relationship.
- Honesty and transparency tends to reduce the likelihood of litigation
- Failure to disclose and subsequent discovery by a patient may increase the likelihood of legal action.
- Disclosure promotes a culture of safety; promotes learning for the purpose of system improvement.

(Youngberg & Hallie, 2004; Wu, 1997)

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Literature reinforced what Patients Want

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- An accurate explanation of what happened and the consequences.
- To receive assurances that action will be taken to reduce the likelihood of similar incidents.
- An apology.

(Vincent, Young & Phillips, 1994; Raskin, 2001)

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Guiding Principles Agreed Upon

- Patient-Centered Care
- Health Care Must Be Delivered in the Safest Manner Possible


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- **PATIENT CENTERED CARE:**
 - *Disclosure is the Right Thing to Do*
 - *Patient Autonomy*
 - *Early Acknowledgement*
 - *Immediate Expression of Regret*
 - *Patient Expectations are Honored and Respected*

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- **Health Care Must Be Delivered in the Safest Manner Possible**

Quality Improvement & Risk Reduction are Paramount to Safety

 - *Honesty & Transparency*
 - *Support for Health Care Providers*


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- Draft framework distributed to over 60 stakeholders in Alberta and with key national organizations (September 2005).
- Feedback obtained through:
 - Focus group with patient and family members
 - Forums
 - 5 held across the province
 - Over 100 individuals participated
 - Included physicians, nurses, pharmacists, health region board members, allied health professions
 - On-line survey completed by 28 health regions and organizations
 - Direct Submissions (CMPA, AMA, Health Board of Alberta, CPSA)

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Primary Barriers to Disclosure Identified:

- Fear of litigation
- Fear of being judged by peers
- General attitudes of professionals about errors

CULTURE

Recently Confirmed: Investigation by: Gallagher, et. al. US and Canadian's Physician's Attitudes and Experiences regarding Disclosing Errors to Patients Arch. Intern Med/vol. 14/28, 2006 © 2006 American Medical Association

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Education is essential to move from talking the talk to walking the walk

- Methods and processes for disclosure in situations where there is a known human error or a perceived human error, are not comfortable.
- Observations about attitudes indicate that there is a significant difference where the adverse outcome results from known risks

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To facilitate the education on disclosure processes we engaged Dr. Dan O'Connell from the Institute for Healthcare Communication to provide:

- general education to healthcare practitioners and administrators
- Training of "situation managers"
- Training for trainers

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The IHC teaches different process for disclosure when there is a KNOWN deviation from the standard of care.

This supports:

- The desired change in attitudes about "error"
- The desired attitude about investigation of error

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Open Disclosure

Who should I identify as a support person?

- Someone you are comfortable with and can talk to easily.
- Someone to whom we can give personal information about you.
- Someone able to take the time, if necessary, to be with you.

Who will talk to me?

The person who talks to you about what happened will be someone who:

- Has been involved in your care and knows the facts.
- You are comfortable with and can talk to easily.
- Can contribute to action to stop the problem from happening again.

Every patient has the right to be treated with care, consideration and respect.

We respect this right, and we're committed to improving the quality and safety of the care we deliver. That's why we have a disclosure policy to help patients who have been harmed during their health care treatment.

This brochure aims to inform you and your family about the disclosure process. It also tells you what to expect if harm occurs during your health care experience.


We are committed to assisting you to recover from any harm that may occur during your care.

For more information:

Information for Patients

Insert Logo Here

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What can I expect if something goes wrong?

If something goes wrong during your care, a member of the health care team will talk to you and your family about what happened. You can also discuss any changes to your care that may be needed.

Who else will be present?

The health care provider who will be discussing what happened may also have someone present to assist and support him or her. When something goes wrong, it is not only distressing for the patient and family, but also for the health care team involved.

What will happen next?


When something does go wrong, steps are taken to prevent it from happening again. The health care team will investigate what went wrong. You will be informed of the results and changes that will be made to prevent the same thing from happening to someone else.

If the investigation takes a long time, you will be kept up to date with its progress. If you wish, a meeting will be arranged for you to discuss what actions have been taken to try to prevent a similar incident from happening again.

When we visit a health professional or organization, we expect to receive the safest health care available, but sometimes things don't work out as expected. For example, a patient may receive the wrong dose of medicine. In the health care field, we call this an adverse event. Most adverse events are minor and don't result in harm. But when an adverse event does occur and/or the patient is harmed, he or she has a right to know what happened and what will be done to prevent it from happening again.

If an adverse event causing harm occurs, the health care provider and he or her organization will follow a process of open disclosure. This means as soon as possible after the event patients, and at their request their families, are told what has happened and what will be done about it.

An important part of the process is finding out what went wrong, why it went wrong and how it can be prevented from happening again.





Open Disclosure **HQCA**
Health Quality Council of Alberta
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It's about...

- Talking openly with your patients about their care.
- Telling your boss if a patient has been harmed or if a patient has experienced an unintended outcome.
- Being sorry to a patient if the care has been hurt rather than helped.
- Being there for your work colleagues if they've involved in an adverse event.
- Looking for skills and solutions rather than blaming individuals.
- Asking patients to excuse.

For more information, contact:

1-800-962-0800
1-403-293-2222
Toll-free in Alberta
1-403-293-2222
1-800-962-0800

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Something not right with your patient's care? **HQCA**
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Don't keep them in the dark.

Your organization has a disclosure policy that will guide you as you tell them:

- What happened.
- That you're sorry it hasn't worked out right for them.
- What you're going to do to stop the same thing from happening to someone else.

Help them get on with their life.

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Open Disclosure

Prior to initiating the disclosure conversation with a patient, refer to your organization's policy and/or your professional code of ethics.




Effective communication techniques for disclosure:

1. Use language the patient and family will understand.
2. Speak slowly and pause frequently.
3. Listen.
4. Express empathy.
5. Be at eye level with patient/family (sit).
6. Consider any cultural differences.
7. Avoid the statement: "I know how you feel...".

The initial disclosure conversation should include:


1. An apology.
2. Known and agreed upon facts.
3. Patient's questions/concerns.
4. Consequences of harm and any side effects to look for.
5. Discussion of ongoing care.
6. What happens next (investigation of adverse event and feedback).
7. Arrange for future meetings.
8. Contact details in case of further concerns or questions.

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Checklist for Disclosure Team Discussion

This checklist may be used for identifying tasks to be completed or delegated during a meeting of the disclosure team prior to conducting the patient and/or family interview.



Support Person:
Individuals from an adverse event investigation will be given a patient's identified support person(s) in appropriate circumstances. Making the support person(s) available to the patient and/or family in the hospital setting or otherwise, about future care and long-term health, is the patient's choice.


Access to a disclosure team and patient or family about who should receive information, the patient's expressed wishes on consent:

Item	Yes	No
All relevant health care professionals involved in the adverse event have been notified/consulted		
Identify and agree upon issues to be discussed		
Identify person(s) to take responsibility for the initial disclosure conversation with the patient:		
- Known to the patient		
- Familiar with the incident and care of the patient		
- Good interpersonal and communication skills		
- Willing to maintain a relationship with the patient		
- Received disclosure training		
- Name(s):		
Support person(s) (e.g., family member) for patient identified and available		
- Name(s):		
Identify support for the disclosing health professional		
- Consider appropriate timing of the initial discussion (as soon as possible following discovery of harm)		
- Availability of key staff and support		
- Availability of patient's support person(s)		
- Patient preference		
- Policy and content of the patient		
- Emotional and psychological state of the patient		
- Designate communication of appropriate staff to those staff that need to know (e.g., those managing the patient or who may be questioned by the patient or family) to one team member		
- Special considerations or support required		
- Ongoing clinical care needs managed		


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s health system.


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Attitudes, that support a culture where transparency about errors is the norm, are facilitated by a good understanding of the science of error



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The new science of error is based in developing an understanding that:

- Humans are human
- Human behavior is influenced by the information gathered at the time
- Investigation of the entire spectrum of circumstances is essential

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THE POINT OF THE INVESTIGATION IS NOT TO FIND WHERE PEOPLE WENT WRONG....

IT IS TO UNDERSTAND WHY THEIR ASSESSMENTS AND ACTIONS MADE SENSE AT THE TIME

P. 65, Decker, Sydney; The Field Guide to Human Error Investigations; Ashgate Publishing, Vt, 2002

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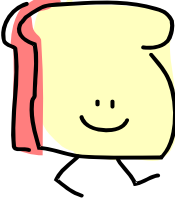
Attitudes about litigation are changed with education about:

- The realities behind the legal finding of negligence
- The purpose and processes of investigations into adverse events


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DISCLOSURE IS ONLY ONE PART OF CREATING A QUALITY HEALTHCARE SYSTEM




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A safe and useful mechanism for the reporting of actual harm or potential for harm is required.

Collection of data is NOT enough – reporting must have some real meaning to support the purpose

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The normalization of dealing with unforeseen outcomes must be culturally enforced. Organizational leadership **MUST** be engaged.

- Clarity around the consequences of human error must be stipulated and followed.

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Other challenges

- The interpretation of privacy legislation is inconsistent- information learned in investigative processes may not be released
- Where there is little guarantee of confidentiality – there is a reluctance to participate in a full and complete investigation

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Next Steps include:

National Disclosure Project (CPSI)

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The Alberta Framework was intended to ensure that all citizens – wherever they are receiving health care in the province ought to have consistent treatment.

The national project is intended to broaden the scope to all Canadians...

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This requires:

- The adoption of similar beliefs around patient rights
- Speaking the same language

It may mean:

- Creating consensus around insurance practices
- Creating consensus around legal practices
- Creating consensus around privacy and confidentiality laws

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Known challenges

- Privacy legislation differs from province to province
- Insurer practices differ from province to province
- Beliefs related to the need for confidentiality differ
- Some provinces have specific legislation related to the protection of information learned in investigations – others do not

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Cultural diversity is anticipated to be greater nationally than provincially.

What are the varying Attitudes toward human error, consequences of error and how best to disclose?

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Changing attitudes changes **CULTURE**

This national forum is a significant step toward creating a culture of safety through transparency.

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On a personal note –

“The only thing you have absolute control over is your attitude”

(author unknown)

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