



PRACTICALITIES OF OPEN DISCLOSURE

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Arranging open disclosure discussions

A face-to-face discussion is preferred wherever possible. The patient and/or their support person(s) should be consulted about who they would like to be present or prefer not to be present. This includes the option of having their own support person(s) in addition to those provided by the health service. It is important to be aware that the number of health care staff attending the formal open disclosure discussion does not overwhelm the patient and/or their support person.

If a patient and/or their support person prefer, or circumstances determine that open disclosure is by telephone, it is important to check that appropriate support is available to them during and after the discussion. It may be possible to enlist the assistance of a local health care professional with appropriate skills.



Open disclosure discussions should be held, wherever possible:

- in person
- at a location and time that is suitable, convenient and easily accessible for the patient and/or their support person(s)
- in a quiet, private area to maintain confidentiality and provide privacy for the patient and/or their support person(s), especially if they are distressed
- away from the clinical area, in a space that is free from interruptions – for example, ask colleagues to cover your pager and turn off your mobile phone
- with sufficient time to apologise, explain the known facts of the incident, listen to the patient and/or their support person(s) and address any questions they may have
- in a manner that empowers the patient and/or their support person(s) and avoids the barriers or demonstrations of rank that may intimidate or discourage them from speaking openly and asking any questions – for example, a round table creates an equal space for all participants in an open disclosure discussion.

If a patient does not have the physical or mental ability ('capacity') to participate in the disclosure discussion, their support person(s)* must be notified and involved until the patient is able to fully participate and make decisions on their own behalf. If the patient has died (as a result of the patient safety incident or otherwise), the support person is the lead contact for open disclosure about the incident.

*See Chapter 11 *Key Definitions and References*

The importance of open and effective communication

It is the responsibility of the health care facility and health care staff to:

- create an environment that supports open and effective communication
- work with the patient and/or the patient's family, carers and other support persons (as well as people who understand the patient's communication needs, if necessary) to determine the best way to communicate.

Information about a patient safety incident should be provided to a patient and/or their support person verbally and in writing, and in a language or communication style that they understand.

Chapter 9 *Open Disclosure in Specific Circumstances* provides information about open disclosure in circumstances when the patient and/or their support person may have specific communication needs.

Tips for good communication in open disclosure discussions

- Be aware of and sensitive to cultural, language and communication needs of the patient.
- Convey an open and sincere approach with body language and the words that you use: empathic communication is essential.
- Structure the disclosure discussion around the expectations and needs of the patient and/or their support person(s).
- Ensure the style of the disclosure discussion is appropriate to the kind of patient safety incident that has occurred – for example a minor problem may require a short conversation and a simple apology, while a serious incident may require a series of discussions over many months, with long term support.
- Use words that are likely to be understood by the patient and/or their support person(s) – avoid or explain medical terminology and jargon.
- Present the facts using a simple description of what happened and what is known of the outcome at that point. Use visual prompts where possible.
- Carefully pace the delivery of information, allowing pauses and time for you and the patient and/or their support person(s) to process the information and ask any questions at that point.
- Active listening helps with understanding the patient's experiences and needs. This means reflecting back what you have heard to the person you are communicating with.
- Ensure enough time for the disclosure discussion, including ample time for the patient and/or their support person(s) to tell his/her story and ask any questions.
- Ensure that the discussion is not interrupted – turn off phones and pagers (or ask a colleague to look after them for you).
- Check and clarify that the information that you provide is understood by the patient. Ask them to feed back to you their understanding of what has been said. Avoid using the words 'Do you understand?', which tends to elicit a positive response even where uncertainty exists.

The open disclosure advisor will be able to offer assistance with preparation and communication skills.

Documenting open disclosure

Following a patient safety incident, essential documentation includes **notifying the incident** via the incident management system (IMS) and recording the reference number in the patient's health record. This includes incidents notified to the Ministry of Health using a Reportable Incident Brief (RIB)²⁵.

a) Recording clinician disclosure

Managers are responsible for noting in the **patient's current health record** (electronic or paper-based) that a clinician disclosure discussion with the patient and/or their support person(s) has occurred, if not already recorded by the clinician. Key points and outcomes from the discussion may also be recorded. The IMS identification number must be noted in the patient's health record. The manager may also enter brief notes into the Clinical Notes screen (or similar) in the IMS.

Documentation should be clear, concise and legible, and include only facts relevant to the incident. The record should be objective, not apportion blame, and should include:

- the date and time discussions were held
- who was present: patient and/or support person(s), health service staff by their position (not name)

**** health care staff names are not to be entered into the IMS****

- agreed actions and next steps
- any documentation provided to the patient and/or their support person(s).

The following may be helpful as an example of what to record in the patient's health record for clinician disclosure, and/or to enter into the IMS in the progress report on the Manager Tab:

The senior registrar and the NUM met with the patient and her daughter on 13/9/2013 at 1400hrs, shortly after the patient safety incident (IMS number) was identified. The patient received an apology. They discussed what happened, the treatment that the patient will require and what the ward staff will do to prevent this happening again. The patient has been provided with the contact details for the NUM should she have any further concerns or questions.

For the most serious patient safety incidents, a RIB is submitted to the Ministry of Health which requires the recording on the RIB form of whether an initial open disclosure discussion has occurred. If initial disclosure has not yet occurred, a free text box allows for an explanatory statement.

b) Recording formal open disclosure

Initiation of formal open disclosure should be recorded:

- in the incident management system (IMS)
- in the patient's health record – noting the IMS reference number

Managers may also record that formal open disclosure has occurred in the clinical notes section of the incident management system (IMS) or in the progress report on the Manager tab in the IMS. The sample paragraph below provides a guide for recording a summary of formal open disclosure discussions.

Documentation relating to open disclosure discussions should be kept as part of the health service's clinical governance records. It should not be filed with the patient's health record. The file may include open disclosure checklist/s, minutes of open disclosure discussions, any summaries of formal open disclosure discussions, the incident report and evidence of the ongoing monitoring of outcomes.

A reference to the existence and location of these records relating to open disclosure, for example, an open disclosure file, should be included in the patient's health record and the incident management system.

25. NSW Health Incident Management Policy PD2014_004 Section 3.3

Information about open disclosure discussions which is kept in the clinical governance records may include:

- > time, date and place of the disclosure discussion and the names and relationships of those present
- > confirmation that an apology was given
- > plan for providing further information to the patient and/or their support person(s)
- > offers of support and the responses received
- > questions asked by the patient and/or their support person(s)
- > plans for follow-up as discussed with the patient and/or their support person(s) and responses that were provided
- > progress notes relating to the clinical situation and accurate summaries of all points explained to the patient and/or their support person(s)
- > copies of letters sent to the patient and/or their support person(s) and their general practitioner and other relevant health professionals.

A contact person at the health care facility, for example the open disclosure coordinator or manager responsible for insurable risk, should be available to advise clinicians and health care facility staff about processes for documentation and sharing of information.

Financial considerations

When a patient has been affected by a patient safety incident, actual or potential financial impacts should be discussed unless circumstances dictate otherwise. This includes advising the patient and/or their support person(s) of the potential for additional time commitments and costs associated with treatment required as a result of the incident.

Billing and costs

Ensure that consideration is given to waiving the costs to a patient associated with billing for investigations and treatment that are required as a result of the patient safety incident – for example blood tests, x-rays, extended hospital stay, and/or further surgery. Explain to the patient and/or their support person(s) that if they do receive any bills, to contact their open disclosure liaison person for assistance.

Reimbursement of out of pocket expenses²⁶

Early recognition and approval for reimbursement for out-of-pocket expenses incurred as a direct result of a patient safety incident sends a strong signal of sincerity. Practical support offered through reimbursement does not imply responsibility or liability. Out-of-pocket expenses may include, but are not limited to, meals, travel, accommodation and childcare.

Offers of reimbursement are made at the discretion of the local health district/specialty network (LHD/SN) and on a case-by-case basis. Reimbursement of any out-of-pocket expenses must be documented in the open disclosure records. It may be preferable that detailed discussions about financial considerations with the patient and/or their support person(s) are arranged separately to open disclosure discussions.

Each LHD/SN should have processes in place to enable reimbursement of the immediate and/or ongoing out of pocket expenses of a patient and/or their support person(s). The Finance Branch at the NSW Ministry of Health supports each LHD/SN developing clear local processes to facilitate early offers of reimbursement as a gesture of goodwill.

26. NSW Health Open Disclosure Policy PD2014_028 Section 4.6

Points to consider for local processes include:

- Nominating key contact people in each LHD/SN who are able to advise on and facilitate the reimbursement process
- Linking the reimbursement process to the patient's identification number/incident identification number
- Requiring any request for reimbursement to be accompanied by a receipt or statutory declaration
- Establishing clear lines of delegation/responsibility at site level in relation to authorising reimbursement of out of pocket expenses
- Facilitating the tracking of expenses by providing a Purchasing card (P Card)²⁷ or debit card with a pre-set limit. (A policy is in development for the use of a new Health Credit card called the Purchase Card (P card))
- Ensuring local staff are aware of the processes in place for reimbursement, through education and training.

If the amount requested is likely to exceed \$5,000 and/or the LHD/SN intends to seek reimbursement from Treasury Managed Funds (TMF), then the LHD/SN must contact its manager responsible for insurable risk who will liaise with TMF prior to any agreement with the patient and their support person(s) for reimbursement for out-of-pocket expenses.

If reimbursement is requested for a significant amount, for example, to assist with funeral expenses, the support person(s) should be advised to put their request in writing so the LHD/SN can refer the matter to TMF. In some circumstances, the LHD/SN may assist the patient and/or their support person(s) to write to the TMF in order to initiate the reimbursement process.

Expenses incurred as a result of the incident but not related to the disclosure process

Patients and/or their support person(s) may ask about expenses that are not related to out of pocket expenses, such as funeral costs, long term placement, continuing care expenses or expenses not covered by an insurance program. Health services should anticipate these types of questions and be prepared to respond with appropriate information.

Privacy and confidentiality

Health care staff: Health services are required by legislation to protect the privacy of patients, health care staff and others when conducting investigations, creating reports and making any disclosures during open disclosure.

Health services should ensure that staff participating in open disclosure are aware of and adhere to the relevant privacy principles and other obligations of confidentiality during open disclosure. As part of open disclosure discussions, health care staff are encouraged to inform patients and/or their support person(s) of these requirements and to explain the reason/s that some information is not able to be provided.

Open disclosure advisors can advise on how to provide information without breaching privacy and confidentiality obligations in the context of a particular patient safety incident and the open disclosure process.

Patients have a right to expect that their personal health information will be given to another person only if this is important for their health care or can be otherwise legally and ethically justified²⁸. The safest way to ensure that there is not a breach of privacy or confidentiality is to obtain the consent of the patient (or their parent/guardian) to disclose specified information to a person or people that they nominate. In circumstances where the patient is able to make decisions (i.e. the patient has capacity), only the patient (or their parent/guardian) can determine who this person or people will be.

The discussion about patient's consent to release of information to support person(s) should have been held at the time of admission to the health care facility.

The following points should have been included in the discussion with the patient:

- the names of the person or people who can provide assistance and support to the patient
- the names of the person or people to whom the patient has agreed that information about their health care can be given
- the names of the person or people who can make decisions on behalf of the patient should he/she be incapable of making decisions about their health care

27. NSW Treasury Circular 11/15 13 December 2011

28. PD2005_593 NSW Health Privacy Manual version 2 Section 3.4

- > The Health Records and Information Privacy Act 2002 (HRIP Act) does not give the patient's next of kin any authority to receive information about or make decisions on behalf of the patient. The health service should check whether the next of kin has been nominated by the patient.
- > any special restrictions on openness that the patient would like the health care team to respect.

After a patient has been involved in a patient safety incident, he/she may decide that a person or people different to whom he/she had previously agreed should now receive information about his/her care.

When a patient does not have capacity to decide for themselves who can receive information about their health care, and if they have not nominated a contact person on admission, an "authorised representative" can decide on their behalf who the person (or people) is to receive information and make decisions about the patient's health care.

The HRIP Act sets out the list of people who can be an authorised representative²⁹.

An authorised representative is appointed by the patient before they lose capacity. Once the patient has lost capacity, it is too late to make such an appointment. The appointment is usually made by Power of Attorney or Enduring Power of Attorney and will state when it is to come into effect. By way of example, it may say that it is to come into effect when the patient ceases to have capacity or if the patient is in a coma or unconscious.

If the patient is deceased the authorised representative is the Executor/Executrix or Administrator/Administratrix of their Estate. An Executor/Executrix is appointed by a valid Will. If there is no valid Will a person is said to die intestate and the Administrator/Administratrix is appointed by the Court. Advice can be obtained from the NSW Trustee and Guardian if there is uncertainty as to who can look after the affairs of the Deceased.

Open disclosure on compassionate grounds:

When considering open disclosure without explicit consent on compassionate grounds³⁰, such as in emergency situations or when a patient has died without nominating a contact person, the following restrictions must be considered:

- > the individual must be incapable of giving consent
- > disclosure must be limited to "what is reasonably necessary" in the circumstances
- > disclosure must not be contrary to any wish the patient has expressed and not withdrawn, or any wish that the health care facility is aware of, or could reasonably make itself aware of.



29. ibid Section 5.6

30. PD2005_593 NSW Health Privacy Manual version 2 Section 11.2.9