UNIVERSITY OF TECHNOLOGY SYDNEY

THE UNIVERSITY OF MELBOURNE

THE UNIVERSITY OF QUEENSLAND AUSTRALIA

"Data collection, analysis and evaluation of

The Open Disclosure Standard: A national standard for open communication in public and private hospitals following an adverse event in health care"

Final Report for

Queensland Health

As Project Manager for:

The Australian Commission on Safety and Quality in Health Care

November 2007

CONTENTS OF THIS FINAL REPORT

0 EXECUTIVE SUMMARY: RECOMMENDATIONS AND FINDINGS

This report sets out findings of the evaluation of the National Open Disclosure Program. The report's contents address the questions that govern this evaluation as defined in the original Call for Tenders: "what it is about this kind of intervention that works, for whom does it work, in what circumstances does it work, in what respects does it work and why does it work". The Report brings together the research work done by the Evaluation Team, which includes staff from the University of Technology Sydney, The University of Melbourne, and The University of Queensland. Short biographical statements can be found in Appendix L.

This Report presents analyses of data collected in Victoria, South Australia, Queensland and New South Wales. This data includes:

1. **154 interviews** with health care professionals and consumers. Of these interviews, 131 were conducted with health care professionals, 15 were conducted with patients and 8 with family members.

2. **80 questionnaire surveys** (health care professionals only).

Details about numbers of interviewees and survey respondents per State and per site are included in the Appendices.

0.1 Overview

Data analysis reveals three main aspects of Open Disclosure:

1. Open Disclosure is met with approval and relief on the part of health professionals and consumers:

   a. staff can now discuss matters that in the past were often seen as too difficult to discuss

   b. consumers express feeling pleased for being told what happened

2. Open Disclosure is not a temporary fad: health care staff and consumers interviewed and surveyed see Open Disclosure as integral to fostering and maintaining good relationships in health care, and to enhancing health care services

3. as emerging practice, Open Disclosure creates uncertainties about:

   a. which incidents 'trigger' (High or Low Level) Open Disclosure

   b. the impact of Open Disclosure on their and their organisation's reputation

   c. the legal and insurance implications of Open Disclosure

   d. whether colleagues will support those carrying out Open Disclosure.

0.2   Main Recommendations

Staff and consumers highlight the importance of:

1. Staff conveying their apologies in ways that are sincere

2. Patients and families becoming involved in the incident management and practice improvement processes that contextualise Open Disclosure by staff making it possible for consumers[1] to contribute their views on, questions about and insights into health care service work that they or family members have been involved in, thus helping staff to broaden the scope of their enquiries and their learning

3. Open Disclosure training being provided to health care staff across Australia to ensure that clinical staff do not remain exposed (as they are now) to the risk of their and/or their colleagues' inadequate approaches to disclosing adverse events

4. Junior staff being engaged in Open Disclosure training to

    a. equip them for disclosure of adverse events

    b. intensify their attentiveness to patients' experiences, needs and feelings

5. Policy makers considering undertaking a review of the legal processes and practices bearing on institutional apology, Qualified Privilege and no-fault liability

6. Clinical professionals committing to a shared and cross-organisationally networked responsibility for health-service-produced (unexpected) outcomes

7. Researchers being directed to produce Australian evidence to show whether Open Disclosure benefits local health care organisations and consumers.

0.3   Main Findings: The Interview Data

0.3.1 For health care staff, what works is when:

1. Open Disclosure provides frontline clinicians with the opportunity to discuss unexpected outcomes in a way that is

    a. morally justifiable

    b. not constrained by professional and/or organisational status

    c. mindful of how health organisational complexity mitigates individual blame

2. High Level Open Disclosure[2] occurs when:

    a. the adverse event is a Sentinel Event,

    b. it attracts a SAC 1 (and on occasions a SAC2) rating, and

    c. it is experienced by the patient (and/or family member[s]) as significantly impacting on their physical and/or emotional well-being

3. Low Level Open Disclosure occurs of 'intercepted' mishaps (including if they do not 'reach the patient') that:

    a. are judged to provide shared learning opportunities for the patient (family), the organisation and for staff,

---

[1] In this report, the terms 'consumer' and 'patients and family members' are used inter-changeably.

[2] 'High Level Open Disclosure' is distinguished from 'Low Level Open Disclosure' as follows: High Level Open Disclosure occurs in cases of serious harm (attracting a Severity Assessment Rating of 1, possibly 2). In contrast to High Level Open Disclosure, Low Level Open Disclosure allows clinicians to conduct a more 'local' (to the unit or department) organisational response (Australian Council for Safety and Quality in Health Care, 2003: 37).

    b.   that are experienced by the patient (and/or family) as distressing

    c.   peer judgment classifies as breaches of an accepted standard of skill, a formal rule or an established fact of knowledge

    d.   whose decision to disclose is achieved dialogically – through negotiation with the relevant stakeholders

4. Open Disclosure – particularly High Level Disclosure – is planned, conducted and/or closely supported and monitored by staff who have been trained and have gained experience in carrying out Open Disclosure

5. Open Disclosure – particularly High Level Disclosure – is coordinated and supported by staff with specialised administrative-managerial appointments (e.g. the Patient Safety Officer, the Quality Coordinator, the Patient Liaison Officer, the Manager of Patient Safety, or the Director of Clinical Governance)[3]

6. Open Disclosure is participated in by senior clinical (particularly senior medical) staff

7. Open Disclosure is conducted by staff who have excellent communication and listening skills

8. Open Disclosure is conducted in circumstances where clinicians involved in the adverse event have pre-established a good relationship and understanding with the patient (and family)

9. Open Disclosure is a sub-component of an established clinical governance system that encompasses:

    a.   well-established multi-disciplinary team processes,

    b.   flexibly systematised work practices[4],

    c.   vigorous incident investigation and practice improvement structures, and

    d.   interpersonal attitudes and relationships that afford questioning and critique of a kind that is not constrained by hierarchical difference and professional experience

10. Open Disclosure encompasses careful pre-planning, responsive disclosure, adequate follow-up and internal as well as independent counselling support

11. Open Disclosure is structured to include consideration of paying for patients' and/or family members' out-of-pocket expenses

0.3.1.1 For patients and family members, what works is when:

1. Patient (and/or family members) are shown respect by being offered an immediate and sincere apology

---

[3] While this works for frontline clinical staff, consumers' views of the roles and effectiveness of such personnel depend on the extent to which the consumers expect and are enabled to meet with those most closely involved in the adverse event (see Section 2.5 below).

[4] 'Flexible systematisation' refers to clinical teams actively negotiating the contours of their work practices with each other on a regular, iterative basis (Timmermans & Berg, 2003). 'Flexible systematisation' involves (i) devising formal pathways that describe how the work is done and (ii) on-the-job examination and negotiation of how in situ work articulates with those pathways (Iedema & Degeling, 2001).

2. Open Disclosure is conducted as much as possible by those originally involved in the patients' care, or contact is instigated at some point with those originally involved in the patients' care

3. Those in charge of carrying out Open Disclosure enable patients (and/or their families) to appoint a support person

4. Those carrying out Open Disclosure engage consumers on three levels:

    a. negotiating with consumers the details and impact of the adverse event

    b. eliciting from consumers matters they want to see clarified and taken action on

    c. sharing with consumers carefully structured feedback as matters come to light rather than delaying feedback until the end of a closed-door investigation

5. Open Disclosure counter-balances the fragmentation of health care occasioned by:

    a. relevant staff moving to other institutions;

    b. different staff expressing conflicting or accusatory perspectives on the causes of the unexpected outcome

    c. revelations of adverse events being made by staff at alternative institutions without such staff initiating appropriate, pre-emptive communication with the health care facility where the original care was provided

    d. different staff engaging consumer(s) in repeated questioning about the case (without the reasons for asking such questions or the conclusions drawn from the answers being made clear)

    e. lengthy investigations of adverse events producing a hiatus in the contact between the health facility and those harmed

6. High Level Open Disclosure is deployed appropriately for all high-severity adverse events[5]

7. Open Disclosure is enacted by staff who are proficient in 'active (or reflective) listening' (Egan, 2006), ensuring patients and family members gain the opportunity to express their grief, guilt, and/or anger

8. Open Disclosure is carried out in a way that is sensitive to consumers' culturally and linguistically diverse backgrounds

9. Open Disclosure is planned, arranged, conducted and concluded as part of an ongoing dialogue with the patient and/or family

10. Open Disclosure meetings are complemented with written notes for staff and patients (and/or families) containing

    a. a summary of what is verbally discussed during the meeting(s)

    b. an explanation concerning the medical-technical dimensions of the adverse event

    c. a statement that outlines the positions and responsibilities of staff involved in Open Disclosure

---

[5] See footnote 2.

     d. an overview of the organisational-administrative-managerial roles, structures and processes describing the service where the adverse event occurred

11. A summary of these Open Disclosure notes (see point 10 above) are included in the clinical notes to inform clinical colleagues.

0.3.1.2 In what circumstances and in what respects does Open Disclosure work?

1. Open Disclosure works well particularly in the case of low-level incidents where Open Disclosure is regarded as being continuous with existing disclosure practices, and where it is generally be enacted by those originally involved in the care[6]

2. Notification of adverse events occurs internally (by clinicians on the team involved in the adverse event) rather than externally (by staff at other institutions, by complaints bodies, by media outlets, etc)

3. High-severity cases lead to rapid and sensitive preparation on the part of the Open Disclosure team to ensure the Open Disclosure meeting is enacted in a way that acknowledges both patients' and families' expectations and staff's reactions and needs

4. Support for staff and consumers may involve emotional debriefs and independent counselling; debriefing and counselling for staff and consumers may be required before and following an Open Disclosure event[7]

5. Open Disclosure works well when staff treat it as a dynamic and emergent process; that is, what triggers Open Disclosure, how Open Disclosure is conducted, how frequently patients and families need to be followed up are matters that are situationally determined

6. The practice of Open Disclosure is supported by staff involving patients and families more openly in discussions (pre- and post-admission) about the risks inherent in health care treatment, including:

     a. *medical risk* (scientific evidence of the percentage chance of success of a particular treatment)

     b. *clinical risk* (information about the types and training levels of the professionals involved in carrying out the treatment, including specification of medical and nursing personnel; information about risks of cross-infection and mis-medication) and

     c. *service risk* (referring to organisational resource constraints, capacity, under-staffing, etc)

7. The practice of Open Disclosure is supported by public education that alerts consumers to the shortcomings inherent in much public reporting about health care systems and services, including:

     a. the limited attention paid to health service complexity in favour of simplistic, alarmist and blame-oriented reports

---

[6] We raise a caveat with respect to the notion that "we [clinicians]'ve always done it" in Section 2 below.

[7] Pre-Open Disclosure debriefing and counselling will focus on people's experiences of the adverse event. Post-Open Disclosure debriefing and counselling are more likely to also focus on people's experience of the disclosure itself.

> b. the constant emphasis placed on the gee-whiz facets of medical care at the expense of sober assessments of what contemporary health services can be expected to provide.

0.4 Main Findings: The Questionnaire Survey Data[8]

1. **Survey responses (80, response rate 74%) show that respondents are in agreement that Open Disclosure is of benefit:**

   a. respondents strongly agree that Open Disclosure benefits health care staff and health care services

   b. respondents strongly agree that Open Disclosure benefits patients and families

2. **Survey respondents also agree that Open Disclosure:**

   a. imposes an emotional burden

   b. imposes a resource burden

   c. has advantages that outweigh its emotional and resource costs

3. **Survey respondents are uncertain about:**

   a. whether Open Disclosure can be detrimental to professionals' or organisations' reputation

   b. whether colleagues will support them in their disclosure of adverse events

   c. when, how and with whom to enact Open Disclosure

4. **Nursing and medical survey respondents differ on the following points:**

   a. nursing staff responses suggest nurses may be more burdened than other health care professional staff by the emotional impact of Open Disclosure

   b. medical staff responses suggest that doctors may be more conscious (than other health care professional staff) of unexpected outcomes not always being appropriately communicated to consumers.

---

[8] The questionnaire survey used for this project can be found in the Appendices to this Report.

Final Report:
Evaluation of the National Open Disclosure Program

Authors of this report:

Professor Rick Iedema
Ms Nadine Mallock
Dr Roslyn Sorensen
A/Professor Elizabeth Manias
Dr Anthony Tuckett
Dr Allison Williams
Dr Bruce Perrott
Dr Sue Brownhill
Ms Donella Piper
Ms Suyin Hor
Professor Desley Hegney
A/Prof Hermine Scheeres

November 2007

1 INTRODUCTION

1.1 Overview

This Final Report is the second of two reports written by the Evaluation Team for the National Open Disclosure Steering Committee, to satisfy the requirements of Tender N0001 issued by Queensland Health in 2006 and contracted to the National Open Disclosure Program Evaluation Team at the University of Technology Sydney. The Interim Report was submitted in June 2007. The present Final Report brings to a close the Team's evaluation of the pilot implementation of the National Open Disclosure Program.

This Final Report is organised in four main sections.

Section 1. Introduction (the present section)
Section 2. Analysis of the interview data
Section 3. Analysis of survey data
Section 4. Open Disclosure – Innovative Policy and Practice

1.2 The Research Team

This Final Report has been prepared by a team of cross-disciplinary researchers from three major Australian Universities: The University of Technology Sydney (UTS), The University of Melbourne and the University of Queensland. The team brings together expertise in, among others, communication studies, hospital and clinical ethnography, adult education, law, health policy and management, and clinical expertise including pharmacy, nursing, and allied health. The team boasts an impressive international reputation for initiating research at the interstices between health policy (reform), in situ hospital work, clinical communication and innovative social science. The present report represents the fruit of their collaborative effort: Within 12 months the team arranged Human Research Ethics Approval from 28 Ethics Committees across Australia, conducted in-depth interviews with more than 150 staff and consumers, and produced a report that is likely to become a global benchmark for frontline staff engaging in Open Disclosure.

1.3 Human Research Ethics Committee Approval

Approval was received from 28 Human Research Ethics (HRE) Committees for this project. There was a very high level of scrutiny of the science underpinning the project,

the project plan, and the researchers' credentials. One HRE Committee rejected our application on grounds that no Open Disclosure was taking place in the relevant pilot site. Other HREC applications were delayed by some months; again others were delayed beyond the time frame of the current project, obviating data collection at those pilot sites (see Appendix D). Not many committees accepted the National Ethics Application Form (NEAF), and still fewer committees accepted approvals gained elsewhere using the NEAF as deserving their ratification (see Appendix D).

1.4 The Methodology

Data Collection: Staff interviewed were identified by the Open Disclosure project officers at the pilot sites (41 hospitals around Australia that had signed up for the Open Disclosure pilot project in 2006), and they were requested to allow the research team to make contact with them for the purpose of an interview. Health care staff interviewees were sent project information and consent forms. Upon completing and returning these they were sent a questionnaire survey and they were approached by phone for an interview appointment. Consumers were also identified by the relevant pilot facilities and initially contacted by the Patient Liaison Officer or equivalent, for permission for the research team to contact them. Some facilities declined to invite their patients (and/or family members) to be part of this research. The interviews were thus entirely voluntary for both the interviewees and the health facilities involved. This does mean however that we have been able to interview only an average of six to seven staff per hospital pilot site, and one consumer per hospital pilot site (see Appendix C for details). Some sites were much more forthcoming however than others in their support for this project, indicating experience and confidence with Open Disclosure. Other Open Disclosure pilot sites limited their involvement in the project, either because there were reservations about consumers being interviewed as well as staff, or because no Open Disclosure program was as yet known to have been initiated. Queensland stands out as the State where most of our data was gathered, from staff, consumers and central agencies. Interviewees have been very cooperative and enthusiastic. The consumers showed appreciation of the opportunity to talk to an external party about what happened to them while they (or family members) were treated in hospital, and about how the hospital conducted Open Disclosure.

The total number interviews conducted is 154. Of these, 131 were conducted with health professionals[9] and 15 were conducted with patients and 8 with family members. All interview sessions were audio-taped and transcribed, resulting in almost 2000

---

[9] Of these 131 interviews with health care staff, 24 were conducted in New South Wales, 29 in South Australia, 33 in Victoria, and 68 in Queensland. Most of our consumer interviews were conducted in Queensland (15 out of a total of 23).

pages of data. The interview schedules and questionnaire survey are included in Appendices F-J at the back of this Report.

Interview Data Analysis: The interviews were semi-structured and in-depth, ranging from 45 minutes to 2 hours in duration. Interviews were transcribed from the sound files by project team members. Most interview transcripts were coded by three (and in some instances four) team members independently[10], supplemented by summary reports prepared by team member interviewers. The transcripts codings were tabulated and brought together for verification, comparison and further refinement, ensuring the data is processed in a way that is credible, reliable and retrievable. In line with the tender brief, analytical attention was given particularly to distilling interviewees' practical suggestions and solutions that ensure Open Disclosure becomes part of everyday practice.

The transcripts were analysed using semantic discourse analysis (Iedema, 2003). The importance of this approach is borne out by how this analytical method was able to capture not just the exquisite detail of health care professionals' and consumers' experiences, but also the emotional and interpersonal subtleties that were embedded in their responses. The significance of staff and consumers having been able to articulate (and of researchers having been able to analyse) these situational, emotional and interpersonal matters, is that now we have an in-depth map and State-of-the-Art outline of current Open Disclosure practices and perceptions in Australia, complemented with individual people's stories ('Vignettes') enriching these descriptions with contextual and personal detail.

Survey Data: In total, in excess of 80 survey questionnaires have been received. Because it was not possible to determine the sample size for the cohort of survey respondents (due to insufficient information about how many staff nationally are involved in carrying out Open Disclosure) we have had to limit our survey analysis to percentage comparisons across the cohort of respondents.

Ethnography of Open Disclosure: The research team has had no opportunity to observe a 'live' Open Disclosure session. The circumstances and matters discussed at Open Disclosure sessions proved too sensitive for researchers to be allowed in to 'live' Open Disclosure sessions to carry out their observations. We were fortunate enough to attend several 'real play' Open Disclosure training sessions in both Queensland and New South Wales.

---

[10] Interviews conducted between April and August 2007 were analysed by between three and four investigators. Interviews conducted between September and November 2007 were analysed by between one and two investigators due to time constraint (the Final Report was due 30 November 2007, with some interviews still being conducted late November as a result of delayed and highly complex project approval processes).

1.5 Structure of the Report

This Report is presented as follows. In the first part of Section 2, we begin with an overview of the interview data and of the specific recommendations that interviewees conveyed on the basis of having been (or being) engaged in Open Disclosure. The data is arranged in the order in which frontline staff is likely to be confronted with news of an adverse event, a decision (or directive) to initiate Open Disclosure, the processes of pre-planning and scheduling the Open Disclosure meeting, conducting the Open Disclosure meeting, following the Open Disclosure meeting up with specialised support for staff and/or consumers, involvement in adverse event investigation, and disseminating findings from such investigation to relevant stakeholders.

In the second part of Section 2, the Report moves on to consider patients' and family members' views of how staff conduct Open Disclosure. We present the data as follows: we follow the unfolding of Open Disclosure (like in the previous section detailing the staff interview analysis) as it would involve the consumer. We then itemise consumers' accounts to take stock of the number of Open Disclosure events, the number of successful Open Disclosures, the types of problems and main concerns, and a range of further related issues.

In Section 3, we present our analysis of the questionnaire survey. We collected 80 surveys. The responses found in those surveys provide an important source of confirmation for the conclusions drawn from the interview data.

In Section 4, we present our conclusion and some remaining questions.

2 ANALYSIS OF THE HEALTH CARE PROFESSIONALS', PATIENTS' AND FAMILY MEMBERS' INTERVIEW DATA

2.1 Executive Overview

At a most general level, interview responses reveal the following.

1. **The interview data confirm the positive conclusions derived from our analysis of the questionnaire survey.**

2. **Interviews with health care staff revealed that:**

   a. All of the 131 health care staff interviewed, without exception, expressed approval of the Open Disclosure initiative.

   b. Open Disclosure enhances relationships not just with consumers but also among health care staff.

   c. Open Disclosure is challenging because (particularly in the case of severe adverse events) it requires

      i. ongoing attention to how the various stakeholders see and experience responses and initiatives;

      ii. dynamic adaptation of Open Disclosure strategy to stakeholders' perceptions and experiences.

3. **Interviews with consumers revealed that:**

   d. Open Disclosure was in most cases experienced as an attempt on the part of clinicians and the organisation to show respect for the dignity of the patient.

   e. Open Disclosure is not necessarily enacted according to policy, respecting the appropriate level of organisational involvement and realising the appropriate level of formality of disclosure.

   f. The less severe the adverse event, the more likely it is that the patient and/or family is given the opportunity to speak with the clinicians who were involved in the treatment and closest to the incident, and vice versa.

   g. Open Disclosure was only in isolated instances experienced as inappropriate.

2.2 Introduction

This Section 2 of the report presents the analysis of the interview data.

2.3 The Perceived Benefits of Open Disclosure

Almost without exception, health care staff and consumer interviewees expressed approval of Open Disclosure as policy principle and in terms of how it is experienced in practice.

All of the 131 health care staff interviewed, without exception, expressed approval of the Open Disclosure initiative. While it is clear that it places an extra burden on staff, Open Disclosure is a measure that enables staff to pay attention to how relationships with patients are maintained. The relationship with the patient goes to the heart of health care, and this may explain the relief expressed by interviewees at being asked to be open about unexpected outcomes.

> *"Everybody that's been involved with it have felt quite relieved."*
> [Support Personnel 51-91][11]

> *"I think in some ways they [staff] are relieved because ... there is a plan: this is what we are going to do with this family." [12]*
> [Director Clinical Department 88-19]

Besides the moral importance of Open Disclosure requiring staff to do the right thing, Open Disclosure has gained interpersonal and personal importance for staff. That is, Open Disclosure is seen as important for enhancing patients' healing as a result of their trust in the health care organisation, and it improves the health of working relationships among staff.

> *" I think ...it makes for a healthier organisation."*
> [Medical Manager 38-170]

---

[11] This coding convention provides a generalised (de-identifying) organisational position description of the interviewee, a confidential State identifier code, and a transcript page number. The organisational positions are kept general for the purpose of de-identification and confidentiality: Medical Clinician, Nursing Clinician, Medical Manager and Nursing Manager (a Medical or Nursing professional who spends more than 20/25% of their time on managerial matters), Support Personnel (Patient Liaison Officer, Quality Coordinator, Patient Safety Officer, and related roles), and Senior Medical/Nursing Manager (staff with no or very limited clinical duties).

[12] Interview quotes have been edited to facilitate their reading. Editing involves omitting hesitations, repetitions, and any non-ideational content (e.g. 'um', 'well', 'you know'). Words added in square brackets are our additions to clarify the meaning of what is said. Three dots are used to indicate that language deemed unnecessary is omitted from the quote. Full quotes are available upon request. However, Ethics Committee approval was granted on condition we preserve interviewees' confidentiality, and it is therefore not possible to provide full transcripts as they may be identifying.

"We had a massive case of an absolutely horrendous situation involved and we went through an Open Disclosure process and that was the most amazingly kind of positive experience."

[Senior Medical Manager 32-84]

For those who have had the opportunity to handle the emotional intensity of Open Disclosure, there can be significant pay-offs, as the vignette below illustrates.

Vignette: **Open Disclosure creates trusting relationships**	*"The clinician had made an error in judgment and had not picked up on something. Now he wasn't the only one that didn't pick up on it, there were other people involved, and there was a series of things that had taken place that would have allowed that to happen. And, it was an amazingly big group in this [meeting] room [to do Open Disclosure], I'll never forget it, it must've been about fifteen people and a couple of relatives because the patient was unconscious at that time. And it was just the most powerful thing I've ever seen, this guy [clinician] sort of saying, 'I really don't know what happened. I really can't explain what happened, but it shouldn't have happened, and I have to take the responsibility for that. I was the one that had the responsibility for it'. You could see he was gutted and the family responded to that. This was a human and their loved one was in there not well and really nobody knew how things were going to progress. [But] then she [patient] did wake up and, and the relationship that was formed between the patient and her partner and the clinician was really quite phenomenal and they both learnt such a lot from that whole episode and over time the patient came back on board. But we were there every step of the way supporting [her], and when it was evident she was going to need ongoing rehabilitation, then we organised transport and all those little things."* [Support Personnel 14-33]

Patients and family members have commented positively too on having had adverse events disclosed to them.

"They explained things to my other children and I. They explained the obvious. They didn't tell lies, they told the truth. [They said] 'Your son and your brother will never ever have you know a decent quality of life.' But by the same token they also said that miracles can happen. And they have been, all of the doctors and most of the nurses they have been so wonderful, caring and compassionate. So, I found it helpful, we could ask questions, and the basic thing is they told us the truth, they did not tell any lies. I appreciated that. Me and my kids found it very helpful."
[Mother of patient; 5][13]

"They [clinicians] explained all these things. So, it was helpful I found. It's cleared up a lot of things. It was very useful."
[Patient; 8]

Patients and family members have also commented on their experiences of what they perceived to be inadequate disclosures. We analyse their comments in Section 2.5 below.

2.4 Health Care Professionals' Views On Open Disclosure

The findings from the health care workers' interviews are presented under five over-arching headings:

- Before the Open Disclosure Meeting Takes Place (Section 2.4.1);

- Conducting the Open Disclosure Meeting (Section 2.4.2);

- Following up: What happens after the Open Disclosure meeting (Section 2.4.3);

- Open Disclosure – Success Factors (Section 2.4.4);

- Open Disclosure – Perceived Challenges (Section 2.4.5).

2.4.1 Before The Open Disclosure Meeting Takes Place

Before Open Disclosure takes place, different activities need to occur.

1. Notice of the adverse event needs to reach those who are in charge of arranging Open Disclosure (Section 2.4.1.1).

---

[13] These numbers indicate page numbers in the patient/family transcripts.

2. Staff need to decide whether Open Disclosure is needed, and whether High or Low Level Open Disclosure is warranted (Section 2.4.1.2).

3. High Level Open Disclosure (but in some instances Low Level Open Disclosure too) requires careful pre-planning as part of which staff establish what the mood is of those harmed, what the attitude is of the clinicians involved in the incident, what the legal and insurance issues are, how to disclose the adverse event given this information, and where to conduct the session (Section 2.4.1.3).

2.4.1.1 Notification of unexpected outcomes to those in charge of arranging Open Disclosure

Initiating Open Disclosure is in the first instance contingent on notification of an unexpected outcome. Notification in itself will not guarantee Open Disclosure is necessary, but notification plays an important role in enabling those who are in charge of organising Open Disclosure to formulate a decision about whether and how to provide the patient (and/or family) with Open Disclosure.

> *"Any facts like, has there been something come in from complaints? Has the [complaints body] got involved? You need to know these things otherwise you're sitting there having the meeting and half way through, 'Why didn't someone tell me?'"*
> [Support Personnel 30-190]

Complicating the task of those in charge of organising Open Disclosure is that there is no predictable route by which unexpected outcomes are brought to their attention. Interviewees identified both *self-initiated* and *other-initiated* ways in which information about unexpected clinical outcomes reaches those in charge of arranging Open Disclosure. Self-initiated notifications are those initiated by the health facility staff involved in the patient's care; other-initiated notifications are those initiated by people not belonging to the facility where the adverse event occurred.

Interviewees comment that *self-initiated* adverse event notifications include the following (table 2.1) (cf. Queensland Health, 2006a: 7).

Table 2.1: Self-initiated Adverse Event Notification - Types

	Self-initiated adverse event notification types	Relevant interview statements
1	In-house incident reporting, analysis and management processes	*"[there are] instances where we've started an RCA [Root Cause Analysis] and recognise that there hadn't been a disclosure"* [Support Personnel 24-100]
2	Analysis of medical notes	*"they realised [when] they went back over the notes … she wouldn't have got an apology"* [Support Personnel 29-9]
3	Morbidity & Mortality reviews	*"we've also got Morbidity and Mortality reviews [through which incidents come to light]"* [Medical Manager 27-22]
4	Death audits	*"it might be through our death audits [that adverse events come to our attention]"* [Senior Medical Manager 20-8]
5	A report or phone call from the clinician(s) involved in the adverse event alerting senior staff	*"I think you actually get pro-active in reporting errors because they actually see it as being a way of protecting themselves"* [Senior Medical Manager 20-37] *"Sometimes it's just staff members won't put it on [the local incident reporting system] and they'll go, 'I just want to let you know this', so it might be a phone call or an actual face-to-face [someone] wanting to let you know"* [Senior Support Personnel 46-49]
6	A phone call from the onsite clinical manager	*"I would expect to be notified at a suitable time by a phone call from one of the site managers who'd become aware of the incident"* [Nursing Manager 38-31]
7	Support personnel picks up news of an adverse event	*"If the [Support Personnel colleague] picks something up they come straight to me and lets me know"* [Senior Support Personnel 48-50]
8	The health service's own complaints department	*"Interviewer: Is that through the Complaints Department? Interviewee: May be complaints …"* [Senior Medical Manager 3-8]

The Queensland Health Incident Management Implementation Standard lists additional
health service internal sources of notification, including: iPharmacy and eICAT (Queensland
Health, 2006a: 7). Equally of course adverse event notification can travel along multiple
paths simultaneously:

> *"… our [Support Personnel Office] alerts us when there's been a sentinel event or a high level adverse clinical incident, and at the same time we often get a parallel complaint coming in from the family or the patient themselves. So in this instance, it was not only the adverse incident reporting, but also through our [Support Personnel], because it arose from a complaint at the same time."*
>
> [Senior Support Personnel 35-65]

Other-initiated adverse event notification is done by staff at other institutions and by members of the public themselves (table 2.2).

Table 2.2: Other-initiated Adverse Event Notification - Types

	Other-initiated adverse event notification types	Relevant interview statements
1	The patient's GP notifies the health service	*"… it [notification] came through the patient's GP, through to the Deputy Director of Medical Services"* [Support Personnel 26-172]
2	The patient notifies the health service after 'picking something up from other clinicians that something's wrong'	*"And quite often patients can pick up from other clinicians that something's wrong"* [Senior Support Personnel 27-60]
3	A health care complaints body contacts a health service and/or a staff member	*"HQCC are actually external, obviously externally to us, are personally contacting the clinician involved"* [Support Personnel 40-141]
4	Another patient conveys what they have seen to a family member or a staff member	- *"… the other ladies in the bed in the room told us [family members] exactly what happened."* [Family member 144]
5	Publication of reports in the public media (newspaper, television report)	*"I actually got notification of one through the newspaper a week after it happened"* [Senior Support Personnel 27-49] *"…about six weeks later we read in the paper, and on the local television news, this lady's mum talking to the media saying how this lady … died"* [Medical Manager 43-161]

The Queensland Health Incident Management Implementation Standard lists additional externally sourced notifications, including notification through medico-legal channels and the State Coroner's office (Queensland Health, 2006a: 7).

For different reasons, and acknowledging the source of adverse event notification is not easily controlled, *self-initiated* adverse event notification is preferable to *other-initiated* adverse event notification. *Self-initiated* adverse event notification:

a. Provides those in charge of arranging Open Disclosure with time and resources to plan disclosure.

b. Means staff at the treating facility will be seen to have initiated the disclosure, rather than an outsider (whose notification may lead to suspicions and even claims of unwillingness to disclose).

c. Improves the opportunity to choreograph the conduct and unfolding of the disclosure as well as shape its aftermath.

In sum, if adverse events do not first come to the attention of those responsible for monitoring and improving the safety and quality of the care provided by the health service, this limits their opportunity to plan and take control of how the details and background of the adverse event are disclosed. This in turn is likely to diminish if not cancel out the impact of the health service's 'disclosure', and places staff in the difficult position of having to manage potentially inaccurate and conflicting reports.

To obviate other-initiated adverse event notification, interviewees recommend the following four '(minimal) specifications'[14]. The table below includes these minimal specifications for optimising Open Disclosure, the rationales provided by interviewees, and the relevant interview quotes (table 2.3).

---

[14] The term 'minimal specification' is used to underscore that these are abstract principles – not step-by-step procedures - provided to give guidance in highly complex circumstances. In such complex circumstances, procedures do not provide sufficient or even appropriate guidance because how the practice unfolds in situ remains contingent on the dynamics of the here-and-now (Dekker, 2005).

Table 2.3: Adverse Event Notification –Specifications For Optimising Open Disclosure

	Adverse event notification Specifications	Rationale provided by interviewees	Relevant interview quotes
1	**Ensure quicker turn-around of adverse event information through the health service's incident reporting system**.	Comments were made about electronic incident reporting delaying management's ability to hear about and act on adverse events. Adverse event reporting into web-based systems needs to be complemented with systems that enable senior health service staff (with Open Disclosure responsibilities) to have access to and to analyse incident reports.	*"[with the web-based incident reporting system] It can take a considerable period of time before we know there is an incident, so I actually keep a separate folder [for] reporting"* [Medical Manager 29-22] *"Interviewer: 'Do you have an electronic system in place where you can report incidents?' Interviewee: We've got, well it's more than that. It's the phone call. … This has happened, directly to our DON or our DOMS who can then say, 'Okay, this is how we're going to handle this incident.' So we now have our co-ordinators. Our co-ordinators ask us every day on every round, 'Have you had an incident here', but we would hope that we would hear about it even before that."* [Support Personnel 59-99]
2	**Encourage staff to self-report, ensuring their participation does not incur blame on the part of the health service**.	Comments were made about the need for a no-fault approach in Australia to acknowledge that many mistakes are unintentional, and to reassure staff that the point of error reporting is to learn, not blame.	*"if you actually self-report an error, unless it falls into a certain series of categories, you cannot be disciplined in relation to that error. That's a really powerful statement by an organisation that says, 'Yes, we know people make mistakes, yes we acknowledge that ninety-nine percent of mistakes are innocent mistakes caused by a variety of factors that are generally outside the control of the individual and if you self-report, then you cannot be disciplined in any way, shape or form in relation to that error, and it's embedding into that system the culture of 'Yes, we're highly skilled professionals, but yes, we do make mistakes and we actually need to learn and act on those mistakes, and not blame."* [Support Personnel 35-6]

Table 2.3: Adverse Event Notification –Specifications For Optimising Open Disclosure (cont'd)

	Adverse event notification Specifications (cont'd)	Rationale provided by interviewees	Relevant interview quotes
3	**Familiarise staff with the types of adverse events that require Open Disclosure**.	It was suggested that publication of event types can inform staff in neighbouring organisations about the kinds of adverse events that attract Open Disclosure.	*"I think it's important that they have the release of SAC, sentinel events and that sort of thing, as a number throughout [State name] but not apportioned to any particular facility."* [Support Personnel 33-184]
4	**Minimise the chance for conflicting accounts of adverse events to circulate around the health service by setting up 'a single adverse event desk'**. Such a 'desk' encompasses a pre-determined set of people who share access to a location where relevant information and documentation are securely stored.	The problem of staff disclosing adverse event information before talking details through with colleagues can lead to different stories circulating. To ensure frontline staff know where to go for information about an adverse event, there needs to be a clearly identified place and person that can provide that information.	*"[things went wrong because] there was no single desk person who'd pick up the phone and hear the call for Open Disclosure"* [Support Personnel 33-185] *"… the story there was there was conflicting information … there was an acknowledgment there was an incident with the patient. That was done poorly from a clinical disclosure by a junior staff member with conflicting information. And that was actually then, in itself the incident in that that's what really caused the anxiety for the patient."* [Support Personnel 33-191]

Finally, self-initiated adverse-event notification is seen to be contingent (by interviewee Senior Medical Manager 24) on characteristics that are shared by excellent teams: trust, resilience, reflexivity, attentiveness to one's own and others' ways of working, willingness to share and learn from information, and a no-blame attitude towards those involved in adverse events. We expect the specifications offered in table 2.3. above to be equally contingent on these characteristics.

2.4.1.2 Determining whether and how to do Open Disclosure

The decision about whether to initiate Open Disclosure is a complex one. Interviewees were clear that Sentinel Event List or Severity Assessment Coding ratings will not provide unambiguous answers to the question of whether to initiate (what level of) Open Disclosure. Interviewees emphasised that staff in charge of organising Open Disclosure should be flexible with regard to which adverse events incur Open Disclosure and what level of Open Disclosure is required ('low' or 'high').

> *"Usually if it's something that's … incontrovertible on the shift, then the senior doctor will get involved … If it's less obvious, you know what's gone on, or there needs to be some investigation [i.e. it's more serious], then it will be referred to the Director or the Clinical Director of the ED and we'll do an investigation and then follow it up with the patient."*
> [Medical Manager 74-130/1]

Interviewees see the need for Open Disclosure as depending on both the nature of the adverse event, and on the reaction to the unexpected outcome by the patient (and/or family). The Sentinel Event List and the Severity Assessment Coding provide staff with a first indication of whether (and what level) Open Disclosure is needed, after which more in-depth analysis of the adverse event is needed.

Analysis of the nature of the adverse event itself and of the mood of those harmed is crucial to determining one's strategy. This analysis is important because on occasions adverse events may not qualify for Open Disclosure if assessed purely on their Sentinel Event status or Severity Assessment Coding rating. In these instances, it is not technical specifications, but personal needs and people's perceptions that determine whether and how Open Disclosure is initiated.

2.4.1.2.1 'Hits': The adverse event that 'reaches the patient'

Interviewees are aware that State policy documents require High Level Open Disclosure to occur for SAC 1 (and some SAC 2) rated adverse events (NSW Health, 2006, 2007; Queensland Health, 2006a).

> *"If it's going to be a SAC1 or SAC2 as per the [error reporting system] regulations, of course, they have to intervene."*
> [Nursing Clinician 2-64]

In general, High Level Disclosure is deemed necessary when it has one or more of the following characteristics:

a. the adverse event is a Sentinel Event,

b. it attracts a SAC 1 (and on occasions a SAC2) rating, and

c. it is experienced by the patient (and/or family member[s]) as significantly impacting on their physical and/or emotional well-being.

SAC 3 and SAC 4 rated adverse events may require 'low level' Open Disclosure, but this decision still depends on the perceived significance of the outcome for the patient (and/or family members). The following statements provide evidence of how complex circumstances can be due to contradictory indicators:

"But there are some [adverse events] where we've done one Open Disclosure where, in fact, it didn't meet the criteria as an incident. Now that seems really odd. But it became evident over the progression of time that perhaps we should have called it an incident. Perhaps there were elements that started to come from the family that we weren't quite aware of and then we said in the first meeting, 'Okay, we need to go back and do some analysis on this and see what we can improve and we'll come back and see you again.' So you sort of have to be guided by the family's needs."
[Support Personnel 28-194]

"The consequence of the outcome was small. The significance for the patients or relatives or something may have been higher than that. So we've done those and we've certainly done an Open Disclosure on a SAC3."
 [Support Personnel 28-190/1]

For these interviewees, **the high/low distinction does not do justice to the complexity of the decision making involved**. Not surprisingly, those who have less extensive experience with Open Disclosure (than do Support Personnel who tend to have extensive experience in Open Disclosure) regard the question as to what triggers Open Disclosure as a vexing one.

"Perhaps we need more clarity about severity of things that need disclosing. There are clearly very minor things. I reckon Open Disclosure about minor things causes havoc without benefit that things must be disclosed. So, guidance about what do disclose and what not to disclose in a more corporate way might be helpful."
[Medical Clinician 54-8]

"The question is about whether to tell someone something that will not cause any future harm and cause anxiety or do you not? ... What I would like to see is clarification. Nationally, which cases are we talking about here?"
[Nursing Clinician 55-4]

What is reassuring is that interviewees with higher levels of Open Disclosure experience consider the task of determining whether there is a need for Open Disclosure to be a less vexing issue:

"I suppose anything where the planned event hasn't gone according to those plans [requires disclosure]. [In] Maternity we know that not everything goes to plan, so we're used to talking to our clients fairly openly and honestly in regard to what happened or why they needed to go to theatre for a Caesarean or what happened to the baby ... so I couldn't tell you exactly what events [we disclose] because they're different with each pregnancy unfortunately, but, basically if it doesn't go to plan the way the woman hoped it would go, as in a normal vaginal birth, then we always sit down with all of our clients and discuss what happened and what we can do to change that next time."
[Allied Health Clinician 88-90]

The next two quotes show that staff interviewed simplify matters for themselves by regarding disclosure appropriate for 'complications' as well as (what this interviewee refers to as) 'stuff-ups'.

"There is a difference between complication of treatment and stuff-ups of treatment. We have to be open about complications and stuff-ups."
[Senior Medical Clinician 66-16]

"It does not have to be something really that arises from a mistake. And the ones I have been involved with especially have been complications that are considered even routine or considered part of what would be expected in the care of a complicated and unwell patient. Even just identifying that even if there is a complication can be considered an adverse outcome,

not just a surgeon made a big mistake. That in itself improves not only patient's perceptions but also their outcome at the end of the day."

[Medical Manager 64-26]

These encouraging statements need to be read with the following caveat in mind: disclosure of unexpected outcomes as yet means different things to different health care staff. As our patient and family interview data analysis shows, adverse events that should have been disclosed on the basis of formal Open Disclosure – that is, utilising formal notification and recording processes, involving appropriate clinical and support personnel, and structured on the basis of careful pre-planning, enactment and follow-up of Open Disclosure[15] – were not always disclosed appropriately. In light of that, and without wanting to downplay the importance of clinicians' showing themselves to be comfortable with disclosing adverse events, news of health care staff's confidence in 'doing Open Disclosure' needs to be balanced against consumers' claims about clinicians' preference for informal, non-apologetic disclosure, even in the case of high severity adverse events (see Section 2.5).

2.4.1.2.2 'Near hits': The adverse event 'just misses the patient'

The question whether to initiate Open Disclosure for 'near hits' (usually referred to as 'near misses' in the patient safety literature (cf. Runciman, Merry, & Walton, 2007)) is a troubling one for many interviewees. Many responses we received to questions about when health care staff would deploy Open Disclosure are characterised by uncertainty and confusion, as discussed above.

Attempts proposed to impose clarity on this complex domain of decision-making fall into three categories.

Category 1. The decision whether to deploy Open Disclosure in the case of 'near hits' is subjected to *medical* reasoning only. By way of example, the interviewee cited below formulates the principle that underpins their decision making for them with relative ease. This ease however is achieved because the criteria governing the decision whether or not to deploy Open Disclosure are framed in purely medical terms. Such framing enables the decision-maker to omit considering the impact of the adverse event on the patient (and/or family):

---

[15] State-based and organisation-based policy documentation has been created to accompany and refine the Australian Open Disclosure Standard. That documentation sets out exhaustively what formal Open Disclosure entails (e.g. NSW Health, 2007; Queensland Health, 2006b).

"if the harm has resulted in a temporary reduction in function or any effect that is felt by the patient then it is, we will determine it as a serious adverse event, so anything that we risk rate and classify as a serious adverse event is, becomes a High Level response. And anything that we just call a low, not a serious adverse event, it's a moderate or a minor impact on the patient, like, you know, somebody has had a medication delayed by triage, but hasn't really affected them, that's a low level."
[Senior Medical Manager 60-106]

This same interviewee regards disclosure to depend on whether the incident 'reaches the patient'.

"Our clinical practice is that any adverse event should be disclosed. Any incident where an error has reached the patient, and that's the way we describe it, if an error has reached the patient it should be disclosed to the patient."
[Senior Medical Manager 60-106]

On this principle, in cases where the adverse event does not reach the patient, no disclosure is made on grounds that you would not be able to specify the implications of the near hit/miss for the patient.

"Near misses, the way we describe near misses is that there was a potential for an error to occur but it hasn't reached the patient, so therefore we don't [disclose], because it has not happened. You know, somebody stopped it from happening."
[Senior Medical Manager 60-106]

The implications of this principle are that:

1. organisational processes that have put the patient at risk without causing obvious harm are not discussed with the patient on the assumption there was and will be no harm;

2. control over the decision to disclose may remain entirely within the purview of the health professional;

3. risk is created of other-initiated adverse events notification: someone other than the treating clinician may alert those (potentially) affected and issue a request for disclosure.

Category 2. The decision whether to deploy Open Disclosure in the case of 'near hits' is subjected to *organisational* reasoning only. Here, disclosure of SAC 3-4 rated adverse events is made to depend on whether the event was a divergence from planned action. If planned action failed to occur, the organisation should take steps to find out why it did not occur, communicate to the patient that it did not occur, and take steps to ensure that it will occur in future.

However, not all processes in health care can be comprehensively mapped out due to their complexity (Lillrank & Liukko, 2004). On the one hand, many patient management plans are short-term requiring constant review (Cox, 1999). On the other hand, many clinical processes that could potentially be 'path-wayed' (because they are relatively predictable) are not pro-actively mapped out because clinicians lack organisational support and skills enabling them to do so (Degeling et al., 2001). Given clinicians' high professional skill and knowledge levels, and particularly in emergency and other unplanned situations, it is not surprising that standards of care and service are expected that go well beyond pre-determined plans and procedures (Hollnagel, 2006). It may be problematic, then, to limit disclosure of 'near hits' to instances where care has been pro-actively planned.

Category 3. The decision whether to deploy Open Disclosure in the case of 'near hits' is approached as a dialogic process. Given Open Disclosure is a dynamic and complex process that cannot be fully proceduralised, staff need to apply professional, organisational *and* ethical judgments when determining which events to disclose. At the minimum, and without dismissing arguments that there are cases where Open Disclosure may not be appropriate (see table 2.6), it is necessary to obviate non-disclosure of events whose impact is (or would be) considerable in the eyes of the person (people) involved in the event. Were it to become a common cultural norm, standard disclosure of unexpected outcomes could benefit the organisation as a result of the dialogue that the event gives rise to.

> *"So they [staff] not only benefited from it [Open Disclosure], they learned from it and they're now teaching others."*
> [Support Personnel 73-37]

This does not mean that 'near hits' are per definition subjected to Open Disclosure. Importantly, this third category of decision-making involves delving more deeply into the nature and circumstances of the adverse event:

"You don't need to go and necessarily tell a patient, 'Oh, we had a near miss with you'. You still need to couch it, and the organisation needs to treat them as important as other clinical incidents ... often a near miss could be a representative pattern of a series of near misses where you may not know the whole pool of people who have potentially had that near miss. What are you going to do? Put out a recall on all patients between X and Y, dates, where you think they may or may not have had [the incident]? ... I certainly meet with my Clinical CEO, we run over our clinical incidents, and if there is a trend or a near miss where you would ask the question, 'Have other patients been potentially affected?', you've also got to be able to isolate who those patients are that actually derive some benefit, otherwise it's a fixing-the-near-miss-system failure"
[Support Personnel 26-191]

The stance advocated here is that 'near hits' need to be carefully discussed and closely thought through. Such discussion and analysis is dialogic, involving all relevant stakeholders, including patients (and/or families). Two principles apply:

i. 'unexpected outcome' is a phrase that should incur two questions: unexpected for whom? and 'outcome for whom'? The answers to these questions cannot always be determined by clinicians on their own, requiring negotiation with colleagues and consumers;

ii. any unexpected outcome is worthy of attention and learning.

Finally, the importance of discussing a 'near hit' with colleagues (*"so the debate was should we tell this woman"*) about whether to disclose or not is evident in the following vignette reproduced on the next page.

Vignette:

The ethics and pragmatics of disclosing a 'near hit/miss'

"If I can give you an example of that, where I did an Open Disclosure in relation to a near miss and I, I was sure at the end of the process that it was the right thing to do. So maybe this illustrates the problem. … We had a woman who went under a general anaesthetic for a minor procedure and the anaesthetist gave her the wrong anaesthetic. It was a muscle blocking agent, a paralysing agent. Now, there was a very small risk to the patient because she was there being monitored, the anaesthetist recognised the mistake straight away, and reversed the anaesthetic given, etcetera, etcetera. So it was controlled, no risk, the patient woke up and wouldn't have known, well we didn't think would have known anything about that near miss but it was potentially, conceivably a life-threatening mistake … so the debate was, should we tell this woman that we made this mistake, and we actually decided that we would. I was in two minds about it. I rang her and I said (I did it by phone because I suppose it was considered to be not that serious to have to sit with her, but that's another issue of judgment as to whether it was the appropriate way of doing it), …'I'm phoning from this hospital, and so on, and I understand that you recently had an anaesthetic', and she said, 'Yes, I did' and I said, 'How are you? Are you okay?' and everything and anyway I said, 'Look, I need to…I've rung you because I need to tell you that in fact we made a mistake when we delivered your anaesthetic. There should be no adverse consequences for you, you won't come to any harm, but you know, we have this approach that we're always open about the errors that we make so that you trust the system. And she said, 'Oh, I wondered about that because when I woke up I had muscle aches' and one of the side effects of that drug of the paralysing agent is that it can give you sort of muscle spasm that can give you muscle ache. So she knew something was strange about that and she'd been wondering about it. So when I told her that she said, 'Oh, I see now. I understand that.' And she was very happy to be told and to have an explanation for that feeling. So you can see the value in that case."
[Senior Medical Manager 23-9]

In sum, the decision whether to deploy Open Disclosure should encompass:

1. the patient's (and family's) need and right to know,

2. the clinician's duty to apply professional-ethical judgment to their ways of working,

3. the clinical team's preparedness to discuss and analyse unexpected outcomes over and beyond the adverse event's medical-technical dimensions, and

4. the organisation's obligation to engage staff in life-long learning and practice improvement (under clinical governance).

In the final analysis, these rights, expertises, attitudes and obligations are and remain dialogic: they cannot be subjected to fixed principles about whether to engage in Open Disclosure. Important to emphasise at this point is that disclosure does not mean 'discussing the unexpected outcome with the patient (and/or family)', and that involvement of the patient (and/or family) in considering the unexpected outcome therefore does not pre-empt or obviate Open Disclosure. The distinction between conventional approaches to sharing information with patients (and/or families) about adverse events ('the clinician popped in to see the patient a few times') and Open Disclosure is addressed in table 2.6 below.

The following minimal specifications may help determine whether to deploy Open Disclosure.

Open Disclosure should be deployed under these circumstances:

1. Open Disclosure occurs in cases leading to unexpected outcomes that create unintended harm (leaving aside wilful, malicious and negligent harm);

2. disclosure occurs of 'intercepted' mishaps (even if they do not 'reach the patient') that are judged to provide learning opportunities for the patient (family), the organisation and for staff, or that are experienced by the patient as nevertheless distressing;

3. disclosure occurs of events that peer judgment classifies as breaches of an accepted standard of skill, a formal rule or an established fact of knowledge, and

4. decisions to disclose are achieved dialogically – through negotiation with the relevant stakeholders.

2.4.1.3 Pre-planning the Open Disclosure session

Pre-planning the Open Disclosure session is seen as very important, particularly for High Level disclosures. Pre-planning is composed of a complex set of activities and objectives, a diverse group of people, and it generally happens rapidly. Pre-planning is seen to encompass at least the following overarching tasks: 1. **Understand the adverse event**; 2. **Assemble the team**; 3. **Assess the patient/family dynamics**; 4. **Plan the disclosure**

dialogue, and 5. **Decide how to interface Open Disclosure with other dimensions of Incident Management** (tables 2.4.1 to 2.4.5 below).

Table 2.4.1: Open Disclosure Pre-Planning Activities 1: *Understanding the adverse event*

Open Disclosure Pre-Planning Activities *Understanding the adverse event*	Relevant Interview Quotes
1 **Establish the (nursing, medical, allied health and administrative-managerial)** *facts of the adverse event*	*"Usually we'll talk to the person [the clinician most closely involved in the adverse event] and make sure we've both got a common understanding of what the event entailed and make sure we've both looked at the history and the medical record and make sure that the Nurse Unit Manager has got a handle on all the nursing issues and I'm okay with all the medical issues [because] we've talked to the relevant people."* [Medical Manager 67-133]
2 **Decide whether the adverse event requires** *High Level Open Disclosure or Low Level Open Disclosure*	[see Section 2.4.1.2 above]
3 **Establish whether the adverse event needs to be reported to the** *Coroner or Crown Solicitor*	*"… not every event is notified to the Crown Solicitor, but because of insurance requirements, the hospitals are obligated to notify the Crown Solicitor if they think something may occur out of it"* [Allied Health Clinician 91-98]
4 **Establish whether there are any** *legal, insurance and financial implications* **(such as ex-gratia payments) and related information that needs to be gathered beforehand**	*"And I'll know whether I'm offering um payments for taxis or compensation or whatever."* [Medical Manager 42-94] *"And we look at 'will there be financial costs'. There's a whole pro-forma that [State] has got and you actually go through all that. You look at legalities. You look at financial support. You look at what we might offer. Um, social work, counselling. There's a whole gamut of things that we actually work through."* [Senior Support Personnel 27-56]; *"A number of times that they [the patient] will sit there and say, 'Well, now we're going to pursue litigation. Can you on the spot agree to pay us X amount of compensation?' That always floors the clinicians. Because I've had a medico-legal-management role I just say, 'Well, you know, here I'll pass on your, our details, our insurer's details and you're welcome to get in touch with them, and we're quite happy to consider unmitigated claims."* [Support Personnel 2-104]

Table 2.4.2: Open Disclosure Pre-Planning Activities 2: *Assemble the team*

	Open Disclosure Pre-Planning Activities: *Assemble the team*	Relevant Interview Quotes
1	Establish *a reliable team of clinical and/or administrative-managerial staff* that can be drawn on for urgent High Level Open Disclosure meetings	*"… what we try and do is, consistent with the policy, we have a team of three for the major disclosure processes. So we ideally have the senior clinician involved in the case, a patient representative/client liaison officer, and a representative of the administration for the hospital or wherever the incident occurs."* [Senior Clinical Manager 1-2]
2	Enquire into *staff attitudes towards and feelings about the adverse event*	*"I've got a clinical superintendent who I mobilise immediately for the medical officers [and] who reports back to me and lets me know how the staff member is travelling."* [Senior Medical Manager 24-48]
3	Determine *who of the clinical staff to invite to the Open Disclosure meeting* and to what extent it is necessary to involve them in a separate pre-planning meeting	*"… you [might] get someone who's inexperienced running a [Open Disclosure] session, and that person might slip up and therefore be exposed."* [Medical Manager 33-26]
4	Decide whether *the person most closely involved in the incident* should be invited to come to the Open Disclosure meeting or not	*"… if you are in a situation where you've got to do an open disclosure and you've got a choice between two clinicians to do it, then you're going to go for the person that you know has a better way of doing it."* [Support Personnel 23-35] *"We make an assessment: we bring the doctor in and say 'so tell us all about it'. And if they're saying 'That bastard of patient did this and that and the other thing', they're not getting back near them [the patient]."* [Senior Medical Manager 47-88]
5	Negotiate with *staff who are attending the Open Disclosure meeting* the disclosure strategy that is to be adopted; this needs to be done without fully scripting the meeting and thereby risking its authenticity	*"I mean the preparation with the clinician was minimal, like the registrar just walking to the meeting, I was just briefing him that I'll do the introductions, you just say what happened, and then I'll just explain the process, and wrap up the meeting. So that's pretty much quite limited in preparation, because … you've got to be natural, you can't be not natural. You want to be prepared, but yeah, [you] can't be scripted."* [Support Personnel 48-137]

Table 2.4.2: Open Disclosure Pre-Planning Activities 2: *Assemble the team* **(cont'd)**

	Open Disclosure Pre-Planning Activities: *Assemble the team*	Relevant Interview Quotes
6	**Devise *a strategy for junior staff* who are involved in adverse events:** This strategy should resolve whether junior staff should be protected from confronting victims of (particularly serious) harm and talked to separately, or whether they should be invited to observe or participate in the Open Disclosure process. This involves carefully selecting the Open Disclosure sessions so junior staff are likely to benefit from being present.	*"If there are apologies to make and I thought they [junior staff] were competent [to do that], and there are some that are competent, I would involve them in that process. But in general terms most of my difficult patients … come back to a special clinic where I have control of that situation."* [Medical Manager 29-20] *"The junior staff member, no. We wouldn't involve them at all. What we would do, though, is that we would have the senior clinician or the director of that area be the person who's going to talk to that [junior] clinician and advise them how we're proceeding, so they're not having an anxiety attack in the background."* [Support Personnel 44-193] *"If there are any juniors, they are there when they discuss the first meeting to say, 'This has happened', you know, 'Your dad or whoever', 'this has happened and we are doing an investigation. We will follow up and let you know'. And usually at that second meeting it is the Senior Consultant who has been involved in the care who would have that second meeting and the registrars usually follow them up and make sure they [the juniors] are involved and they know exactly what is the conversation."* [Medical Manager 70-112]

Table 2.4.3: Open Disclosure Pre-Planning Activities 3: *Assess the dynamics of the patient/family*

	Open Disclosure Pre-Planning Activities *Assess the dynamics of the patient/family*	Relevant Interview Quotes
1	**Find out *details about the patient's and family's reactions to the unexpected outcome***	*"We really just try and predict what sort of things might be their concern and see if we can understand the facts around what their concerns might be so that we can actually explain it well enough back again."* [Senior Support Personnel 2-103]
2	**Determine *who of the patient's family should be invited to the meeting***	*"… we encourage them to bring a cast of thousands if they wish."* [Support Personnel 28-195]
3	**Identify a family member as the *single spokes and contact person*;** this is important to obviate different family members conducting unrelated conversations with staff	*"You need spokes people so you need to be able to talk to the patient and one person who fully understands and if you start getting outside that field you start running into difficulties."* [Medical Manager 29-28]

Table 2.4.4: Open Disclosure Pre-Planning Activities 4: *Plan the disclosure*

Open Disclosure Pre-Planning Activities: *Plan the disclosure*	Relevant Interview Quotes
1 **Plan *language to use* and practise how to apologise given the specifics of the adverse event**	*"We sit down and go through who's going to do what and organise who's going to say what."* [Support Personnel 34-5] *"Yes, [we plan] who's going to open the discussion, who's going to say the apology … is there going to be any offer of support to the family, counselling or monetary support. [Pre-planning] takes you through all the practice steps and it takes you right through that journey, [including] who's going to talk about the investigation."* [Support Personnel 54-98]
2 **Prepare a strategy for and position on how to *record the Open Disclosure meeting* and whether to share that record with the patient (family)**	*"… they will often come and ask, 'Can we tape this?' or sometimes they even do it surreptitiously. They'll bring a tape recorder in. Some mobile phones can tape, you see, so they just put their mobile phone on the table and put it on and we don't even know, so that's another risk inherent in the system. But in this case they asked us to tape it and we agreed, rather than …giving them a tape we'd actually do a transcript of it."* [Senior Clinical Manager 4-9]
3 **Arrange *a suitable space* for the Open Disclosure meeting;** such space may need to be an isolated one in case privacy is needed for the expression of emotions, one that has easy access and exit, one where there are no dangerous unattended (throw-able) objects, and one that has a low table with tissues and water (or tea) for everyone	*"First and foremost, make sure they're comfortable. Actually happy with the room, you know, 'Are you okay here?' I always tell them where it will be, who'll be there, you know, are they happy, because sometimes some people aren't happy going up to the fourth floor of A Block. They prefer somewhere away from that area because it might be that, I don't know, for whatever reason, so just to make sure that they're happy with the place."* [Support Personnel 29-182]; *"Nice low coffee table, water, tissues. Plenty of. They shouldn't need to ask for any of those. They should be there. A good room is a social work room, a reasonable amount of space, comfortable chairs."* [Support Personnel 46-202]

Table 2.4.5: Open Disclosure Pre-Planning Activities 5: *Deciding how to interface Open Disclosure with other dimensions of Incident Management*

Open Disclosure Pre-Planning Activities: *Deciding how to interface Open Disclosure with other dimensions of Incident Management*	Relevant Interview Quotes
1 **Decide on how to *interface Open Disclosure with Root Cause Analysis (1).*** Interfacing Open Disclosure and Root Cause Analysis can have advantages, in that staff can cross over between these two tasks and benefit from being familiar with both the clinical and the personal dimensions of the adverse event. Interfacing can also be problematic, however. RCA's basic principle is to objectify clinical error through 'hindsight bias' (Dekker, 2005). Then, RCA seeks to formalise procedural constraints rather than nurture shared personal insights and error wisdom (Reason, 2004) in that it proscribes those originally involved in the adverse event from acting as anything other than as interviewee. Most important within the context of the present report, in Australia RCA is largely conducted without involvement of consumers (Iedema, Jorm, et al, 2006). Evidence is emerging from the US where openness is found to mitigate consumers' urge to complain and litigate (Wojcieszak, Banja, & Houk, 2006), leading to novel partnering with insurance companies (Berlinger, 2005; COPIC, 2004). UK-based consumer involvement research provides models for 'collaboration' with consumers' in incident management and practice improvement (Mansell, Harris, Carthey, & Syed, 2005).	
2 **Decide on how to *interface Open Disclosure with Root Cause Analysis (2).*** Interfacing Open Disclosure and Root Cause Analysis is seen to be particularly problematic in South Australia. In that State, Root Cause Analysis information falls under Qualified Privilege, obviating disclosure after the Root Cause Analysis process has started[16].	*"In this state [SA] and probably others if you have SAC1 or sentinel event they say in this state we have to do an RCA. And in this state, there also has to be, we want you to use 64D or qualified privilege. So, we said sorry but this does not actually fit with Open Disclosure"* [Support Personnel 93-81]

---

[16] Jurisdictions other than South Australia also protect information generated as part of RCA. For example, the NSW Health Administration Act 1982 s20Q is substantially the same as the sections applying to quality committees, the only difference being the insertion of the term 'RCA team' instead of 'quality committee' in the South Australian legislation. It is also important to note that the South Australian health legislation is currently being reformed. Legislation currently before parliament in South Australia - The Health Care Bill 2007 - has a new Section s66 which protects information from quality activities (this is not very different from the former s64D) and a new Section s73 which protects information arising from RCA's. Noteworthy is that the South Australian Bill states that "Most people were happy" with protection of information that is produced as part of quality improvement activities.

Table 2.4.5: Open Disclosure Pre-Planning Activities 5: *Deciding how to interface Open Disclosure with other dimensions of Incident Management*

Open Disclosure Pre-Planning Activities: *Deciding how to interface Open Disclosure with other dimensions of Incident Management*	Relevant Interview Quotes
3 **Deciding to what extent to involve consumers in these processes.** This study recommends erring on the side of consumer involvement in investigation and improvement processes (see Section 2.5).[17]	*"… in those instances where we've started an RCA and recognise that there hadn't been a disclosure and there's pressure on to do the disclosure because the Area's policy is very much that we try and gather information from families or give them an opportunity to pose any questions for the RCA team to consider, we put a bit of pressure on our teams to actually make contact with the family via the nominated person"* [Support Personnel 11-100]

Two points about *pre-planning pro-formas*:

1. *Does using pre-planning pro-formas diminish the Open Disclosure meeting's authenticity?* For several interviewees, scripting strategies and language for the Open Disclosure meeting using pro-formas can become an activity that detracts from the authenticity of the Open Disclosure meeting.

    "I think … not that you're in there with a script that you're disclosing. I think that this uh notion of um um, um being in your communication just open and honest and I think that's the thing that makes it work, I think families genuinely react to … if you go in there with an agenda about how you're going to do this." [Dir Clin Gov Gr120]

    Pro-formas are recognised as being useful for those with limited experience, but they are seen to be less useful by those who have Open Disclosure experience.

    "It structures that meeting using that form. But given it's pro-forma the way it's written now, it invites you to have to write something" [Support Personnel 47-196]

---

[17] This particular recommendation raises a question about Root Cause Analysis (RCA) as it has been defined in Australia (New South Wales Health Department, 2004) as well as querying the way Open Disclosure currently links in with RCA and other forms of incident investigation such as HEAPS (NSW Health, 2007; Queensland Health, 2006b). See Section 4 below.

For one interviewee, the pro-forma proves useful to script the initial contact call aimed at inviting the patient (or family) to the Open Disclosure meeting, to make sure all important points are made.

> *"We actually had a party-line script that we all worked to for the initial telephone conversation, um, now that was to ensure we said just enough, ... our aim of the telephone call was just to get them to come into hospital ... So, yeah, we effectively did work to a script for that one."* [Dir Ment Gr56]

Thus, pro-formas aid pre-planning because they help staff prepare the language to use for the meeting, but interviewees emphasise the importance of staff acting naturally.

> *"What we've actually done here is, instead of trying to say it up top, is to let it happen naturally"*
> [Senior Support Personnel 45-55]

2. *Does the information recorded on pre-planning pro-formas pose a Freedom of Information or a Discovery risk?* For some interviewees, the information that is written on pro-formas, including provisional details about the adverse event, tentative understandings of the patient's and family members' state of mind, and related kinds of 'soft information'[18], potentially pose a Freedom of Information or Discovery risk. They are conscious that the generative intent of the pro-forma ('jot down provisional understandings and possible scenarios and utterances') incurs a legal risk due to such 'soft information' being subpoenable.

> *"It structures that meeting using that form. But you've got to be careful what you write in case it is FOI-able. So you would never include some things in a meeting."*
> [Support Personnel 28-196]

The following quote highlights the uncertainty this same interviewee has about the legal status of the pre-planning pro-forma:

---

[18] 'Soft information' is information that remains subject to change. In contrast, 'hard information' is information that has stabilised and is therefore considered appropriate for publication.

> *"I would see that [pro-forma] document as a working document. It's not the document I would say should be the FOI-able component of Open Disclosure. [But] I don't think it's protected. I think it probably does have some concerns because we don't know where that document sits in FOI land or its disclosurable-type status. Some places don't use it or write on it [for that reason]."* [Support Personnel 28-196]

There will inevitably be 'soft information' that turns out to be based on wrong assumptions, incomplete or inappropriate, and that therefore will be changed. For that reason, soft information may be useful only for *tracing the development of clinicians' thinking* about the adverse event and how that bears on the disclosure (see Section 4 below, table 4.3).

Pre-plan the Open Disclosure meeting in the knowledge that:

1. staff will not be able to predict entirely how the Open Disclosure meeting will unfold, and

2. staff need to remain flexible with regard to how the Open Disclosure meeting unfolds and how many meetings they may need to have with the patient (and/or family).

2.4.1.4 Scheduling the Open Disclosure meeting

Scheduling the Open Disclosure meeting is not quite like making a formal appointment. Since staff need to be sensitive to how the adverse event unfolds, and to how the victims of harm are responding to the adverse event, scheduling involves more than arranging a meeting time and date. As the vignette below shows, scheduling the Open Disclosure meeting can be a complicated matter.

Vignette:

Scheduling the Open Disclosure meeting

"… it [the incident] happened on a Sunday evening, knew about it on Monday, the Tuesday I was working to find out what was going on, and I was speaking to the clinician. So we thought, well we'll … we'll talk to the family on the Wednesday, um and we planned to approach, and let them set up the meeting, um but the boy fell … more critically ill, so we decided not to, it wasn't appropriate timing. But then, that same day … we did the tracking of the [surgical] instrument, and the … the previous patient was Hep B positive …. So it … just kept on getting worse, more intense as to what we were going to disclose. Um, um, but thankfully, before … we went and approached the family, we had found out that the young boy was Hep B immune, because he'd had … he'd had … his immunisations for that, so that was good. Um, yeah, so we sat … with the family … . The registrar approached them that evening, no, it wasn't, that was a Thursday … and said, 'Can we meet with your family?' … and went to the boy's father … and set up a meeting."

[Support Personnel 30-135]

Considered most important, scheduling the Open Disclosure is seen to involve *appropriate timing*. 'Appropriate' harbours four distinct expectations:

Table 2.4: Scheduling Open Disclosure

	Scheduling Open Disclosure	Relevant Interview Quotes
1	**Schedule the Open Disclosure meeting in a timely manner**. On the one hand, interviewees are clear about disclosure needing to take place in a timely manner. Here, what is considered important is dealing early and quickly with the problem. As noted above with regard to adverse event notification, the earlier an incident is registered the earlier it can be acted on, and the better able staff will be to manage the ways in which the adverse event is presented, discussed, and handled.	*"I think it's early recognition [of] a problem where a mistake has been made, where it's reported and the appropriate report [has been filed], and someone actions it, and we get in there quickly and try to deal with it. Early flagging it is important, early meeting with the family and the patient. Obviously the key principles are early acknowledgment of a mistake and an apology for it."* [Medical Manager 26-215]

Table 2.4: Scheduling Open Disclosure (cont'd)

	Scheduling Open Disclosure	Relevant Interview Quotes
2	**Do not rush to arrange the Open Disclosure meeting**. Paradoxically, interviewees advise us also that it is important 'not to rush into the situation'. They state that it is easier to recover people's trust following deferred disclosure than to maintain trust following premature and unsuccessful disclosure. Taking time to assess the situation (patients' and family members' responses and views on Open Disclosure) will prevent the meeting being organised in a way that does not meet (or contravenes) the needs of the patient (family). While these two principles may appear to be contradictory, they nevertheless have one thing in common. They point to the need for staff to be sensitive to *how consumers perceive and experience time since the occurrence of an incident*. Timing the disclosure under these circumstances depends on being able to listen to how patients and family members are responding to the event, and to schedule the disclosure such that it reaps maximum interpersonal benefit for them.	*"… there's a lot of emphasis … put on timely disclosures. I think in our experience that's not always been necessary and, where people have rushed in we've had problems. Sometimes of course you need to sit people down and say 'look something bad has happened, we don't know the details yet but we'll keep you in the loop as we try and work through this'. That is I suppose a reasonable opening gambit for an Open Disclosure. But, equally, where we've missed the boat with early disclosure, we've often been able to recover it very successfully weeks or months down the track. And in some ways that's been some of our more successful disclosures, because people have gone away and realised that there's something wrong and they're very grateful that it's been identified and they've been contacted after the event."* [Medical Manager 29-92] *"… when I spoke to [patient's name] in regards to the meeting she was okay about the idea of it, but she said the more she thought about it the more she got a bit daunted that somebody fairly high up was going to come and speak to her. When I explained to her, 'Look, we just want your word that, we're not having a go, it's not a big meeting', but I think within the hospital system, having a woman with that title [senior hospital staff who was going to attend the Open Disclosure meeting] was just kind of like, 'Whoah.' But also she [the patient] was actually really to open to the idea of having a meeting. It just happened to be not the right time on that particular day."* [Allied Health Clinician 99-96]
3	**Arrive at the Open Disclosure meeting on time** An important additional point is that once the meeting has been scheduled staff need to show up on time:	*"And you've got to turn up on time. Don't turn up late, alright. There's nothing worse. Where one went pear-shaped … he [clinician] turned up late"* [Support Personnel 32-202]
4	**Respect consumers' wish to change the time (place) of the Open Disclosure meeting**. Making an Open Disclosure meeting appointment should not be regarded as exhausting staff's responsibility to schedule a meeting with the patient/family members. If the patient/family members request a change of time, it is important that staff respect their wishes.	*"There was a lot of work done. … Not 'Well, we'll have a meeting next Tuesday at ten o'clock and catch you there and we'll talk to you about it then'. You know you're dealing with people's feelings and they take a while to generate trust on that."* [Support Personnel 32-202-3]

The vignette below illustrates staff need to be sensitive to context when scheduling a meeting.

Vignette: **Scheduling the Open Disclosure meeting #2**	*"Something has occurred that shouldn't have occurred. But it could've, it could've occurred because of one of three reasons. So, if you did an open disclosure at this point in time, you're not quite sure, what you're openly disclosing. And equally, it, it's such a fragile stage at this point in time, that are you really adding value? Are you actually contributing anything at this point in time? Now it's not saying, no we're not going to do it, it's saying okay, this is not the right time at this minute. You know, there's too much happening right at this moment in time for family members to be able to take on anything more. And, so we're doing some quick preliminary investigation to try and determine what indeed it is that needs to be disclosed to them, at this point in time. And so we haven't done the initial disclosure within twenty four hours, because we've discussed it and felt, no, we're not at that point where we can actually do something, it's going to do more harm than good, right at this moment. So you certainly, you need to change it a little bit sometimes, but it shouldn't be a decision made in isolation, it should be a consultative decision, so that people that need to be involved are involved in that decision making."* [Support Personnel 7-31]

Appropriate timing and scheduling require that staff:

1. arrange the Open Disclosure meeting in such a way and at such a time that patients' and their family members' needs and expectations are met;

2. balance the need not to delay the Open Disclosure meeting for too long with an equally important need not to rush into the meeting and risk giving out explanations that have been not been thoroughly checked and discussed with colleagues.

2.4.2 Conducting the Open Disclosure meeting

2.4.2.1 Introduction

Once the Open Disclosure meeting has been prepared and scheduled, and the relevant people have been invited to the meeting, staff who have taken it upon themselves to lead the meeting confront the reality of negotiating the news of the adverse event formally with the patient and their family. Here, the pre-planning that staff have done is put to the test of the dynamics of patients', family members' and clinical colleagues' responses and actions.

Invariably, when asked about how they generally enact the Open Disclosure meeting, interviewees' first response is to point to the unpredictable dynamics of human interaction in the context of unexpected outcomes and harm. Not surprisingly, one of the most frequently occurring phrases in their responses is 'it depends'[19]. In our Interim Report, we referred to this unpredictability as embodying the *emergent* dimension of Open Disclosure: Open Disclosure has a minimal set of characteristics, but its practice is difficult to proceduralise in terms of a simple set of steps. Interviewees acknowledge Open Disclosure needs to be approached as a dynamic kind of decision-making and strategising[20]. Its unfolding depends

---

[19] The frequency of use of the term 'depend' (as the root of 'depends', 'depending', dependent' and 'depended') outnumbers that of 'doctor', with 'depend' occurring 248 times in the transcripts (total words: 414,046).

[20] Open Disclosure is typical of a "decision setting [which] does not allow the decision-maker enough time of information to generate perfect solutions with perfectly rational calculations. Decision making in action calls for judgments under uncertainty, ambiguity and time pressure. [hence] Decision and action are interleaved rather than temporally segregated. The decision maker is thus seen as in step with the continuously unfolding environment, simultaneously influenced by it and influencing it through his or her steps" (Dekker, 2005: 80).

on what transpires about the incident, how the adverse event is experienced by all involved, what is said about it, and how these things in turn are responded to.

To capture this emergent dimension of Open Disclosure while at the same time not losing track of important general advice about how to run the meetings, we frame interviewees' experience and advice in terms of 'minimal specifications' rather than in terms of a rigid protocol (Plsek, 2001). This is to encourage health care staff to recognise that the application of Open Disclosure rules is contingent on their comprehensive understanding of the adverse event itself, of people's feelings and perceptions, and of the consequences of everyone's actions and statements. For this understanding to be comprehensive, it must be anchored in ongoing attentiveness to others' words, perceptions, feelings, and needs.

The complexity of realising one's Open Disclosure plans is evident from the vignette below.

Vignette: **How the Open Disclosure meeting can disrupt plans**	"[it was an incident involving] an over-toxic drug given in overdose … and the um, [the clinician] who was a trained support person sat down with the family and went through the disclosure process. And I have absolutely no doubt that it had been done very, very competently. The family's reaction however was really interesting. … the child was still in care and was going to be there for several months still to come, and the family went around and undermined the confidence of every other parent in the unit by telling them what had happened. So, you know, there is this real balancing act about was that the right thing to do. I don't know. Would we'd been better to have disclosed towards the end of the care. Don't know. But, there's a real down side which we then had to manage. I think in retrospect, it was the right thing to do to disclose early, but we needed to give more thought to the follow effects. And I think what we tend to do is focus on the disclosure as the event rather than part of the process. It can't be taken in isolation." [Med Mgr Blck85]

That said, and when the pre-planning of the Open Disclosure meeting has been concluded, the enactment of Disclosure minimally involves the following components (table 2.4).

Table 2.5: Components Of Open Disclosure Meetings

	Component of Open Disclosure	Probe
1	*Saying sorry*	How, and how often, does the Open Disclosure team say sorry in an environment that is emotionally charged, legally risky, and personally and organisationally confronting?
2	*Doing 'reflective listening'.*	How can staff practise 'reflective listening' in circumstances that can be highly confronting?
3	*Maintaining the Open Disclosure team's standard of excellent communication.*	How can the team keep those participating in Open Disclosure from jeopardising its intent by saying 'the wrong thing'?
4	*Dealing with complex patient-family dynamics.*	How can the team limit the impact of complex the patient's family dynamics?
5	*Determining the cultural appropriateness of the way staff do Open Disclosure.*	How can the team disclose adverse events when (their approach to) disclosure may not be perceived to be appropriate by the patient and their family?
6	*Distinguishing between conventional ways of dealing with unexpected outcomes and the practices required by Open Disclosure.*	How do staff differentiate between 'the conventional way of disclosing complications' and the new practice of Open Disclosure?
7	*Managing staff who were most closely involved in the adverse event.*	How can the team manage involvement of staff who were closely involved in the adverse event?
8	*Ensuring patients and family members have the right support people present without jeopardising confidentiality.*	Where do Open Disclosure teams draw the line with inviting outside support people to the disclosure meeting?
9	*Preventing Open Disclosure from going wrong.*	How can Open Disclosure teams prevent Open Disclosure from going wrong?
10	*Determining when disclosure of adverse events information is not appropriate.*	How can staff determine whether there are occasions when disclosure of adverse events information is not appropriate?

In what follows we address and elaborate each of these components in turn.

Table 2.6: Conducting Open Disclosure Meetings – Essential Components

	Conducting Open Disclosure meetings: Essential Components	Relevant Interview Quotes
1	**Saying sorry.** How, and how often, does the Open Disclosure team say sorry in an environment that is emotionally charged, legally risky, and personally and organisationally confronting? Interviewees regard the initial moment of making contact to alert the patient (family) to the need for Open Disclosure as the appropriate place to offer the first apology. The wording of the apology is a vexing issue however for many interviewees. Interviewees explain why apologising for adverse events remains a challenging matter: clinicians are restricted to offering partial apologies ('I'm sorry this happened to you') in situations where the full apology is often expected ('I'm sorry we did the wrong thing'). Interviewees with Open Disclosure experience are realistic about the potential consequences of refusing to accept responsibility for an adverse event. By the same token, interviewees acknowledge that it is not unusual for them to rely on their own judgement when it comes to negotiating liability in cases where fault is clear. They do so however in full cognizance of the insurance and personal implications of such admission. A number of interviewees comment on the unexpected benefit following their acceptance of responsibility due to its 'cathartic' effect:	*"No, we say sorry then too. We acknowledge the error and apologise for what they're experiencing."* [Senior Clinician Manager 9-4] *"No, you cannot admit liability. You can apologise and say … we are sorry that this has happened to you, but we cannot turn around and say, yes we can offer you [an explanation] … and that is some of the anger, because they keep coming back through the course of the meetings and say 'Why don't you not just say that you stuffed up?'"* [Nursing Clinician 55-5] *"I'd sooner someone who was shitty with me about failing to admit liability early than to admit prematurely and do more harm, basically. Providing I'm confident that I've done the right the thing, that I'm accountable for what I've done and that, in a sense, they get shitty with me but I don't want them to lose their relationship with the organisation, so they can go to somebody else."* [Senior Clinical Manager 22-140] *"Yes… we certainly do admit liability when we've done the wrong thing. We do it in a controlled way, though. We will check with our insurer first, because we want to be sure that we're indemnified. We will all have a good think about whether we're going to create a fresh wave of innocent victims, which is always possible if you use the wrong words and do it the wrong way."* [Senior Clinical Manager 22-140] *"And you know, ah it was one of the most dramatic experiences I ever had. As soon as I offered that [statement about taking responsibility for the adverse event] to them, it's almost like there was a breath of fresh air coming into this room, and you really could see him physically change … His tone changed, his body language changed, and he was saying things like, 'so where do we go from here? So that to me was a very eye-opening experience, very."* [Medical Manager 30-124

Given the rules embedded in the Open Disclosure Standard and the current legal climate in Australia, Open Disclosure does not sanction making full apologies. On the one hand, this is wise. The complexity of health services is now such that there are rarely if ever easy explanations for unexpected outcomes. Mandating the 'partial [Open Disclosure] apology' provides a way of preventing staff from rushing in and offering overly simplistic and potentially self-incriminating responses to patients' and family members' questions and accusations.

On the other hand, in a situation where an experienced staff member judges a full apology to be justified and to everyone's advantage, and where that staff members utters a 'responsibility-accepting' apology ('We are sorry our service failed'), such a person would be in breach of policy, thereby risking their and their organisation's insurance and indemnity cover.

As Nancy Berlinger has argued, while legal considerations are an important component of how we do Open Disclosure, health care professionals (and policy makers) should not unduly privilege their own legal, financial and reputational concerns over consumers' desire to have their dignity acknowledged. Consumers' dignity is acknowledged in simple ways: by being sincere about one's knowledge about what happened, and by accepting responsibility for anything that clearly is the responsibility of the health service (Berlinger, 2005). At this juncture, it becomes evident that while the apology may have legal ramifications for practitioners, it often principally has social and interpersonal meaning for those harmed. In that regard, the Australian Open Disclosure Standard has chosen to privilege the legal and self-protective dimensions of apologising over its social-interpersonal ones (Wojcieszak et al., 2006).

For the moment, and with the complexity of clinical practices and the existing legal dimensions of apologising in mind, advising clinicians to use the partial apology may be preferable. However, legal reform might consider making the full apology an inherent component of Open Disclosure by rendering full apologies inadmissible in Court (as it has done in New South Wales and the Australian Capital Territory). Alternatively, Australia could consider reviewing its hesitation to move towards no-fault liability (Kirby, 2000) as this exists in New Zealand, Quebec and Sweden (Vines, 2007)[21].

Such reform becomes all the more pressing in view of interviewees' accounts of dilemmas faced. In attempting to balance clinical experience, sensitivity to human feelings and needs, moral decency, strict procedure and legal norm, interviewees describe how they at times have no choice but to take risks of a kind that are

---

[21] "Adoption of no-fault legislation would be the best possible outcome. At the moment clinicians in NSW and the ACT in Australia are already fully protected however and can give a full apology. It is a pity to hold them back because of a desire for uniformity in open disclosure across the whole country" (Professor Prue Vines, personal communication, 22 Nov 2007).

proscribed by the Open Disclosure Standard and by State policy. These interviewees' honesty about the complexity of Open Disclosure lend force to the need for no-fault legislation, rather than calling for requiring stricter protection, more rules, tighter protocols, and more forceful sanctions favouring privilege or the 'partial apology'.

Table 2.6: Conducting Open Disclosure Meetings – Essential Components (cont'd)

	Conducting Open Disclosure meetings: Essential Components	Relevant Interview Quotes
2	**Doing 'reflective listening'.** How can staff practise 'reflective listening' in circumstances that may be highly confronting? Open Disclosure training emphasises the importance of listening to patients' (and family members') concerns (see table 2.10 below for a definition).	*"The Standard thing is really just to listen to them [patients/family members], and allow them to develop their arguments and then to repeat it. I think that's probably the critical issue. If they have problems, then you go through them all and you repeat them to them so you're telling me these are the issues [to] get rid of the poison. … I've had some very, very difficult patients, and you find at the end of it they will say, 'thank you.'"* [Medical Manager 37-28]
	Not everyone has the ability to enable patients and family members to 'get rid of the [emotional] poison'. Crucial in these situations is that staff participating in Open Disclosure become attentive to their own conducts, assumptions and expectations, so that they know when 'their buttons are being pushed' and the moment has come when they need to suspend their habitual responses and reactions:	*"Oh, you're opening all sorts of emotional cans of worms, and I think that if it's not done carefully and sensitively by people who have a bit of an idea of what they're doing, you can do quite a lot of damage emotionally to the clinicians involved and family members. You're dealing with some pretty raw emotions and people are hungry and you can do a lot of damage if you don't know what you're doing. Certainly you get your buttons pushed, [and] you're going to push them right back. It's those sort of situations [into which] you certainly wouldn't stick a junior untrained person who's trying to defend their professional reputation and there's an opening gambit."* [Medical Manager 28-170]

The Open Disclosure training provided in some States is considered by many interviewees as an important resource for fostering the self-reflexivity needed for staff to suspend their habitual responses and reactions. Many interviewees comment on the need for more staff to be given the training – not merely to make them better at disclosing errors, but also to make them better and more attentive communicators in general.

By the same token, once staff has mastered the art of 'reflective listening' they need to recognise that they have a degree of power over patients and family members. Reflective listening needs to be deployed wisely and ethically. It should be practised in acknowledgement that it is not applied to silence consumers' concerns, but to enable them to begin to deal constructively with the future (Iedema, Jorm, Wakefield, & Ryan, submitted).

Table 2.6: Conducting Open Disclosure Meetings – Essential Components (cont'd)

Conducting Open Disclosure meetings: Essential Components	Relevant Interview Quotes
3 **Ensuring that the Open Disclosure team maintains excellent communication standards.** How can the team keep those participating in Open Disclosure from saying 'the wrong thing'? Those trained in Open Disclosure need to monitor not merely their own utterances and their effects on patients and family members, but they also need to monitor colleagues' utterances – particularly those of colleagues who have had minimal or no training in Open Disclosure. Central to doing Open Disclosure, then, is fostering appreciation among colleagues of the challenging nature of appropriate Open Disclosure communication. Monitoring colleagues' communication is a crucially important issue, because those whose communication skills are variable represent a liability in sensitive situations such as Open Disclosure.	*"It is all about having the right people and I think that there are some people whose manner and interpersonal skills perhaps would be counterproductive in that sort of process. These people might be involved in the event. … You can imagine someone [saying] 'I go off and do Open Disclosure with this patient'. And you think 'Oh, my god. Please don't' [or] 'Can I come with you?'"* [Medical Manager 86-51]

As discussed above under the section on pre-planning, the decision to invite or not invite those involved in the adverse event to the Open Disclosure meeting(s) depends on the seniority of the clinician, and on their organisational and professional knowledge of the processes surrounding the adverse event. Their participation is ultimately conditional however on their ability to communicate appropriately (without blame) about their role and others' roles in the adverse event, and on their ability to listen (non-judgementally) to the patient and the family members. In light of that, it may happen that those in charge of Open Disclosure have to 'dis-invite' colleagues (i.e. ask them not to come to any more meetings) due to their lapsing into blame and judgementality.

Clinicians' communicative ability is now an increasingly important criterion for job selection. It is not just that those professionals who lack the appropriate communication skills constitute a liability in sensitive situations such as Open Disclosure, but it is now also increasingly clear that communicative ability plays a prime role in the prevention of errors in the first place (Leonard, Graham, & Bonacum, 2004).

Given the aim is to roll Open Disclosure out across the rest of the health system, communication training skills are therefore becoming increasingly important. While medical schools in Australia continue to teach communication in ways that underplay the need for reflexivity, attentiveness to patients' needs and feelings, and 'listening skills' (Iedema, Degeling, Braithwaite, & Chan, 2004), it is undeniable that communication is now at the heart of clinical-professional expertise rather than being peripheral to it.

Table 2.6: Conducting Open Disclosure Meetings – Essential Components (cont'd)

	Conducting Open Disclosure meetings: Essential Components	Relevant Interview Quotes
4	**Dealing with complex patient-family dynamics.** How can the team limit the impact of complex the patient's family dynamics? Interviewees commented that dealing with patients alone was often easier than dealing with family members, and that dealing with single family members is easier than dealing with any number of family members.	
	In addition to the patient's wife, husband, son or daughter, there may also be less closely related family members who may wish to share their interpretations and expectations. As a general rule, each additional person has the potential to exponentially complicate the disclosure dynamic. The less involved with the patients' care family members are, the harder it is to convey and explain the complexity that comes into play in many care processes. This, in turn, exacerbates the 'blame risk': a family member at one or more removes from the day-to-day care of the patient may not appreciate how or why particular things happened (e.g. the need for appointing an agency/locum staff who may not be as familiar with patients' care as salaried staff) and how this played a role in the adverse event.	*"[with] The patient…you get everything right. But there's a relative … out there who says … 'that's what I would expect'."* [Medical Manager 26-28]
	Staff involved in Open Disclosure need to be prepared to handle complex family dynamics and insist on dealing with **a pre-identified family spokesperson**.	

Table 2.6: Conducting Open Disclosure Meetings – Essential Components (cont'd)

	Conducting Open Disclosure meetings: Essential Components	Relevant Interview Quotes
5	**Determining the cultural appropriateness of how Open Disclosure is done.** How can the team disclose adverse events when (their approach to) disclosure may not be perceived to be appropriate by the patient and their family? This concern that clinicians may not always be able to 'get it right' may derive from the emotional volatility of Open Disclosure meetings, but it may also emerge from Anglo-Australian assumptions about truth-telling being out of step with Culturally and Linguistically Diverse Groups' or CALD practices (Tuckett, 2004, 2005), with how CALD patients and families enact their family dynamics, how they interpret and understand the purpose of Open Disclosure and 'the patient's right to know', and how well they understand the nuances of Open Disclosure talk. Dealing with people from diverse cultural and linguistic backgrounds requires additional resources on the part of those disclosing adverse events. These cultural challenges are not made easier by the difficulty staff often have finding interpreters.	*"Ah, causing more harm to the patient [is a risk]…not saying the right words at the right time … as an Open Disclosure person you're always trying… to say the right thing, and then you just hope that you do because sometimes it perhaps doesn't come out the way it should have."* [Support Personnel 44-10] *"[we need] cultural awareness. [For example] a lot of indigenous people will give you eye contact and this older guy was really annoyed at the nurses because they wouldn't give him eye contact [but we] don't understand the various community groups and their nuances."* [Nursing Manager 34-115] *"On one occasion I should have used an interpreter but was assured by the people I was talking to that they fully understood when clearly they didn't. And sometimes it's very hard to judge that. You know, some people sit there and they [say], 'oh yes yes yes', and then they speak to someone who's got a command of English and it's a whole new ball game."* [Support Personnel 12-28]
	In addition to the issue of CALD patients and families possibly needing interpreters, there is the matter of overseas trained (junior) doctors also not always being properly inducted to appreciate the purpose, practice and cultural nuances of Open Disclosure.	*"After that happened, I just made a point of [saying], if it was an older person who was non-English speaking I just made a point of getting someone there. And I would say 'look, we don't have to use this person, but this person is here just in case there's any difficulties because it's a very hard time for you and I don't want you to have to worry about not being able to understand everything that we say'."* [Support Personnel 12-28] *"… but of course sometimes it's incredibly difficult to get an interpreter. Some of the dialects aren't available. And then you get into family members who don't interpret correctly. There's no end of little barriers. [laughs]"* [Support Personnel 12-28]
	This latter challenge touches on the extent and nature of Open Disclosure training for staff. The need for Open Disclosure in the case of adverse events introduces requirements with regard to how staff are educated professionally and how they are inducted into their organisation.	*"[name overseas-trained junior doctor] needed it to be explained to him what was going to happen because it's probably not as common a thing in [his] sub-continent. And most junior clinicians aren't aware of it in the [name State] system."* [Medical Manager 46-167]

Table 2.6: Conducting Open Disclosure Meetings – Essential Components (cont'd)

	Conducting Open Disclosure meetings: Essential Components	Relevant Interview Quotes
6	**Distinguishing between conventional ways of dealing with unexpected outcomes and the practices required by Open Disclosure**. How do staff differentiate between 'the conventional way of disclosing complications' and the new practice of Open Disclosure? No doubt, staff have moved a long way from the view that "[if] a patient doesn't know about [it] they can't get angry about it" [Nursing Manager 94-55]. By the same token, interviewees expressed concern about colleagues expressing undue confidence in their understanding of what Open Disclosure involves.	*"… that's the feedback: 'We already do that well', 'We deliver bad news all the time. We do that well', and if you're dealing with someone who already thinks they do things fine … I'm finding, they don't see any need for improvement."* [Senior Support Personnel 90-142]
	A persistent theme in the interviews is that Open Disclosure is seen as making little difference to what clinicians would conventionally do when things go wrong. Interviewees say they are unsure whether colleagues' references to 'Open Disclosure' mean that disclosure of adverse events is done in the way it is prescribed in the Open Disclosure Standard (Australian Council for Safety and Quality in Health Care, 2003).	*"I mean we've been doing informal Open Disclosure for years"* [Medical Clinician 45-220]
	In view of the prevalence of comments that emphasise 'this [Open Disclosure] is what I've always been doing', it is important that training make explicit the differences between past practice and that required by Open Disclosure.	*"I suppose that previously we wouldn't necessarily have gone and had anyone else involved such as the [Support Personnel]. It would have been more informal within the Unit situation where we sit down and discuss with the patient and [address] their concerns, so I suppose it's a lot more formalised now than it used to be."* [Medical Clinician 48-220]

In contrast to how staff handled adverse events in the past they are now mandated to do the following (see table 2.6a)

Table 2.6a: New expectations that Open Disclosure imposes on frontline clinicians

	New expectations that Open Disclosure imposes on frontline clinicians
a.	Classify 'complications' and 'known risks' as adverse events potentially requiring Open Disclosure;
b.	Segregate High Level from Low Level adverse events;
c.	In the case of high level adverse events, involve specially trained staff in preparation for the disclosure;
d.	Make yourself available for pre-planning and conduct of Open Disclosure meeting(s);

Table 2.6a: New expectations that Open Disclosure imposes on frontline clinicians (cont'd)

New expectations that Open Disclosure imposes on frontline clinicians
e. In case you were closely involved in the incident, consider and discuss with others the possibility of attending the Open Disclosure meeting(s) and the implications of doing so;
f. Skill yourself in eliciting from patients (and family members) perceptions and feelings to establish whether the disclosure satisfies their needs and expectations;
g. Show in what you do and say that disclosure communication is integral (not peripheral) to your clinical-professional role and skills;
h. Acknowledge that Open Disclosure requires learning from the adverse events that is not purely technical and systems-based, but also team-based, interpersonal, and even personal, in so far as that each disclosure inevitably reshapes the patient-clinician relationship.

Table 2.6: Conducting Open Disclosure Meetings – Essential Components (cont'd)

	Conducting Open Disclosure meetings: Essential Components	Relevant Interview Quotes
7	**Managing staff who were most closely involved in the adverse event.** How can the team best manage involvement of staff who were closely involved in the adverse event? As discussed under 'Pre-planning' (Section 2.4.1.3), those arranging the Open Disclosure meeting(s) need to think carefully about involving clinicians who were close to the adverse event when it occurred. Their decision requires gauging of those clinicians' communicative skills and feelings about the adverse event, the threat of the family blaming the clinician, and the possibility that the patient and family might benefit from having the clinician there. The closer the clinician is to 'the sharp end of the incident', the more likely this person is to need support from and work closely with the Patient Safety Coordinator/Officer. At the same time, involving this clinician will require extremely careful preparatory work: how will the patient and family respond to this person being there? What information is available to throw light on their attitude towards the clinician in question?	*"I strongly believe that the people who are involved in the care should be involved in the disclosure, um, but there's as many health practitioners who aren't actually up to it."* [Medical Manager 26-85] *"If … it's sort of like … an obvious sharp end incident … where the clinician has directly caused the harm, definitely they need so much more support, than when it's something that's indirect. … So again, it all depends, some clinicians will need more support than … others. I think it comes down to the actual nature of the incident, the disclosure."* [Support Personnel 27-141]

Table 2.6: Conducting Open Disclosure Meetings – Essential Components (cont'd)

	Conducting Open Disclosure meetings: Essential Components	Relevant Interview Quotes
8	**Deciding the implications of the need to ensure privacy and confidentiality of the Open Disclosure information.** This task has two dimensions: *Participants present in the meeting*, and *Recording of Open Disclosure information*. First, where do Open Disclosure teams draw the line with inviting outside support people to the disclosure meeting? Interviewees are uncertain about the extent to which the disclosure meeting is a private and confidential meeting; to what extent its discussion can be recorded and shared with the patient and family, and whether it is acceptable to open the Open Disclosure meeting up to outsiders (friends, neighbours, colleagues, acquaintances who happen to be lawyers or doctors). While Open Disclosure resembles mediation and is in that sense comparable to 'Alternative Dispute Resolution' (cf. Berlinger, 2005), what constitutes confidentiality is ultimately and currently determined by those running the Open Disclosure meeting. Some interviewees err on the side of inclusiveness. Other interviewees regard the relative as the cut-off point beyond which no other people can be invited. Open Disclosure policy may not be able to fully determine whether only relatives can be invited to Open Disclosure meetings. Such invitation may need to depend on the nature of the relationships in question. Second, the privacy/confidentiality issue also affects decisions about whether and how the Open Disclosure meeting is recorded by the consumer. While taking notes is generally regarded as acceptable, tape-recording draws a full spectrum of interview responses, ranging from outright 'no' to 'yes of course'. Some interviewees regard tape-recording as a disturbance of the purpose of the meeting, while others consider the question of tape-recording the Open Disclosure meeting to require a carefully negotiated agreement, with copies to be distributed to all parties.	*"… for the patient not to have a support person and not wanting to have a support person, I would never, ever recommend that and I probably wouldn't organise a meeting if the patient didn't have a support person. If they had no family or friends I'd get someone from the community."* [Support Personnel 26-183] *"And we do try to make sure that they have someone with them. We always try to make sure that they have got a partner or a friend or a family member, we will ring them, get them in.* [Allied Health Clinician 98-7] *"I think the onus on management is to invite the next of kin… and give them a semi-open offer to bring with them whoever they choose. Having said that, you've then got to be careful about issues such as privacy … I attended [an Open Disclosure meeting] recently, where there was no family member present but there were significant friends … who didn't have closure following a death, and they wanted information that they had no right to had because they weren't relatives."* [Medical Manager 9-58] *"I would not normally [allow tape-recording]. Personally I would not participate in a recorded session … because I think … that it hinders the relationships that you should be forming, the dialogue between yourself and the patients, and if you make a recording, even a good recording, it can't pick up all the nuances that go on. What I have been prepared to do in the past is take minutes of the meeting and provide a draft of the minutes to the family and the patient. So I'm not averse to recording it but I'm against, well I personally wouldn't take part in one with either a tape recorder or a video machine."* [Senior Medical Manager 29-46] *"I think you have to be especially wary of it [tape-recording] and would absolutely insist that, say a recording made locally for us as well, [we'd make] copies of that tape or we'd take away a recording at the same time."* [Senior Medical Manager 29-23]

Table 2.6: Conducting Open Disclosure Meetings – Essential Components (cont'd)

Conducting Open Disclosure meetings: Essential Components	Relevant Interview Quotes
Some interviewees stated they have no problem with patients or family members tape-recording the meeting. This range of responses can be seen to suggest that some staff are more confident about their disclosure skills than others, more trusting of the motives of patients and family members, or less fearful of the consequences of transcripts ending up in the hands of lawyers. Legally, of course, a tape-recording does not exacerbate risk, as long as staff do not transgress the rules of the partial apology, of no-blame, and of non-conjecture (about the causes of the adverse event).	*"there's been a couple of occasions where people have wanted to tape and that's fine, we've done that. I have no problems with that. We've allowed them any sort of record taking they want and we've tried to always ensure that we close off with the appropriate correspondence."* [Senior Medical Manager 46-91] *"Yes, I often do [participate in meeting that are tape-recorded]. It's Open Disclosure. They [patients, families] can take whatever they want from the meeting. …We allow tape recording. When you're speaking to the family you're also speaking to everybody and you have to realise that so you just have to be cautious in the way you say things. When I say cautious I just mean that you have to be clear cut about how you say things so it can't be misinterpreted in another way, in another venue."* [Medical Manager 35-155]
9 **Preventing Open Disclosure from going wrong.** How can Open Disclosure teams prevent Open Disclosure from have adverse outcomes? In some instances interviewees talk about Open Disclosure meetings going awry. Staff's greatest fear in this regard is 'saying the wrong thing'. To prevent staff saying the wrong thing, it is considered important to pre-plan the meeting and rehearse what is going to be said. But even then things do not always go to plan: Also considered important is to arrange to have an expert in the relevant specialty area who is also familiar with Open Disclosure, such that technical questions from patients and family members can be dealt with. What needs to be prevented however is that more than two experts attend whose views diverge, potentially giving rise to contradictory answers to 'curly questions'.	*"Ah, causing more harm to the patient [is a risk]. In an emotional [sense]… not saying the right words at the right time."* [Support Personnel 26-10] *"[I was unable to] see the bloody question coming … Too slow, I'm afraid. I put my hand up. Saw it, blindsided me, killed me. The exchange happened that quick that I was not on to it and, look, I don't know if I should persecute myself because it was foreseen in that pre-planning meeting and agreed, and when it still happened I was a bit annoyed."* [Support Personnel 27-200] *"If you actually involve two [clinicians] from identically the same field, you may have some issues there because you don't want any contradiction in between them going on when there's a curly question."* [Support Personnel 27-194]

The vignette below provides an instance of Open Disclosure going wrong.

<table>
<tr><td>

Vignette
Open Disclosure going wrong

</td><td>

'Why did this happen?' and [the mother] was sad [about the death of the foetus] but sort of felt well this was unexpected and unexplained and these things just happen and you just sort of get over it. So I, of course, put my great big foot in my mouth as is my wont, and said 'Well, because the baby was small'. And she said, 'But didn't that get picked up?' [she wanted to see] antenatal records […] measuring her tummy, stuff like that, all the measurements looked alright […] and I said, 'Well, you couldn't predict it from that […]'. And she said, 'But I had ultra sounds.' And in fact she'd had ultrasounds for looking at her placenta […].if you plotted the growth of those, the baby was on a very small size, and depending on which chart you use it was either just below the normal or just on the bottom of the normal range of size, and I had some dispute with a radiologist about which chart should have been used and where you plot it, and so on. But anyway it obviously opened up this complete can of worms because what had happened was that the report of the thing said it had shown a normal rate of growth. Whereas in fact it hadn't really grown, it had gone from the top end of the bottom half to the bottom end of the top half which meant it hadn't grown very much at all in that time. And so having done something serious in interrupting her coping process, so it had gone back to 'This has not been explained!', [and] so then someone must be to blame for it', and so on. And I mean I think it really stuffed it, and I think that she is just totally unhappy, and remains totally unhappy, has complained about the doctor she saw in the clinic to the medical board and so on, and this hospital's response is to write a letter to say that basically it's my fault for saying that […] that I'd made a mistake in plotting the ultrasound measurements and I should never had said anything to her. But the answer is that the baby was small and the scan did say it was small.

[Medical Clinician 99-132]

</td></tr>
</table>

Table 2.6: Conducting Open Disclosure Meetings – Essential Components (cont'd)

	Conducting Open Disclosure meetings: Essential Components	Relevant Interview Quotes
10	**Determining when disclosure of adverse events information is not appropriate.** How can staff determine whether there are occasions when disclosure of adverse events information is not appropriate? The complex decision as to whether near misses/hits need to be disclosed was discussed above. That discussion dealt with deciding whether the severity of the (potential) adverse event and the patient's (family's) right to know added up to an obligation to disclose. At the same time, we recognise that a limited number of factors can play a role in staff determining Open Disclosure needing to be deferred temporarily or even indefinitely.	*"… this is one case where we actually didn't disclose…"* [Support Personnel 78-97]

The table below (table 2.6b) lists instances where Open Disclosure might be deferred.

Table 2.6b: Instances where Open Disclosure may be (indefinitely) deferred

	Instances where Open Disclosure may be (indefinitely) deferred	Supporting interview statements
1	The patient has died and has no relatives.	*"Case 1 is where, in fact, there is and are no relatives, there is actually no-one to talk to so that's quite easy, but we have to do Open Disclosure for that."* [Support Personnel 36-189]
2	The patient has gone overseas, necessitating postponing Open Disclosure.	*"In fact there are five cases where they're overseas."* [Support Personnel 36-189]
3	The family refuses Open Disclosure. There may be emotional reasons for the family to (temporarily) defer or refuse Open Disclosure.	*"The next is where there was a birth, a difficult birth. The outcome of the effect of that birth where we felt there may have been an incident on the baby was, as yet, unknown and so that the family actually didn't want to go there. They wanted to enjoy their baby."* [Support Personnel 36-189]
4	Violence perpetrated or threatened by the patient or family. In some instances, staff have reason to believe that they are dealing with an 'unreasonable complainant' (NSW Ombudsman, 2007). Disclosure in the case of an unreasonable complainant might incur an undesirable response towards staff or towards a patient. Violence can interfere with staff adequately planning and conducting Open Disclosure. The interviewee below explains how they were prevented from carrying out a formal Open Disclosure due to 'challenges for staff':	*"And sometimes we take the babies away because the partner's violent. So a lot of it's, we've all been difficult in situations of telling lies to the women and they know that we're telling lies, but do you take the baby away from the violent situation [or not]? It just really affects all of us."* [Nursing Clinician 94-64] *"… it was a period of time in the ward, where we had three male severe head injury patients. And all three of them, were creating challenges for the staff over there and the staff themselves were failing, were starting to fail to cope because, every time they turned around, you know, either one of the patients were punching the staff, or the patients' parents were accusing the staff of not caring for them properly, so you know, that stuff in the background was part of my decision-making around that.."* [Nursing Manager 35-79]

Table 2.6: Instances where Open Disclosure may be (indefinitely) deferred (cont'd)

	Instances where Open Disclosure may be (indefinitely) deferred	Supporting interview statements
5	It is not evident to staff that the patient (family) will benefit from the Open Disclosure of a 'near miss'. In situations where patients and families are already overly distressed, interviewees may see a need to make a separate judgment about whether Open Disclosure could unduly add to people's distress. Interviewees know that there are cases where disclosure can do additional harm to people.	*"the issue of whether we're doing more harm than good emotionally in raising issues has been raised, so I think it would depend on what the near miss was. … you still have to argue whether having an Open Disclosure process, that might make the health service feel good but whether it may actually do more harm than good."* [Medical Manager 66-43] *"Oh the risks are harm. The disclosure process can create great harm to patients and families … even where there has been sensitive disclosure, that the absolute holding of this information by the patient, um, who may have … had some sort of error occurred during their care, um, may have to live with a sense of anxiety about that for many years, and I think that there is a sense that the disclosure process is a double-edged sword for many people. It can be healing and uh um, you know, healthy, and for some patients it will increase their vulnerability and … potentially do more harm than good."* [Senior Clinical Manager 20-111]

In general, of course, most cases of harm render Open Disclosure obligatory: Open Disclosure cannot be avoided or deferred. A proportion of near miss/hit cases may qualify for deferred disclosure and of these a sub-set may qualify for non-disclosure. However, only exceptional circumstances (cf. the previous four scenarios just listed) warrant staff arguing to their senior management that Open Disclosure does not constitute the appropriate response to an adverse event. The Queensland Policy states in this regard, "In the event that a formal Open Disclosure is not progressed for a SAC 1 event, the District Manager/ Clinical CE must document the reasons in a memo to the Area GM." (Queensland Health, 2006b: 11). In general, the option for non-disclosure should be negotiated with and approved by senior managerial staff.

The vignette below provides an example of a case where staff decided not to disclose.

Vignette
Deciding not to disclose

"… this is one case where we actually didn't disclose … Now, the reason being was that it involved a teenager that was really struggling with his disease … who was actually quite seriously ill. To say that something went wrong in his particular care would have actually been a detriment to him, you know. The clinician had a very, very good case not to disclose to this particular person, because it would have meant that the work that they'd done beforehand would have been undone because of the frame of mind that he was in at the time. … It was quite a complex one, but to actually disclose what had went wrong initially, um, was really going to affect his chronic long term management. So that's one where we chose that it was actually better not to. And I think there's got to be room for that."
[Support Personnel 78-97]

Finally, we need to ask the question, 'How can staff be made aware of the risks inherent in not doing Open Disclosure?' Not doing Open Disclosure – that is, not adhering to the overall process of contacting those harmed, pre-planning for the Open Disclosure meeting, organising a single-desk contact for the patient and family whom they can contact, and arranging for appropriate follow-up for both those harmed and for staff – carries increasing risks, given the rise in complaints and the public's strengthening sense of their 'right to know'[22].

---

[22] Chris Wheeler, Deputy Ombudsman, personal communication, October 2007.

2.4.3 Following up: What happens after the (first) Open Disclosure meeting

> *"[Open Disclosure] needs to be continuous, [it] is one of um, frequent and cumulative disclosure rather than just disclosing and then okay now we've done that."*
> [Senior Clinical Manager 12-108]

Following on from the first Open Disclosure meeting, there are a number of strategies that interviewees consider crucial for ensuring that the hard work put into the first Open Disclosure meeting is consolidated. Interviewees propose strategies that seek to realise three things:

1. **Ensuring the continued well-being of patients (and families),**

2. **Providing adequate support for clinical staff (colleagues)**, and

3. **Creating and maintaining organisational memory**.

1. **Ensuring the continued well-being of patients (and families) after the initial Open Disclosure meeting.** Ensuring patients' and families' well-being is critical during the Open Disclosure meeting, but this task continues following on from this initial meeting. Interviewees offer the following strategies for creating continuity for patients and family members following the first Open Disclosure meeting (table 2.7 below).

Table 2.7: Strategies for ensuring the continued well-being of patients and families

Ensuring the continued well-being of patients and families	Relevant Interview Quotes
1 **Make sure that the patient and the family spokesperson can contact a designated staff member**. Consumers may need to check on what was said during the first Open Disclosure meeting, or they may need further clarification. To facilitate this, interviewees recommend giving out the contact person's telephone details at the end of the first meeting. Continuity of contact is important to reassure the patient (and family) that they are not being abandoned, and that the organisation is taking their (near) harm seriously. Continuity of contact also minimises the chance of additional information errors due to inadequate administration of the Open Disclosure process (e.g. sending its letter to the wrong person, or including inaccurate information). Continuity can be achieved through the Patient Safety Officer, the Patient Liaison Officer, or someone in a comparable role. These staff have the crucial role of tracking and storing the history of the Open Disclosure process with specific patients (and/or family members). As will become evident when we discuss the patient and family member interviews (Section 2.5), this continuity and the support it gives are considered crucial by consumers. Interviewees also signal the importance of 'a single desk' where details of progress of an Open Disclosure case are held, and where patients and family members can be referred to. Alongside the strategy of the designated contact person, the single desk helps minimise gaps created by staff turn-over.	*"So in terms of a team, my understanding is that they've changed each time. However, the Patient Safety Officer has been the constant in each of those."* [Senior Support Personnel 30-67] *"It's either the CLO [Customer Liaison Officer] or the PSO [Peer Support Officer] that needs to be involved in every meeting, because … we're the thread to keep it all together. … we're the ones that are … you know, the memory."* [Support Personnel 34-140] *"… my predecessor had moved on to another role so there was this bit of a gap without anyone actually being a single desk contact for it. So it fell off the rails a little bit."* [Support Personnel 34-185]

Table 2.7: Strategies for ensuring the continued well-being of patients and families (cont'd)

	Ensuring the continued well-being of patients and families	Relevant Interview Quotes
2	**Send out a letter out to the patient (and family) within 48 hours that summarises the Open Disclosure discussion and, if there was one, the plan that was agreed on**. Staff benefit from having pre-developed pro-formas that they use for these follow-up letters.	*"… the letter is so important. At the end of it [the Open Disclosure meeting] you've got a plan. 'These are the things we've talked about and these are the things we've offered'. And if you've got a plan at the end of it and they want to go off on a sidetrack, you can refer back to the letter and say, 'Well, this is what we talked about'."* [Medical Manager 45-28] *"… the way I've been writing these[letters] is, 'Thank you for your meeting of X on such a date, here are the attendees. We met to discuss, or the following were key points of concern which were, or you raised or we discussed the following key points', and list the points, number them or whatever, then address those in turn with what their concern was as we felt it was and then what our reply was and where appropriate an apology for the impact that that has had."* [Support Personnel 34-198]
3	**Offer the possibility of additional Open Disclosure meetings.** Interviewees comment that the 'right' number of meetings is difficult to determine, and of course their number depends on the (perceived) severity and impact of the incident. In order to provide sufficient feedback and establish satisfactory engagement more than one meeting may be needed.	*"It [how many meetings to have] is difficult to say. I think it pretty much depends on the incident and on the patient as well. I would say on average probably two or three [meetings], probably. I think you need more than, certainly more than one to get the feedback and engage. Your … processes are actually gone [i.e. it is difficult to plan the number of meetings in advance]."* [Medical Clinician 97-25]
4	**Be pro-active in organising additional Open Disclosure meetings.** It may not be sufficient to offer patients and/or family members one's business card and telephone number. Staff have maintained and persisted with making contact off their own accord, to the satisfaction of patients.	[see Section 2.5]

Table 2.7: Strategies for ensuring the continued well-being of patients and families (cont'd)

Ensuring the continued well-being of patients and families	Relevant Interview Quotes
5 **Ensure the follow-up meeting(s) are appropriately timed.** While this issue is less vexing in the case of low level disclosures, the timing of High Level follow-up disclosure meetings tends to be dictated by the time it takes for the Root Cause Analysis investigation to be completed. This timeframe may not suit all participants, however, and intermediate meetings may need to be called to address burning issues.	*"… the second main meeting is usually after the Root Cause Analysis is complete … seventy days later. So it's quite a long time after but if they've got problems, if they have urgent needs for information between the first meeting and second meeting, we're happy to have a meeting so we may well bring them together and say, 'Look, we haven't yet got the full RCA, but this is what we know so far.'"* [Senior Clinical Manager 10-4]
What is discussed at these 'intermediate' meetings however is not always a simple matter to resolve. In South Australia, Section 64D of the Civil Liability Act enshrines Root Cause Analysis information in Qualified Privilege. This means that no information from the investigation can be discussed outside of the investigation, and this renders offers of tentative explanations unfeasible.	*"… we often have said in the past and the impression that the family is being left with is that there is going to be some big investigation and they get a report. And that causes problems. Because often then we get in the way of litigation and 64D as protected by the lawyers, so you do an investigation but you cannot tell the family. And that is worse. So we had circumstances where we had to do two [investigations]. One for the family and one for the lawyers and this is ridiculous."* [Medical Manager 93-18/9]
Discussing provisional Root Cause Analysis investigations' progress is problematic in other States and Territories too. This is because the Root Cause Analysis investigation will not yet have produced firm conclusions, and discussing preliminary analyses goes against Root Cause Analysis procedure (Wald & Shojania, 2001).	*"If people don't disclose everything it becomes a very difficult process"* [Nursing Manager 70-14]

Additional note: Involving patients and/or family members in patient safety. Recent research promotes involving patients in patient safety (R. Davis, Jacklin, Sevdalis, & Vincent, 2007)**.** A number of interviewees in the present study are positively inclined to involving patients and/or family members in addressing the adverse event. This may involve asking the patient and the family questions about the adverse event, and enabling them to ask questions about it. Such involvement is seen as potentially strengthening both the Root Cause Analysis investigation and as adding to the quality of the Open Disclosure process.

However, pro-active involvement of patients and/or family members may not always or entirely resolve questions about what to discuss during meetings in between the initial disclosure and the Root Cause Analysis final report. If the patient (and/or family) have a desire to have specific questions addressed before the health facility can offer a

ratified explanation, the Open Disclosure staff may find themselves in the challenging situation of seeking input from consumers without being able (as yet) to provide much in return.

Staff may be inclined to call on the patient's (and family members') patience and goodwill to overcome this dilemma: 'Please tell us what you would want to know about the adverse event, and then you have to trust us to produce a reliable explanation in due course'. A more appropriate solution might be to adopt the principle of giving consumers a clearly circumscribed and recognised role in the health organisation's adverse event management program (i.e. the totality of processes that includes Incident Reporting, Open Disclosure, Root Cause Analysis, and Clinical Practice Improvement). Such a role need not be fixed and constrained, and may depend on consumers' levels of interest and knowledge. Research produced by the National Patient Safety Agency in the U.K. suggests that the spectrum of roles may range from 'listing questions for staff to respond to and act on' (consumers 'inform' the health service), 'attending focus groups to address specific issues', to 'attending meetings with clinicians' (in which instance consumers 'collaborate with' the health service) (Mansell et al., 2005).

Consumer involvement in patient safety processes may produce two distinct benefits:

i.   It may be a more effective means of reconciling patients (and family members) with the pace, direction and framing of the investigation following disclosure, and

ii. It may enrich the investigation's scope and outcomes by allowing it to benefit from patients' and family members' experiences and insights.

2. Ensuring **appropriate follow-up for staff** after the Open Disclosure meeting involves two kinds of strategies (see table 2.8).

Table 2.8: Strategies for ensuring appropriate follow-up for staff

	Ensuring appropriate follow-up for staff	Relevant Interview Quotes
1	**Involve staff in a factual debrief.** A factual debrief involves asking questions like: how did the planning and running of the Open Disclosure session go? What could be improved? What was learned?	*"I think it's extremely beneficial because you can talk about what went well, what went wrong, and you can talk about what you would do differently next time."* [Senior Support Personnel -34-57] *"I went and spoke to those medical consultants and said: 'Why did you do that?'"* [Support Personnel 27-13]

Table 2.8: Strategies for ensuring appropriate follow-up for staff (cont'd)

	Ensuring appropriate follow-up for staff	Relevant Interview Quotes
2	**Involve staff in an emotional debrief.** Emotional debriefs can range from staff arranging to have informal 'in-unit' debriefs, to encouraging distressed staff to make contact with formal counselling services. Debriefs may be necessary not merely due to the occurrence of an incident, but also following an Open Disclosure session. In some cases, hospital-internal counselling is not appropriate and outside counselling needs to be arranged. Outside counselling staff will not face a conflict of interest in case organisational-confidential information needs to be discussed (Berlinger, 2005).	*"[we have] an in-Unit sit down and talk about things particularly if people were upset … and there are formal support mechanisms that you can access through the hospital for counselling and that sort of stuff if you need it."* [Medical Clinician 43-224] *"I also keep my people after the person's left the room so that they can debrief, and they've got an opportunity to say, well, you know, I really would have liked to have said that, or I was really angry when that person said, so that they actually get it off their chest in that environment rather than go away still feeling as if they… 'cause it actually can become quite a uh, combative environment."* [Senior Clinical Manager 15-48] *"if we can't debrief them[staff] properly, we also pass them on to psychologists. And we actually have a psychologist attached to our hospital who we will refer people to. I also, in nursing, have a psychologist who is a support person and so whenever there are critical incidents she is available to them as a group as well as singly."* [Nursing Manager 65-55]

3. Ensuring **appropriate follow-up at an organisational level** after the Open Disclosure meeting is seen to require the following activities (table 2.9).

Table 2.9: Strategies for ensuring appropriate follow-up at the organisational level

	Ensuring appropriate follow-up at the organisational level	Relevant Interview Quotes
1	**Staff in charge of Open Disclosure need to liaise with those engaged in Root Cause Analysis**. Firstly, this may be necessary because information may be covered by Qualified Privilege, prohibiting its discussion (and dissemination) by staff who are not on the Root Cause Analysis team. As noted above, in South Australia Section 64D of the Civil Liability Act prevents staff from talking about the details of adverse events considered under Root Cause Analysis investigations with staff not on the investigation team. At least one interviewee understands this to mean that if Root Cause Analysis has started, Open Disclosure needs to cease.	*"I think they [Open Disclosure and Root Cause Analysis] are [mutually exclusive] because in a Root Cause Analysis there is a protection, 64D … against any information that is discovered during the investigation … that means that nothing can be disclosed. Whereas I see Open Disclosure as being more a process where the information is actually not hidden, it gets disclosed to the patient and it is disclosed to everybody really."* [Medical Clinician 76-24]

Table 2.9: Strategies for ensuring appropriate follow-up at the organisational level (cont'd)

Ensuring appropriate follow-up at the organisational level	Relevant Interview Quotes
Secondly, Open Disclosure and Root Cause Analysis team membership may overlap, particularly in smaller organisations. Staff may benefit from participation in both processes by being better placed to: i. integrate patients' and family members' questions into the Root Cause Analysis investigation; ii. update patients and family members about the progress of the investigation, and iii. inform them about details emerging from the investigation, provided these details have been signed off by the Root Cause Analysis team. Staff should be enabled to share with consumers carefully structured feedback as matters come to light rather than delaying feedback until the end of a closed-door investigation (see Recommendation 27.iii above).	*"Sometimes they [teams] overlap [in membership] … because of the size of the organisation. And I have to admit if you can cope with the stress of these things [Open Disclosure] often it helps to be involved in the RCA."* [Support Personnel 66-88]
2 **Open Disclosure process needs to be systematically recorded, and records are kept in separate places**. A comprehensive record is kept in the Patient safety Officer's office. For one interviewee, this full record would not be included in the medical notes ("there would be nothing in the charts"). It seems important however for clinical colleagues to be made aware of the fact that Open Disclosure has taken place and what the facts of the adverse event turned out to be.	*"There would be document that Open Disclosure occurred, a note that Open Disclosure occurred … and that would be kept either in the Patient Liaison office or the Patient Safety office which are all filed and locked and secured and all that stuff."* [Support Personnel 27-8] *" … as far as the [medical] notes go, … there is a form that you put in that just says, 'Open Disclosure was performed on such and such a date, clinician was so and so', and then it's signed … there's not much detail that goes in there."* [Support Personnel 34-179]

Table 2.9: Strategies for ensuring appropriate follow-up at the organisational level (cont'd)

Ensuring appropriate follow-up at the organisational level	Relevant Interview Quotes
3 **The conduct of Open Disclosure follow-up processes will benefit from a well-developed in-house adverse event register.** Such register details the adverse event; (factually-determined) information about the adverse event, information about the patient and family (including the family spokesperson), letters sent out and information provided to the patient and family, plans that have been agreed on, and progress towards realising those plans. This interviewee provides the following reasons for keeping such a register: Given the need for a single-desk contact for the patient (see page 82), it is important that such a register be available to counter-balance the impact of staff turn-over. Staff may also wish to use such a register to aggregate Open Disclosure cases, and link this analysis to an evaluation of case type-specific outcomes.	*"… there is central collation of that information. Anything that's a serious adverse event, it is on a [register]. So that register's maintained by the Quality Unit, and that is where you are able to track, you know, who is following up with the patient, who is the contact person, otherwise it becomes all over the place."* [Support Personnel 66-111] *"So you need to be having that confidence that … we can track back and say that this case has been closed, or whatever. Or there is also the danger that you're waiting and the coroner's process takes two years and no-one has bothered to go back so if you don't have that central register, when you get a coronial report you don't know who was involved."* [Support Personnel 66-111] *" … so with our [register] we would also look at the timeliness of the Open Disclosure process, and how many cases were satisfactorily closed … we'll have to decide on a target time for something that is seen as an adverse event … so we need to decide on what are our KPI's [are that] we want to monitor around that, not too many, so just manageable, one or two things that would give us an understanding of how well the process is happening so it doesn't get lost."* [Support Personnel 66-114]
4 **It is seen to be of benefit to arrange monthly meetings among those involved in Open Disclosure**. At these meetings, staff discuss two types of matters. First, the progress of individual Open Disclosure cases is monitored. Secondly, staff use the meeting to share common problems, useful resources, effective strategies, and emotional issues	*"the Clinical Review Committee which is the peak body committee, and at that committee there is a sort of a checklist we go through to say that, 'This case needs a further follow up. Has it been closed satisfactorily for the patient, and has the patient raised issues around any further follow up, and who is the most appropriate person to follow that through?'."* [Support Personnel 66-112] *"… it is a very … confidential, trusting forum and I really enjoy that."* [Nursing Manager 38-106]

Table 2.9: Strategies for ensuring appropriate follow-up at the organisational level (cont'd)

	Ensuring appropriate follow-up at the organisational level	Relevant Interview Quotes
5	**Community Advisory Committee involvement is recommended to signal progress of Open Disclosure roll-out in the organisation and publicise the level of its success to members of the community**.	*"… we went to our Community Advisory Committee and gave them our report on what has happened so far, and where to from here. We also want to do consumer information things, and also developing some brochures so the Community Advisory Committee is involved."* [Support Personnel 66-115]

Without appropriate follow-up, the effort put into the initial Open Disclosure meeting may be wasted. Consumers may experience delays as abandonment, particularly when harm is serious. Indeed, as the consumer interviews show (see section 2.5 below), consumers appreciate the efforts clinicians make to disclose adverse events, but the time it takes to formally investigate organisational adverse events is often seen as being out of sync with patients' and families' personal time, particularly following serious harm. It follows that strategies need to be devised to ensure consumers' needs and expectations are not subordinated to organisational procedure and timing as a matter of course.

2.4.4 Open Disclosure - Success factors

Interviewees identified the following Open Disclosure success factors (table 2.10).

Table 2.10: Open Disclosure Success Factors

	Open Disclosure Success Factors	Relevant Interview Quotes
1	**Staff are proficient in Active Listening or Reflective Listening.** 'Active listening' (Egan, 2006), already referred to as 'reflective listening' above, is considered crucial to managing the patient's and family members' anger, but also for managing one's own emotions. Reflective listening turns on allowing patients and family members to vent their anger and other emotions, without unduly interfering. Reflective listening creates an interactive space for the patient and family members where they can express their feelings without being interrupted, questioned, or challenged. Reflective listening turns in large part on the clinician's ability to place themselves in the patient's (family member's) shoes.	*"so that it is very much about the patient, and we are sorry that this has happened. You're there for the patient, you're not there for the clinician at that time."* [Support Personnel 30-147] *"it's a fact that you don't just go and tell the patient, you have to sit there and just listen to the patient, and um and let them vent, let them tell you, um what they're thinking. And that's, that's the hard bit in Open Disclosure, is to be sat listening."* [Support Personnel 30-145]

Table 2.10: Open Disclosure Success Factors (cont'd)

Open Disclosure Success Factors	Relevant Interview Quotes
An important component of reflective listening, however, is 'relational ethics'. Relational ethics ensures that reflective listening does not just enable anger to be 'vented', thereby therapeutically silencing the affected consumer. Relational ethics emphasises the importance of *dialogue* as the basis for reconfiguring consumers' emotions from anger and distress into feelings with which they can again engage with others and their own future (Shotter, 1989).	*"I've been on the other side as a family member wanting to know stuff. When a member of my own family had an adverse outcome and died … I'm looking at it from two perspectives, as a clinician but also as a family person."* [Senior Support Personnel 44-58]

The vignette below provides an example of how powerful active listening can be.

Vignette Reflective listening	*"… the family are livid, they're really, really angry. … so I said ok, well we need to … meet with them and talk through this. … it took quite a while for them to just, you know, get rid of their anger. … I didn't try and interrupt them or stop them from talking. I didn't try and deflect the blame because they were wanting to blame somebody, they were wanting to know the name of the nurse that was suppose to be looking after [the patient] … for 25 minutes, they ranted and shouted and were very scathing of, of the service. I guess at the end of that … they were just getting tired from being so angry, I … really just apologised and said, you're right."* [Nursing Manager 27-77]

Table 2.10: Open Disclosure Success Factors (cont'd)

Open Disclosure Success Factors	Relevant Interview Quotes
2 **Staff display and enact sincerity.** Sincerity[23] is considered to be crucial to the success of Open Disclosure by health care staff interviewees. Sincerity becomes possible when staff do not impose pre-determined outcomes on their interactions with consumers. Sincerity means the outcomes of the Open Disclosure meeting are collectively negotiated. Being sincere may be in tension with constraints that bear on Open Disclosure, such as what those doing the disclosure can say, how they should and should not apologise, and how much information to give out. Nevertheless, it is possible for those charged with disclosing adverse events to achieve sincerity by showing they 'share the pain' that patients and family members are experiencing. Sincerity is seen as a crucial success factor because patients and family members are very good at detecting deception and insincere conduct. Sincerity requires staff to be genuine in their dialogue with consumers. One interviewee speaks about a successful disclosure meeting "wasn't cosmetic, it was very organic" [Nursing Manager 28-105]. Another comments that disclosure means that "we can be open about it and not defensive" [Support Personnel 10-104]. It is important for staff to feel that they can engage in genuine dialogue with those harmed, involving themselves in the unfolding conversation (cf. 'relational ethics' above in this table). By the same token, being sincere should not be confused with 'giving the patient and family what they want'. Instead, sincerity involves acknowledging others' distress and needs without taking people's emotions as a licence to blame others or blame oneself. It is important to advise staff not to confuse sincerity with guilt. It is this aspect of Open Disclosure that may be most difficult to explain to and absorb for staff. Staff need to let patients and family members emotionally unburden themselves and they need to respond to this emotionality in a sincere way, without allowing the intensity of the meeting to push them into self- or other-blame.	*"…it's still a very emotional, draining, stressful situation that … you actually go through, and, you really have got no idea when you walk into that meeting. All it's left up to … is your good communication skills … but … most people are going through life-altering change, and they're in crisis, and you don't really know how the people are going to react … so that's what sharing the pain is about."* [Support Personnel 30-142] *"There has to be a sense of trust because often what you're dealing with is recovering from a position of trust which has been lost. So any commitments that you make you have to keep. People have very well-tuned bullshit sensors and you've got to be very careful about being absolutely direct and honest. Which is why we're careful about who we let do it because [if] people sense that you're spinning a story rather than information their bullshit sensors go off and you've lost it."* [Senior Medical Manager 46-92] *"… not 'here comes someone with a cap in the hand to tell you they're sorry for something they've done'. That's victimising the person representing the organisation."* [Support Personnel 41-202] *"… when you're under the gun and if you're a bit weak-willed then it's easy to get out of gaol free by blaming the system or blaming the hospital or blaming the clinician when you're under the pump. It takes a stronger individual to be able to defend those but in a way that actually still benefits the patient and the community. You're not doing the community any good if you sell out on the hospital or a clinician as well as the patient."* [Support Personnel 41-202]

---

[23] Sincere's etymological root is the Latin adjective *sincer-us* meaning **clean, pure,** or **sound**. The first syllable may be the same as sim-, as in simplex. It is not considered likely however that 'sincere' relates to 'sine cera' meaning 'without wax' (Oxford English Dictionary Online).

Table 2.10: Open Disclosure Success Factors (cont'd)

	Open Disclosure Success Factors	Relevant Interview Quotes
3	**Staff enact restorative justice.** Open Disclosure is deemed to be successful when staff are able to engage in restorative gestures that make their apology tangible. Such gestures include (Wheeler, 2007): 1. ceasing action that has, is, or will, cause further harm; 2. refunding fees or charges; 3. waiving fees, charges or debts; 4. providing special assistance and ongoing support. *Financial restoration*: One way in which restorative justice is achieved is by making ex gratia payments available to those harmed for expenses incurred by the harm. Mention of ex gratia payments needs to be handled carefully and sensitively. First, health service lawyers counsel against clinicians' using the word 'compensation'. Second, patient may be offended by offers of money, and such offers need to be couched carefully.	*"…when someone says, 'What if they ask for compensation', I say, 'out-of-pocket expenses. Oh, we can all cope with out-of-pocket expenses'. So you make sure that when you're having an Open Disclosure meeting that if there is that, we offer the ability for them to consider some of their out-of-pocket expenses."* [Support Personnel 41-208] *"On our side of the fence you mention the word 'compensation' everyone goes [swooshing sound], all the doors locked, everything goes shut, pullout, go and see a lawyer. You mention 'out-of-pocket expenses' [sound of ping] you've just hit the right part on the cash register that said, 'Oh, we're actually allowed to make those in-house decisions for you about that.'* [Support Personnel 41-208] *"Now, a lot of people actually can find the question slightly offensive to even talk about money in the middle of that meeting, so it's got to be brought up sensitively, that says, 'Look, we have the ability to assist you with some out-of-pocket expenses'."* [Support Personnel 41-208]
	Personal restoration: It is important for those doing the disclosure to remember that victims of harm cannot dictate how staff who were involved in the incident are dealt with by the organisation. Important restorative gestures, however, are seen to be, among others (see section 2.5): 1. a willingness on the part of the organisation and the clinician(s) to meet with those harmed and maintain contact; 2. rapid adverse event investigation and practice change; 3. a full apology (if appropriate).	*"So families will often want to know the person involved and to know that they're never going to work in health again, that's not always an appropriate response on our behalf. I think we have to be very careful that we don't have, you know, victim um, you know, the victims deciding what the punishment's going to be, because that's not a thing that operates in any of our justice systems."* [Senior Medical Manager 14-122]

Table 2.10: Open Disclosure Success Factors (cont'd)

	Open Disclosure Success Factors	Relevant Interview Quotes
4	**The organisation has efficient staff support measures in place**. Staff support plays a crucial factor in giving the clinicians confidence that they are not alone in facing the consequences of adverse events that they are involved in. Support also signals that the health care organisation does not subscribe to a blame-and-shame culture.	*"… we've got um, staff counsellors … I've got a clinical superintendent who I mobilise immediately for the medical officers … who reports back to me and lets me know … how the … staff member is travelling. We give them time off if they need time off. The clinical director gets involved. So we've got resources … and they're told all about the staff counselling."* [Nursing Manager 12-48]
5	**Senior staff participate in Open Disclosure.** Participation on the part of senior staff in Open Disclosure is crucial for its success. If senior staff adopt the ethos of Open Disclosure – involving others in the organisation in the planning and execution of being open about adverse events – trust is created that it is now accepted to discuss and learn from adverse events. If senior staff are unwilling or unable to accept that they are responsible for an adverse event, there is little hope that more junior staff will be persuaded to adopt Open Disclosure, and accept that as clinician one has to be able to account for an adverse event one was involved in.	*"Well, I think senior clinician involvement is absolutely vital to make it work, and that ethos that it's okay to talk to the patients."* [Medical Manager 75-135] *"Look I think that it's the willingness to accept and acknowledge error [that determines the success of Open Disclosure]. I think that's the one thing that the whole thing hangs on. If there exists within the organisation a resistance to the notion that there was an error, and that we're accountable for that, so I think it's that willingness to accept failure and accountability, and the acceptance of accountability for that are probably the two critical things the whole thing falls on."* [Senior Medical Manager14-120]
6	**Staff have good communicative abilities.** Clinicians, particularly those involved in Open Disclosure, need to hone their communicative abilities to be able to engage effectively in realising in reflective listening, authentic disclosure, and blame-free accountability. This communicative ability is concerned with saying the right thing and timing what is said well. However, communicating well starts with making the patient (family) central to the discussion. Making the patient (and family) central to the discussion turns in large part on being attentive to how the patient and family member(s) participate in the discussion. One way of establishing this is through checking whether the patient and family member(s) understand what is being spoken about.	*" … we always ask, you know, 'What are your needs?' In fact, ideally what we try and do is start the whole meeting with you know, 'What do you want? What would you like from us? What can we do to help you?' … 'What information needs do you have, but also what other needs might you have, you know, in relation to counselling or other support?"* [Senior Clinical Manager 2-3] *" … being mindful of the language … you know, if they looked puzzled then you address, 'do you not understand?' We don't say that but trying to ensure that they do understand what you're saying. [It's about] clarifying, getting them to rephrase and paraphrase and all that sort of stuff."* [Support Personnel 28-3]

Table 2.10: Open Disclosure Success Factors (cont'd)

Open Disclosure Success Factors	Relevant Interview Quotes
While to date clinical expertise has played a primary role in the definition of professional status and authority, Open Disclosure, alongside a range of other initiatives (such as multi-disciplinary team work, Root Cause Analysis, Clinical Practice Improvement, and the like) is bringing communicative ability to the fore as pre-condition for adequately realising clinicians' professional expertise (Iedema, Jorm, Long et al., 2006). Interviewees repeatedly pointed to the importance of organisations' needing to account for staff's communicative ability in the assessment of their clinical-medical effectiveness.	*"There is a need to have a bit of an overview of it [people's communicative abilities] from a clinical hierarchy perspective."* [Medical Manager 95-51]
7 **Clinicians have a pre-established rapport with the patient (and family).** It is important to have a good rapport with one's patients (and their family), to ensure that in the case things go wrong, it is not necessary to build up a social relationships post hoc.	*" … we have already built a rapport with the [patient] so having an established rapport … really added to the comfort and the trust, yeah."* [Allied Health Clinician 92-121]
8 **Staff enjoy good inter-disciplinary relationships.** Interviewees emphasise the importance of good relationships with colleagues and other teams for the success of Open Disclosure.	*"Yes, um, we've got very good interdisciplinary relationships here. Whether it's an executive level or as you move down the line through the organisation, so I think we've got a very supportive culture of one another. In other words, it means you've got the opportunity to talk about Open Disclosure cases and be able to be fairly frank about it without feeling that you're going to be put down or criticized."* [Medical Manager 73-51]
9 **Organisational-structural prerequisites have been put in place.** Interviewees point to the need to have a number of structures in place without which Open Disclosure runs the risk of failing. The systems that should be in place before Open Disclosure occurs include the full array of risk management mechanisms: 1. effective complaints handling, 2. no-blame error reporting and **3.** well-established incident investigation processes.	*" … the time you prepare for Open Disclosure is years back. You try and … work with policies and procedures and frameworks that are already in place and that people are familiar with"* [Senior Medical Manager 8-136] *" … in a sense you're already using systems that are already there, you've got the system for interacting with patients and families, you've got the system for managing corporate legal risk, you got the system for dealing in a just, fair and reasonable way and hopefully in a supportive way with staff, you've got the system for investigating and finding out what really happened."* [Senior Medical Manager 8-136]

Table 2.10: Open Disclosure Success Factors (cont'd)

	Open Disclosure Success Factors	Relevant Interview Quotes
10	**Bereavement counselling benefits patients and family members.** Interviewees emphasise needing to be able to recommend bereavement counselling to patients and family members. Bereavement support enables frontline staff to concentrate on the more technical and mechanical aspects of the adverse event.	*"And that's why I think very, at the beginning when we identify that there has been a serious adverse event that we put in place bereavement support, the families can start to separate out the clinical bereavement response from the um, uh from the feedback process."* [Senior Medical Manager 8-116]
11	**Staff training and general roll-out of Open Disclosure is arrranged.** Interviewees emphasise the importance of staff training in order to enhance clinicians' familiarity with Open Disclosure. A number of training aspects were raised:	*"… [we need] more staff training in what it means and having more than just the [peer support personnel] relied upon to facilitate it. I think … having more key people [is important] because the key people, of course, that we trained originally come and go, and some of them have probably left."* [Senior Support Personnel 34-74]
	a. *Calibrated training.* The training should focus on those charged with doing Open Disclosure, but it should also include frontline clinicians generally to compensate for attrition of those who received training. The strategy advocated is a calibrated one, where those most involved with Open Disclosure are given intensive simulation training and refresher courses, with other staff being invited to more general and less time-intensive overview sessions.	*"There are different levels of training required at each level. There's got to be a basic understanding by the staff that the process is there and what it involves and who to talk to when they need to. Then you have to have the clinicians having a little bit more, or the seniors start having a bit more of an idea of how it all works, then you have to have the facilitator level, and that needs ongoing support."* [Support Personnel 66-100]
	b. *Integrated Open Disclosure awareness sessions.* Alongside a calibrated training roll-out, interviewees propose integrating Open Disclosure into staff induction and orientation sessions, as well as spreading the 'just-in-time' Open Disclosure mentoring approach. This latter approach involves inviting staff who have had no or minimal contact with Open Disclosure to pre-planning and possibly patient/family meetings. Such invitations will of course depend on the nature of the incident, the frame of mind of the patient (family), and the degree of involvement in the adverse event on the part of the personnel invited.	*"OK when something goes wrong there is an open disclosure process for this person and they'll walk you through it. That's five minutes discussion, it's not a two day discussion. And, in many ways I think that's actually more we need to be doing then trying to take people off the floor for a couple of days. We need a big enough group of people who are trained to be support officers and we've got that now. I mean keep renewing that over time but the message out for the rest of the staff I think can be delivered in small bits."* [Medical Manager 34-90]
	c. *On-line Open Disclosure education materials.* Another strategy proposed is to have on-line education modules where front-line staff can go to familiarise themselves with Open Disclosure.	*"… having some kind of on-line education, because it's always difficult for regional [areas] like ours to have time off and to be back-filled to [go to the city] to do training down there."* [Senior Support Personnel 34-74]

Table 2.10: Open Disclosure Success Factors (cont'd)

Open Disclosure Success Factors	Relevant Interview Quotes
d. *Enhanced medical staff participation in Open Disclosure training.* A number of interviewees commented on the low level of participation in Open Disclosure training on the part of medical personnel. Given that medical personnel are well-represented in senior positions of most health organisations, it is crucial to engender interest among doctors in Open Disclosure. One way in which this can be achieved is through engaging junior doctors in Open Disclosure (university- or College-based) education[24].	
e. *Comprehensive risk information.* Interviewees commented strongly on the need to educate consumers about the risks inherent in receiving health care services. This can be achieved in two different ways: 1st. *Extended Informed Consent*: by extending informed consent from a discussion that is narrowly concerned with the treatment provided, to a consideration of the general risks inherent in hospital treatment, consumers' idealised expectations of health care services may be mitigated. 2nd. *Public education through diverse channels*: The public deserves to be educated about the level and quality of services that are available in their public health services. Currently, public 'education' is achieved on the strength of 'gee-whiz' media announcements about medical discoveries many of whose effects and impacts reach well into the future, staged documentary television series that mostly portray medical successes, fictional programs that are filmed in clean, quiet and over-staffed hospitals, and cascades of damning reports targeting 'bad apples' (Lupton, 1998). Forums need to be organised that bring hospital clinicians together with community representatives, health department officials, policy makers and media staff to discuss – in realistic and no-blame terms – what standards of care Australia's health system is resourced to provide.	*"Tell patients about the bad things that can happen up front, so when they do happen it's, 'Oh.' 'Sometimes people get the wrong leg cut off'. 'I got the wrong leg cut off'. It's not a surprise. It happens. I mean we have these ridiculously long consent forms and all that sort of stuff but …we only have consent forms for procedures. When you come in with pneumonia, you never sign a consent form but you might get an infected canula and end up having your finger cut off because of some terrible infection and you get a clot in your legs. Maybe there needs to be some sort of overriding statement [about these additional treatment risks]. You might come into hospital, you might have a drug error, you might have this happen … so when they do happen, 'Oh, yeah, well this is part of the risk of being sick and being treated'.* [Medical Clinician 27-237] *"I think the overall tolerance has changed and people are more um, likely to, you know, develop road rage and supermarket rage and, I think, hospital rage. I think that is also another rage that is not spoken of often. And unfortunately it's the staff that bears the brunt of that very often."* [Clinical Manager 4-36]

---

[24] In New South Wales, junior doctors are currently engaged in Open Disclosure simulation training (involving actors).

2.4.5 Open Disclosure - Perceived challenges

Open Disclosure faces a number of challenges. These are listed below.

Table 2.11: Open Disclosure – Perceived Challenges

	Open Disclosure - Challenges	Relevant Interview Quotes
1	**Consumers may mobilise 'Freedom of Information' and/or 'Discovery' laws.** Consumers may request information relating to Open Disclosure, such as pre-planning documents, to be released. It is advisable that staff not record anything on the pre-planning pro-forma or elsewhere that, if subject to FOI or Discovery, could be used against them.	*"… that FOI-able stuff on the pre-meeting planner sits there, but should it? Should I just push the delete button because it's a pre-planner? I don't know."* [Support Personnel 38-199]
2	**Outside institutions promote and demand blame.** Staff have reason to be wary of institutions whose practices are not (yet) aligned with those of health care organisations that practice Open Disclosure. Such institutions include the media, the law, and politics. Interviewees commented on the need to 'get adverse events' out of the courts. Above we presented our views on the proposal for a no-fault system in Australia (see pages 50 and 75 above).	*"I think part of the problem there is that, you know, we talk about a no-blame culture or a just culture or whatever you want to call it, but the problem still remains that when something goes wrong it ends up in the public domain. Sorry, but the politicians are just after somebody to sack, and we saw that with Bundaberg in Queensland, we saw that with Camden-Campbelltown in New South Wales."* [Medical Manager 27-33] *"I'm of the belief that we should get all compensation issues out of the courts because until you actually get them out of the courts, out of the traditional courts where you're finding somebody to blame and penalising them as a consequence, until we do that I actually don't think that we can put in place a robust system of patient safety and quality in the health care system."* [Medical Manager 27-33]
3	**Primary and tertiary care are misaligned in their communications with the patient.** The primary-tertiary care divide in Australia leads to referral and discharge problems, but also creates problems with regard to expectations that patients entertain about the service they are referred to. GP referral practices need to be aligned with the extended informed consent approach advocated here (Harris, 2002). Patients need to be informed of the treatment they need and of the hospital that is likely to be able to provide it, but patients also need to be told about the broader range of risks that are inherent in hospital treatment. Equally, referral needs to be made in a way that does not overstate what the hospital can or should provide.	*"Of the referrals that are sent to me, over half of my patients are put at risk before they arrive. I do not get adequate information on them. I do not have their drugs. I do not have their past history. I do not have a clear clinical description of what's happening or the blood results or anything, necessarily and the worst folks …a GP who will send a patient up with a pre-conceived idea of what's going to happen. For instance, 'I'll send you up to the hospital and they'll do a CT scan', or 'I'll send you up to the hospital and they'll take your appendix out'."* [Medical Manager 27-33]

78

Table 2.11: Open Disclosure – Perceived Challenges (cont'd)

	Open Disclosure - Challenges	Relevant Interview Quotes
4	**The resource implications of Open Disclosure are considerable.** *Open Disclosure consumes a lot of resources, particularly in terms of staff time.* *Interviewees insisted that enhancing the quality of care inevitably means making care more expensive.*	*"The actual meeting went from two o'clock till after six o'clock. So there was a lot of ground covered."* [Medical Manager 45-167] *"So I spent about three hours that Saturday morning, just going around the parents."* [Medical Manager 41-127] *"People don't like to talk about funding with quality. They think quality comes from nothing and it doesn't require any money. It just requires an attitudinal change or something like that, but, unfortunately that's not true in my opinion. Quality costs money and to have a good quality program costs a large amount of money and usually you can't make guarantees to the family that this will be improved because the amount of funding required to improve it is not available. So that's how it improves it, but that's, mm. I mean we had no radiology at this hospital for over a year so, I mean we had a lot of problems with misses and things on scans. So the family go, 'Well, aren't you getting radiologists?'"* [Medical Manager 45-167]
5	**Clinicians need to engage in work process mapping and design.** For Open Disclosure to work well, explanations are necessary about how the service works and where and why it went wrong. To counter-balance their rising complexity, health care organisations have begun to map their work processes in the form of clinical pathways and related devices. Generally, however, clinicians are not taught well and sufficiently about the organisational dimensions of care: these dimensions are part of the 'hidden curriculum' of clinical education. For staff to be able to offer explanations about how care processes operate, it is necessary for them to take the time to sit down with each other and (re)design their tasks and overall work processes. This process mapping and task design, moreover, should not be a static process, but involve 'flexible systematisation': that is, ongoing discussion about the contours of the care provided to patients (Timmermans & Berg, 2003).	

Table 2.11: Open Disclosure – Perceived Challenges (cont'd)

	Open Disclosure - Challenges	Relevant Interview Quotes
6	**Multi-cultural sensitivity is crucial.** Open Disclosure requires multi-cultural sensitivity. If Open Disclosure with Anglo-Australian patients and families is challenging, it is equally if not more challenging when involving Culturally and Linguistically Diverse (CALD) patients and families. Research done in oncology points to patients and families from most cultural backgrounds wanting to hear and appreciating being told the truth (Atsushi, 1995). This does not mean that approaches to Open Disclosure that suit Anglo-Australian consumers can be directly applied to non-Anglo-Australian patients and family members. Research done in oncology on breaking bad news about cancer diagnoses has relevance here and needs to be appropriated into the Open Disclosure literature (Gattellaria, Butow, & Tattersall, 2001; Goldstein, Thewes, & Butow, 2002).	*"… some of the different ethnic groups, … they have different expectations and different values associated with health care."* [Support Personnel 7-29]
7	**Staff do not sufficiently appreciate the emotional labour that is needed for Open Disclosure.** In cases where staff interpret the problem of the adverse event as being a purely technical matter, disjunctions can emerge between the emotional needs of the patient and the priorities of the staff.	*"Everything he [clinician] was saying was, was um, you know logical, it was rational, it had process behind it, but it wasn't empathic and he never kind of at all acknowledged the fact that she [patient] was hurting. That's all that she wanted to hear. That's all she wanted to hear."* [Nursing Manager 33-101]

Table 2.11: Open Disclosure – Perceived Challenges (cont'd)

	Open Disclosure - Challenges	Relevant Interview Quotes
8	**Open Disclosure can exacerbate the clinician-patient (family) relationship.** Above reference was made to disclosure going wrong. The potential of Open Disclosure failing to achieve its intended objective of improving clinician-patient (family) relationships is not negligible, particularly in this initial period with health care staff around Australia beginning to come to terms with Open Disclosure.	

The reasons for failure can include:

a. 'staff saying wrong or contradictory things',

b. 'staff assuming Open Disclosure puts them (rather than the patient and/or family) centre-stage'

c. 'staff assuming that Open Disclosure constitutes a licence to acknowledge responsibility for the incident before its facts are established',

d. 'staff remaining unwilling to acknowledge the rights and emotions of the patient '

e. 'staff proving unable to manage patients' (family members') distress and anger',

f. 'staff sliding from 'we have made mistakes' towards 'we are mistakes' and guilt',

g. 'staff unable to 'hear' patients' and family members' needs and feelings',

h. 'patients (family members) wanting to blame clinical staff, and

i. 'patients (family members) deciding to sue upon being told of unexpected outcomes'.

Open Disclosure going wrong should not be used as a basis for arguing against this practice, however, even if there are occasions when Open Disclosure prompts rather than

avoids litigation (Studdert, Mello, Gawande, Brennan, & Wang, 2007)[25]. Instead, and bolstered in this recommendation by the resounding support of Open Disclosure by all health care professional interviewees (as well as patient and family interviewees; see section 2.5 below), we advocate that unsuccessful instances should be analysed to benefit staff in their attempt to enhance their disclosures. In addition, research needs to be initiated that matches the *quality* of organisations' Open Disclosure practices to the rates of complaints and levels of litigation. Such research would provide an evidence base useful for promoting Open Disclosure across the health care system.

---

[25] In alerting us to the possibility that Open Disclosure may prompt more claims and complaints than avert them, Studdert et al's paper adopts a highly ambivalent stance. Its title classifies Open Disclosure as 'an improbable risk management strategy'. The article proceeds to deploy a rather idiosyncratic method to assess the economic risk of Open Disclosure (Wakefield, Jorm, & Ryan, 2007). The article acknowledges in its conclusion that Open Disclosure is the ethical thing to do, in terms that establish a zero-sum relation between economics and ethics. This stance positions the article in tension with three related literatures: one that elaborates the positive influence of 'being open' on the clinician-patient relationship (Berlinger, 2005; Woods, 2007); a literature that discusses the increasingly open and deliberative processes needed for the governing of public institutions (Goldsmith & Eggers, 2004; Mooney, forthcoming), and the literature that outlines the benefits of Open Disclosure for the economics of medical insurance and indemnity (COPIC, 2004).

2.5 Patients' And Family Members' Views On Open Disclosure

2.5.1 Introduction

This section of the Final Report presents an analysis of the 23 interviews we conducted with consumers. These consumers included 11 patients and 12 family members.

These consumer interviews provide important insights on a number of fronts. First, consumers' views on Open Disclosure make clear what it is about Open Disclosure that works and what does not work for them. Further, their views are important for assessing whether clinicians are conducting Open Disclosure in ways that are appreciated by consumers. Finally, consumers' views are a crucial means for clinicians to build confidence in their ways of working and communicating, and for validating their approaches to doing Open Disclosure.

The remainder of this sub-section is organised as follows. We will describe:

1. **Receiving news of the adverse event in ways that are problematic;**
2. **Being asked to become involved in Open Disclosure;**
3. **Participating in Open Disclosure;**
4. **Following up the initial Open Disclosure meeting(s);**
5. **A numerical analysis of patients' and family members' Open Disclosure scenarios.**

Before commencing this part of the report, we need to make the following point. Consumers' experiences of Open Disclosure are extremely complex. This is because in several instances consumers received excellent attention and feedback from some staff but not from other staff; some consumers' experiences moved from being positive to negative and vice versa due to how the disclosure unfolded and what and how much they were told, and on occasions consumers' views were ambivalent and/or self-blaming, making it hard to draw firm conclusions about what happened. These complexities notwithstanding, the data reveal important issues that need to be taken account of to improve the ways in which Open Disclosure is practised.

2.5.2 Receiving news of the adverse event

Above in Section 2.4.1.1 we listed the various external and internal channels via which health care staff said they received and communicated notification of adverse events. Interview statements by patient and family members equally demonstrate that there are various ways in which they too are alerted to the occurrence of adverse events. In their

case, news of an adverse event can reach them 'internally'; that is, the adverse event is revealed by staff involved in the care provided or working for the facility where the adverse event occurred. News can also reach the consumer 'externally'; that is, via people not associated with the health care facility where the care was provided. As is evident from the statements provided below, patients and family members prefer to hear about the adverse event from staff at the facility where the incident occurred, although this in itself does not guarantee that revelation of the adverse event will be unproblematic.

2.5.2.1 The patient (and/or family member) is (inappropriately) informed about the adverse event by (staff at) the health facility

Interviewees recount how adverse events may be revealed by clinicians working in the health facility where the care was provided and where the adverse event occurred. Three problematic scenarios were described: informal disclosure, ad hoc disclosure, and contradictory disclosure.

Table 2.11: Consumers receive (inappropriate) disclosure about the adverse event from a clinical team member or members

	Consumers receive (inappropriate) disclosure about the adverse event from a clinical team member or members	Relevant Interview Quotes
1	**Staff should recognise that consumers are sensitive to Open Disclosure being done too informally, and that the patient and/or family may feel the need for a more formal apology and explanation**. Informal and immediate notification of the adverse may be appreciated by consumers ("It was very useful", Cons 12, 103). However, if these informal discussions are not followed up with a more formal meeting they may ultimately fail as a response and information sharing mechanism. If the adverse event is deemed serious by the patient, superficial disclosures and informal apologies made by clinicians on the ward may not meet consumers' expectations, and a more formal disclosure process should be initiated.	*"[my wife] came back and said 'look there's about 8 or 10 doctors standing around in a circle, something's going on'. A couple of minutes later two of these people came over heading our way. So in the meantime [they] must have found the mistake with the wrong plasma and they learned about it. So, they came over and told us what had happened."* [Cons[26] 12, 102] *"Oh, [I had] informal ones [disclosure]. The doctor just kept coming up to my bed and seeing if I was alright. So it was only the doctor [who came and told me about the adverse event]."* [Cons 7, 65] *"He [doctor] came and apologised a few times … [then] I had to press for it, for the information I wanted"* [Cons 7, 62/8].

[26] The abbreviation 'Cons' will be used to indicate quotes are taken from the patient and family members' interviews. The first number represents the Interviewee Number; the second number represents the page number in the transcript.

Table 2.11: Consumers receive (inappropriate) disclosure about the adverse event from a clinical team member or members (cont'd)

	Consumers receive (inappropriate) disclosure about the adverse event from a clinical team member or members	Relevant Interview Quotes
2	**Disclosure of an adverse event should not be delayed as a result of inadequate team communication**.	
	The administration of an overdose during one patient's operation had not come to the wider clinical team's attention, and the seriousness of this only transpired thanks to the patient commenting on feeling 'strange' to their treating doctor some time later. This case suggests there may have been a lack of communication, a lack of attention to the details of care, or a lack of acknowledgement that this adverse event deserved to be formally notified, discussed and disclosed.	*"… nobody told me in the beginning and then I learnt how much I'd had, and I actually was really, really upset … I went for a … two-weekly check up and in that check up I told the doctor then what had happened [near-death hallucination] and he said, 'Oh, my goodness me, I've not heard anything about this.' And from then that's what started the ball rolling so that I had the interview with the other people. I would think it was, probably about a month after that."* [Cons 2, 15-7]
	Clinicians' finding out about incidents in an ad hoc way may result from:	
	1. the patient's documentation not being fully representative of the care that is provided,	
	2. the patient's documentation not having been adequately consulted by the treating clinician, or	
	3. adverse events not being approached as needing adequate preparation, investigation and explanation.	
	Communicating the occurrence of adverse events of relative severity to consumers in ad hoc ways may point to a syndrome of operational shortcomings in the unit or department, including insufficient process control and outcomes assessment.	

Table 2.11: Consumers receive (inappropriate) disclosure about the adverse event from a clinical team member or members (cont'd)

Consumers receive (inappropriate) disclosure about the adverse event from a clinical team member or members	Relevant Interview Quotes
3 **The disclosure should not reveal inter- or intra-professional fragmentation**.	
In some instances, patients and family members recount how a clinician reveals to them that something has gone wrong in the care provided by a clinical colleague, advising them to follow it up with a complaint or otherwise.	
A clinician's advice to file a complaint manifests intra-organisational fragmentation and tensions. Instead of informing the patient and/or family member(s) of the options that are available to them following an adverse event, negotiating the details of the adverse event with the clinicians responsible, and preparing an organisationally-coordinated response, the clinician in the quote on the right 'exploits' the adverse event for their own purpose (alerting senior management to the problems caused by agency staff), disregarding the needs of the patient and family member(s) in the process.	*"… the supervisor of [profession], he came tearing through after the other two [clinicians] had rushed down and told me about it [the incident], and he told me to … immediately … get in contact with the … woman that deals with all complaints."* [Cons 16, 123]
Intra-professional and inter-professional tensions are a not uncommon theme in the consumer interviews, with comments from clinicians about the inadequate standards of colleagues' practices pointing to the possibility that disclosure be used as a mutual blame mechanism.	

Open Disclosure may affect how health care professionals communicate with and relate to one another, since Open Disclosure promotes:

1. people being open with one another;
2. attention to the complexity of adverse events not being sacrificed in favour of hasty conclusions and personal blame;
3. people's right to know being linked to a duty to achieve a more sophisticated understanding of health organisational processes and incidents, and
4. the organisation mobilising a coherent and supportive response to both staff and consumers.

"Taking professional responsibility for an adverse event if it comes to a professional's attention, whatever its source or origin".

Rather than clinicians who become aware of an adverse event having occurred in a colleague's care channelling their judgment through the patient (and/or family), they should remember that their judgment places an onus on them to initiate notification via formal, hospital-internal channels. This does not obviate discussing the adverse event with the patient (and/or family), nor pointing out the various options open to them (including complaint and litigation). However, it is inappropriate for staff to presume that their judgment about an event having occurred while the patient was under the care of others is acquitted by encouraging consumers to take action against colleagues and/or neighbouring services.

2.5.2.2 The patient (and/or family member) is (inappropriately) informed about the adverse event from people not employed at the health facility where the adverse event occurred

As in the case of news being broken internally, when unexpected outcomes become evident after the patient has left the health care facility, the following problems with disclosure can arise.

Table 2.12: Consumers receive (inappropriate) disclosure about the adverse event from someone not connected with the health organisation where the patient was treated

Consumers receive (inappropriate) disclosure about the adverse event from someone not connected with the health organisation where the patient was treated	Relevant Interview Quotes
1 **Clinicians who are not employed at the facility where the adverse event occurred should not burden consumers with both the knowledge of the unexpected outcome and the task of acting on its implications**.	
Patients and/or family members may be informed about adverse events after they have left the health facility where the event occurred. For patients to find out that an adverse event occurred is traumatising. To find out about such an event in a way that is less than ideal can be additionally distressing. In the quote reproduced on the right, the consumer recounts being burdened with knowing and acting on an unexpected outcome, even though it is s/he who is least practically trained and emotionally prepared to act on the implications of such knowledge.	*"I didn't get told that there was an internal investigation going on by [name hospital] into [baby's] death. I didn't get told about that by [name city]. I was told about that by my [clinician] in [name town]. So I then wrote letters to [name hospital] regarding [baby's] death."* [Cons 1, 6]

87

Table 2.12: Consumers receive (inappropriate) disclosure about the adverse event from someone not connected with the health organisation where the patient was treated (cont'd)

Consumers receive (inappropriate) disclosure about the adverse event from someone not connected with the health organisation where the patient was treated	Relevant Interview Quotes
2 **Clinicians should not inform the consumer that there are conflicting expert opinions about an unexpected outcome without asking the consumer whether they expect the clinician to resolve this conflict on behalf of the consumer**.	
If hearing about an unexpected outcome from people not originally involved in the care can be unsettling, being confronted with divergent expert opinions about its causes may be even more so.	*"when I took [name baby] to [name town] then when I came home to see a paediatrician, she told me that what actually happened was, that through my birth, twenty minutes before I had [name baby] I had this really big blood loss"* [Cons 3, 24]
Clinicians are valued for their expert opinions, and for their ability to shed light on the medical-clinical specifics of unexpected outcomes. When they assume care of a patient, and their opinion conflicts with colleagues about the details of care provided in the past (particularly in the case of an adverse event), they should not merely burden the consumer with their views and leave the consumer to act on the consequences. Instead, the treating clinician should ask whether the consumer would like them to assume the task of clarifying this difference of perspective with the relevant colleague(s) (at the facility where the adverse event occurred), in order that the consumer may receive:	*"The [second] surgeon [not originally involved in the operation] said to me there and then there is a hernia suspected, through the stitching, it was not stitched up tight enough, which turned out to be quite true. He said after the operation [done by the first surgeon] he could put his thumb through to the stitching."* [p 13, p. 107]
1. a *professional* (rather than just a *personal*) explanation about what happened, and	
2. be provided with a *coordinated* response that helps them understand and address the implications of what happened.	

> **"From professional autonomy to responsible autonomy"**
>
> Clinical autonomy has functioned as an important principle in medicine: it has ensured that medical decisions have benefited first and foremost the patient (Degeling, 2000). At the same time, an excess of professional autonomy may lead to inadequate negotiation and engagement among clinicians, with patients' processes of care not benefiting from shared discussion among professional experts. What is needed is 'responsible autonomy' (Cruess & Cruess, 1997):
>
> ① *intra-professional* negotiation of opinions, practices and plans, and
>
> ② *professional-organisational* arrangements and agreements to take responsibility for the provision of health care in general (even if that care spreads across services, specialties or systems), and for unexpected outcomes in specific.

2.5.3 Being asked to become involved in Open Disclosure

Patients and family members express the expectation that the Open Disclosure meeting be preceded by at least two activities on the part of the clinical team and/or health facility: involving the patient (and/or family) in establishing the severity of the adverse event, and preparing (the patient and/or family) for its disclosure.

Table 2.13: Preparing for the Open Disclosure meeting

Preparing for the Open Disclosure meeting	Relevant Interview Quotes
1 **The patient and/or family should be involved in determining the severity of an adverse event**. Formal definitions of adverse events as are contained in the Sentinel Event list, and structured approaches to establishing the severity of the adverse event that use Severity Assessment Codings provide important guides for clinicians in their attempt to gauge the seriousness of an adverse event and tailor their response to it. However, it is evident from the consumer interviews that if these activities take place without involving the patient (and/or their family) they run the risk of contravening the expectations of those harmed. The risk here is not just that Open Disclosure is not done when it should be done, but also that Open Disclosure is initiated when those affected do not want to meet with the relevant clinicians or representatives.	*"And, like one said, like, you know, 'It's not life threatening', like, you know, 'You can cope', and 'It's not as if he's got leukemia', but it is bad to me. I would rather him be born with nine fingers or nine toes! There's nothing more important than your sight and your hearing!"* [Cons 3, 26]

Table 2.13: Preparing for the Open Disclosure meeting

Preparing for the Open Disclosure meeting	Relevant Interview Quotes
An important role is played by intermediaries (whether Patient Liaison Officers, Quality Coordinators, Complaints Officers, or clinicians who act as Peer Support Officers) liaising and channelling information between those affected by harm and those intending to disclose the adverse event. It is clearly of great importance that those charged with conducting Open Disclosure act on information relayed from the patient (and/or family) by those intermediaries, to prevent disagreement about the level (high/low) and style (membership, articulation of the apology, framing of the adverse event, and follow-up) of the disclosure.	*"We were offered a family conference but by this time we'd had so much conflict in the family … Speaking to the managers of [name facility] they suggested that we sit down and have it explained what happened. But I didn't think that that would serve a useful purpose because of the amount of anger [in the family]."* [Cons 10, 98]
2 **The patient and/or family should be allowed time to pre-plan for Open Disclosure**. It is as important for patients and family members to have time to prepare for Open Disclosure as it is for clinicians (see Section 2.4.1.3). Interviewees value being given the time to prepare for Open Disclosure. This is achieved by intermediaries signalling they are invited to an Open Disclosure meeting, or by engaging the patient and/or family in an Open Disclosure pre-meeting where the formal meeting is discussed. By having signalled to them that Open Disclosure needs to take place, consumers are enabled to prepare questions, think about statements they want or need to make, and plan for the kinds of support they need to request.	*"I was visited once by the obstetrician when I was in hospital…she came to visit me then, but it wasn't a planned [meeting]… she just popped up to see me… so I didn't have any questions planned or anything."* [Cons 9, 88]

2.5.4 Participating in Open Disclosure

Patients were very explicit about their experiences of the Open Disclosure meeting itself. Issues that came to the fore here include: appropriate timing; clarity about hospital-internal ranks, relationships and functions; active listening and sincerity; planning ahead for kinds of support that are needed; and the possibility of making contact with those most closely involved in the adverse event.

Table 2.14: Participating in the Open Disclosure meeting

Participating in the Open Disclosure meeting	Relevant Interview Quotes
1 **Patients and family members expect clinicians to time the Open Disclosure meeting appropriately**. Above, when discussing the health care staff interviews, we commented on the complex nature of making sure that Open Disclosure is appropriately timed (Section 2.4.1.4). Good timing is difficult to achieve, because it is subject to competing considerations. As just noted, it is important to give the patient and/or family enough time to prepare for Open Disclosure. At the same time, it is also crucial not to leave them too long without information, as is evident from the quotes on the right. Good timing is achieved by being sensitive to the needs and expectations of all parties involved. Here too, the role of the intermediary or liaison person becomes crucial: it is they whose advice about the patient's and the family's feelings, needs and expectations should be carefully heeded. It is this advice that the Open Disclosure team in turn should translate into appropriate action.	*"If it had have been all brought out in the open straight away, if they had've come to me straight away, the doctors that is, explained to me exactly what happened and why, we should never have had that meeting. It should have been all done before I left the hospital."* [Cons 2, 20] *"And it wasn't until after the [complaints body] had done their formal investigation that I finally got notified, it was about a week later, that [Support Personnel] from [name hospital] actually rang me and said, 'We need to talk to you. We need to have an Open Disclosure."* [Cons 1, 9] *"[Were you invited for a meeting?] Well, no, well yes and no. Mum had died by this time. By the time I'd put in the formal complaint and they got round to actually doing a meeting, mum had died in the meantime."* [Cons 18, 147]
2 **Patients and family members should have a patient/family support person present during the Open Disclosure meeting(s).** Interviewees were concerned that they be involved in deciding who (of the staff) be present during the Open Disclosure meeting. Again a delicate balance needs to be struck: the Open Disclosure meeting should not be too informal, but at the same time it may be that consumers dislike being confronted by too many 'suits'. Instead, interviewees prefer that there is a support person who is on their side and who understands their lifeworld. Such a support person would also be able to ensure that the patient and/or their family would receive regular updates about the investigation, and that they are invited to come in for a final meeting when the investigation is completed to ensure consumers can ask questions about the explanatory information provided to them in writing.	*"I probably didn't like the fact that they were in suits and you know like it was 'we're going to fix this because we're the hierarchy' that sort of thing. Do you know what I mean?"* [Cons 13, 101] *"Probably if we had a nurse in there as well and some other support people, that would have made it less clinical. Can I say, we probably would have benefited [and] I personally would have benefited greatly from having some contact with some support from a social worker, for example, just somebody to support us through that time. The nursing staff can't do it. They are too busy. It's not to say that they are not very good, they are, but they can't give the support that I felt we needed."* [Cons 13, 101]

Table 2.14: Participating in the Open Disclosure meeting (cont'd)

	Participating in the Open Disclosure meeting	Relevant Interview Quotes
3	**The patient and/or family need(s) to be told about hospital-internal ranks, relationships and functions**. It may happen that patients and/or family members do not know where hospital staff fit into the overall structure of the hospital or health service: what department are they? How do they relate to the doctors and nurses who originally treated me (or my relative)? Why are they talking to me now? It is important for those arranging Open Disclosure to make clear not just verbally, but also in written form, where they and colleagues fit into the organisation.	*"Um, [there was the doctor] and his off-sider. Um, I'm not sure how she fits in. I think she works directly with him, um… but as doing what, she's definitely not his secretary, she hold a lot more pull or push than that. Um, I'm not sure what her position actually is."* [Cons 4, 37] *"Um. Yeah there was one lady from the hospital, who does the… uh… [asking someone in the background] what was her name? From the hospital? Lady at the meetings? Yeah I can't remember. She was part of the health and safety thing at the [name] hospital."* **Interviewer: Yeah, a patient safety officer was it?** *"Yeah. Yup. And um, oh, can't even remember who the other fellow was."* **Interviewer: Do you know whether they were doctors, or nurses or…?** *"I think they were like um, the managers of the doctors, like the… you know, the… I don't even know what you'd call them. Supervisors of…"* **Interviewer: A medical supervisor?** *"Yeah, something like that."* [Cons 5, 49]

"The 'Open Disclosure advice booklet'"

An Open Disclosure record for the patient and/or family: It may be of value to provide the patient and/or family with a written document or an *Open Disclosure advice booklet* that explains what Open Disclosure is about, how it satisfies the health facility's policy, which staff is likely to be involved (depending on severity), what options are open to patients and/or families (e.g. complaint, etc), and how the Open Disclosure process is likely to unfold. Rather than a single letter being sent following an Open Disclosure meeting, such document provides a much more comprehensive information resource. Additionally, the Open Disclosure advice booklet could contain pages where the patients and/or family can make notes about different meetings, different things that are communicated, and the plans that are agreed on.

Table 2.14: Participating in the Open Disclosure meeting (cont'd)

	Participating in the Open Disclosure meeting	Relevant Interview Quotes
4	**The patient's and family members' concerns need to be heard by clinicians; clinicians need to practise 'active listening'.** Patients and family members express being appreciative of staff taking the time to listen to their concerns. Interviewee are specific about the benefits of being able to 'let off steam', and get angry at the clinicians without having to fear they will retaliate and turn defensive.	*"[The patient liaison person said] 'We need to talk to you about [name son]', and then when we did go to the meeting he actually, well he said he'd like to shut up and let me talk, but it was really good that he sort of, he asked me like, … 'What do you want to get out of it?' And basically my answers were I wanted to make sure that it never happened again. … You know, and it was really good because [name liaison person] allowed me to say that"* [Cons 1, 9] *I liked that I could talk and I could ask questions and I didn't, like even though at times I felt like I was attacking, it wasn't passed on….there was no retaliation like as if I was attacking. Like I said to Dr Sherman, 'Look, I'm sorry for saying this but this is how I felt at the time when you said this….', and I felt like, yes, I was attacking exactly what she said and how it felt to me, but she didn't retaliate, like just defensively. She tried to explain why she said it. [okay, she accepted your views and responded] Yeah. [and you say you felt listened to.]"* [Cons 1, 13]

"The ethics of 'active (reflective) listening'"

Active or 'reflective' listening – remaining attentive and silent while the other speaks - is an important skill for those charged with doing Open Disclosure. Its importance lies in patients and/or family members gaining the opportunity to frame the adverse event in their own terms, whether emotional, practical, or social. The power of 'active listening' (Egan, 2006) is that it mitigates people's distress, anger, and guilt. By the same token, gaining the skill of active listening places an additional onus on staff who wield it: it is important that it not be used to silence consumers' feelings and misgivings, in the interest of reconciling them with self-protective risk-managerial priorities of an organisation, department or unit. Open Disclosure should therefore produce a tangible outcome for those harmed, whether this be an apology, a gesture, or a material reparation.

Table 2.14: Participating in the Open Disclosure meeting (cont'd)

Participating in the Open Disclosure meeting	Relevant Interview Quotes
5 **Patients and family members should be issued a sincere apology.** Patients and family members comment frequently on the nature of the apology they received. In general, full apologies are commented on positively. Consumers may experience disclosure as insincere when staff decline to take responsibility for events that the consumer judges them to be responsible for. Insincerity can also be experienced when staff who were not involved in their care or who have the role of intermediaries are the only ones to offer an apology. The complexity of clinical work and the difficulty – if not impossibility - of separating human from technological errors and pinpointing incident causes means simple explanations for adverse events are rare (Dekker, 2005). Many staff are involved in care, they have demanding working hours and work with complicated technologies and dangerous drugs for patients who may present with multiple co-morbidities. These factors often put the accuracy of clinical decisions and the integrity of medical treatments at risk in ways that is beyond the capacity of well-intentioned and well-trained staff to control. These factors also mean that explaining adverse events to patients and families is challenging, particularly because clinical complexity is often talked about only *after* an adverse event occurs. The problem that arises here is that mention of clinical complexities after an adverse event may be perceived by consumers as clinicians' attempt to obfuscate. Above we noted that this dilemma should be addressed by broadening the scope of informed consent to include comprehensive risk information (see table 2.10 above). Forewarning consumers about the complexities of care therefore is crucial. Doing this more comprehensively may help the difficult discussions following an adverse event, minimising the risk that pointing to clinical complexity as the reason for being unable to specify clear causes is regarded and rejected as insincere.	*"… telling us the procedure they have done and apologising about what happened … Yes, they did apologise, both from [hospital 1] and [hospital 2]."* [Cons 12, 103-4] *"One thing I will say, um, is that the doctor, the patient safety officer um, apologised profusely."* [Cons 4, 39] *"The only thing they really admitted to was losing the document and that procedure is being looked at. They apologised for our [loss]."* ***Interviewer: But not for what happened to your father?*** *"No, they did not take any blame except for the power of attorney document. So, there is three pages of excuses [in the letter they sent]".* [Cons 10, 99] *"Er, I mean…from what I can remember, I was quite sort of upset at the time. They were basically…the whole thing it seemed like they were covering their tails, basically. The doctor at the time did apologise but no-one's really taken responsibility for it."* [Cons 9, 88] *"I would like to have an apology…a sincere apology, that [said], 'yes, we shouldn't have put you in that position.'"* [Cons 9, 91] *"… an apology is one thing [but] this is coming from the patient safety officer, not coming from the doctor who decided not to scan my spine further."* [Cons 5, 41] *"I still don't know. Like all the reports and everything I've got, like, still really I don't know whether the medication did it or whether just all the, like, you know, it was a pretty traumatic birth."* [Cons 3, 25]

A general guide for distinguishing sincerity and insincerity is provided in the work by Chris Wheeler represented in table 2.14b below (Wheeler, 2007). For Wheeler, sincerity realises a focus on and concern with those harmed; insincerity maintains a focus on and concern with self. Sincerity associates with a focus on the victim of harm, where insincerity associates with concern for the apologiser. Equally, sincerity associates with taking responsibility; insincerity with not acknowledging responsibility.

Table 2.14b: Sincerity defined

More Sincerity	Less Sincerity
Focus – on the 'victim'	Focus – on the apologiser
• on the consequences of the action for the 'victim'	• on the apologiser's relationship with the 'victim', or • on the apologiser's reputation
Objective – for the 'victim'	Objective – for the apologiser
• to respond to the 'victim's' pain and suffering • to address the 'victim's' needs • to allow the 'victim' to move on	• to appease the 'victim' – to get acceptance • to justify the action – looking for exoneration or defending the action, or • to allow the apologiser to move on through release from blame
Responsibility – acknowledged	Responsibility – not acknowledged
• for the wrong • for the harm	• responsibility not acknowledged , or • responsibility denied, or • responsibility placed on 'victim'

"The tension at the heart of the Open Disclosure apology"

Apologising for errors in care is challenging. Patients and family members are anxious and not always receptive. Staff are constrained by insurance contracts, the law and their own inclination to protect reputations. Consumers tend to be highly scrutinising of how staff perform their apology, who they are in the organisation and how much weight their apology is therefore likely to carry, how much remorse and acknowledgment of responsibility is invested in the apology, and whether and what kind of reparation accompanies the apology. A sincere apology from the right person can clear the air, even in very serious situations. The Open Disclosure Standard (Australian Council for Safety and Quality in Health Care, 2003) limits staff to the partial apology[27]. Yet it is evident from both health care staff and the consumer interviews that sincerity is most valued and performed if deemed possible and/or necessary, the limit inscribed into the Standard notwithstanding[28]. A problem posed by this limit is that – paradoxically - people's sincerity will lead them to transgress that formal limit. People resolve problems and misunderstandings by being sensitive to their and others' morality and humanity, not by rigidly observing a rule that loses its relevance in the face of lived practice. The unique opportunity offered by Open Disclosure resides in the radical notion that being open about adverse events is more congruent with the objective to provide care and therefore more effective than any legal and bureaucratic protection (Wojcieszak et al., 2006).

Table 2.14: Participating in the Open Disclosure meeting (cont'd)

	Participating in the Open Disclosure meeting	Relevant Interview Quotes
6	**Enabling consumers to plan ahead and plan for their practical, personal and emotional needs into the future**. Immediately following an adverse event, the patient and/or family may not know what kinds of things to ask for, or how to assess the implications of the incident for their own future. For this reason, it is important that the patient (and family) be provided with the resources and opportunities needed for making both a practical and an emotional assessment possible. One interviewee saw himself forced to take legal action because the future implications of his adverse event remained uncertain.	*"So I was, and I knew that … even though I was sort of on the repair, that I'm going to pay for this later on in life. I'll have further consequences down the track. … it was looking like I was going to lose my job… so, I was going to take it further."* [Cons 4, 40]

---

[27] The Standard does not contain the words 'apology' and 'apologise'.

[28] Open Disclosure allows an 'expression of regret' (a 'partial apology') but not a 'full apology' that acknowledges responsibility for harm (Australian Council for Safety and Quality in Health Care, 2003; Vines, 2005).

Table 2.14: Participating in the Open Disclosure meeting (cont'd)

Participating in the Open Disclosure meeting	Relevant Interview Quotes
7 **Making it possible for patients and family members to make contact with those most closely involved in the adverse event if that desire is expressed**. Some interviewees express disappointment at not being allowed to make contact with those most closely involved in their incident. Maintaining a distance between patients (and/or family members) and the clinician(s) most closely involved with the incident is done on the assumption that there will be blame and anger on the part of the victim of harm, that such a meeting will be too hard and threatening for the clinicians involved, and that such a discussion would be too hard to manage for peer support staff (the Open Disclosure Peer Support person or equivalent). These assumptions are not necessarily justified. One interviewee expressed regret at not being allowed to speak to 'the poor students who delivered me' and reassure them that she did not blame them for her inadequate surgery and subsequent incontinence.	*"they wouldn't let me speak to the poor students who delivered me"* [Cons 9, 92]
Another interviewee resented her not being allowed to meet with the clinicians involved in the incident because she felt properly addressing the cause of her baby's disability (a drug overdose and other less distinct factors) was seen as less important than staff protecting colleagues.	*"No [I did not get an explanation for the overdose]. All I could get out of the doctor was, 'The nurses feel very bad. Some nurses even quit their jobs over this', you know, 'when they make a mistake'. And, well, I don't really care. I don't really care if they quit their jobs or whatever. You know, like this is my baby."* [Cons 3, 26]

Additional Note: Arranging and conducting a meeting between victims of harm and the clinicians who were involved in the incident. Arranging and conducting a meeting between victims of harm and the clinicians who were involved in the incident is challenging (cf. Braithwaite, 2002)[29]. To live with the consequences of an adverse event as patient (and/or family) is also challenging, if for different reasons: victims may not just have physical problems to deal with (potentially leading to further injury), but also psychological ones, such as anxiety in the face of upcoming operations, guilt at having allowed clinicians to act as they did, and worry about how the effects of this incident will affect them (physically, financially) in the future. It is further not self-evident that displacing the burden of coming to terms with the

---

[29] Professor John Braithwaite's work on restorative justice focuses on bringing criminal offenders and victims of crime together.

adverse event onto the patient and/or family is entirely and necessarily in the health organisation's interest.

For clinicians involved in incidents, not meeting with the victims of harm and not having the opportunity to explain that they never intended the incident to happen may result in their experiencing a lack of closure themselves. Possibly too, not speaking with those affected may cement in junior staff an attitude of detachment and a lack of personal care for patients and families. This is not just the opposite of what the Open Disclosure initiative is trying to achieve; it also goes against a trend in the clinical professions towards becoming more emotionally open and more affectively attuned to professionals' own, their colleagues' and their patients' experiences and sentiments (Berlinger, 2005).

On both counts, then, Open Disclosure should be structured such as to make it possible for those involved in the adverse event and the victims of harm to meet. This is in the interest of all involved. It obviates imposing organisational views of what is appropriate for the patient and/or family and thereby making light of their expectation to talk to the original clinician(s) about how the event occurred and reach closure, and it reverses the kind of professional disregard of patients that has been normalised and legitimated in clinical education as 'detached concern' (Lief & Fox, 1963).

In the final analysis, of course, staff in charge of Open Disclosure need to make decisions about these matters in ways that are in the best interest of all involved. However, if patients and/or family members express a desire to meet clinicians who were 'close to the incident', and who may be able to reveal details that others don't have access to and thereby produce closure, serious consideration needs to be given to patients' and family's right to have this wish granted.

Table 2.14: Participating in the Open Disclosure meeting (cont'd)

Participating in the Open Disclosure meeting	Relevant Interview Quotes
8 **Conducting the Open Disclosure meeting with an appropriate level of respect.** It is of great importance that the Open Disclosure meeting is treated with respect by those who participate in it. One interviewee expressed disappointment at her meeting being disrupted, and at the senior clinician bringing along a student without this being negotiated in advance. Given the relative severity of this particular adverse event (this patient was given unsuccessful surgery resulting in incontinence and requiring further surgical interventions), staff's handling of the meeting was inappropriate. Health facilities need to ensure that staff who are in charge of Open Disclosure have appropriate communication and social skills. This is important: if Open Disclosure is handled badly the purpose of the meeting will be defeated.	*"And the doctor at the time who repaired me had a student of his own [when they came for the disclosure meeting], and was … being paged, and was being called to theatre. Like, just the whole thing had been so rushed, and then they tried to sort of brush it under the carpet and, yeah, so … I just didn't feel comfortable with the whole situation at all."* [Cons 9, 88]

2.5.5 Following up the initial Open Disclosure meeting(s)

Patients and family members express dissatisfaction with the lack of continuity following the initial Open Disclosure meeting(s). Table 2.15 presents the sources of discontinuity mentioned.

Table 2.15: Following up the initial Open Disclosure meeting

	Following up the initial Open Disclosure meeting	Relevant Interview Quotes
1	**Obviate discontinuity that may result from staff movement.** Involving several staff in handling Open Disclosure is at times inevitable due to staff turn-over, leave and shift constraints. It is important for these reasons that a 'single desk' be maintained; that is, a specific group of people who are able to locate the necessary information and documentation pertaining to specific cases.	*"Um, while I was in hospital, the first day was a Wednesday because, like he was born [and died] on a Tuesday night, so Wednesday a social worker came to see us … and I went through the story and everything. Then the Thursday, because the social workers were job share, I had the other social worker come so I had to tell her about the whole story again. And then when I left hospital I got the name of yet another counsellor to talk to. Then I came back to … well [name patient liaison person] had a meeting with us."* [Cons 1, 8]
	In health care, the risk of discontinuity of minimised by asking consumers to repeat their version of events to several different staff. This repeated questioning can become embarrassing for the patient however. One patient interviewee felt her case became too widely known around the hospital, and she resented too many clinicians visiting her to talk about her case.	*"I had a lot of people coming up to me asking me how [name son] was when I was in hospital, and I was happy for their concern, like I was thankful for their concern but after a while it was a little overwhelming because I still felt like I was in a bit of shock over what had happened and sometimes I just didn't want to see…like I didn't want to make eye contact with someone or… because I knew that they would just ask me and just having to explain over and over again I guess."* [Cons 8, 84]
2	**Prevent discontinuity that results from incident investigations taking very long**. Discontinuity can also result from the incident investigation taking too long in the eyes of the patient and/or family. This may prompt them to write to the health facility for an update or a report. Further discontinuity can result when the health facility is unable to respond appropriately to such correspondence and address people correctly.	*"I probably would like to have known a bit more of the process that went on after that interview. We were just left … by both parties. We were just given an idea of a date where we might receive information … I actually had to write to [name health facility] to get any feedback from them … And then the letter came back and they were … addressing it to him [not to me], as [if] I … wasn't a part of it."* [Cons 13, 106]

Appropriate follow-up of the Open Disclosure meeting involves remaining sensitive to the dynamics of patient's and family's expectations and needs. Such sensitivity can be shown by the patient liaison person, and interviewees are appreciative of such person's care. To enhance the tangible impact of Open Disclosure and the reality of its intent, staff need to

consider involving patients and families in their efforts to improve their own practices. For example, patients and family members may be invited in for interviews about the adverse event. During such interviews, questions about what happened can be coupled to eliciting views about what might resolve the problem. This would grant patients and affected family members a constructive role in ensuring the adverse event does not reoccur, and in strengthening their sense that the health facility is not just capable of erring but also of being responsive to those most seriously affected.

"Involving consumers in patient safety"

Open Disclosure is a communicative practice that can mitigate negative public experiences and perceptions of their health care (Woods, 2007). Conducting Open Disclosure in inappropriate ways however can exacerbate patients' and families' experiences and perceptions through multiplying inadequate care by inadequate communication. For consumers, the obligation on the part of health services to be accountable for inadequate care is not discharged by uttering a 'few more little sorries'[30]. Open Disclosure is contingent on sincerity and a relationship that arises from a mutually (by the consumer and the clinical team) satisfactory form of closure; that is, a sincere apology and tangible reparation. As part of this aim to render the relationship and the reparation tangible, consumers should be asked to become involved in organisational investigation and improvement processes.

---

[30] Viz. *"we do pop in a few more little sorries now"* [Support Personnel, 23-31].

2.5.6 A numerical analysis of patients' and family members' Open Disclosure accounts

The table below (table 2.16) includes information about the twenty-three cases revealed in interviews with patients and family members. It shows that in eight cases High Level Open Disclosure was arranged (as defined in the Australian Open Disclosure Standard), and in another ten cases, Low Level disclosure was conducted (clinicians disclosing adverse events informally: during ward rounds, while 'popping in' to see the patient, or as part of brief consults). In another four cases no Open Disclosure was said to have taken place (although these interviewees were referred to us by organisations as having participated in Open Disclosure).

The table also provides severity estimates and information about whether interviewees judged Open Disclosure to be successful. Overall, the patients and family members interviewed had been involved in nine High Level cases. Of the twenty-three interviewees, eight interviewees judged their experience of Open Disclosure to have been satisfactory, twelve judged their experience of Open Disclosure to have been unsatisfactory, and two were unable to state clearly whether Open Disclosure could be judged to be successful in their case.

The table further displays how the adverse event was notified, and whether an apology was offered. Ten notifications were made via channels external to the hospital; eleven notifications occurred internally (by the staff involved or by representatives of the hospital), and one notification was a mixture of internal (a second surgeon at the hospital alerts the patient to a problem produced by previous surgeon's treatment) and external (the husband files a complaint). Out of the twenty-three interviewees, eleven acknowledge that they were apologised to fully (that is, staff expressing regret and accepting responsibility for the error); eight state they were not offered an apology; three state that they were offered a partial apology (an 'expression of regret'), and one states that some staff apologised and then appeared to retract their apology.

Finally, the table sets out whether the consumer(s) was (were) able to meet with the clinicians most closely involved in the adverse event, and whether there was evidence of tangible reparation and/or support. As the table shows, in thirteen instances the patient and/or family were able to make contact with one or more staff who were close to the incident. This contact was not always achieved at the time of a formal Open Disclosure meeting however, and includes occasions when staff were on the ward and engaged in an informal exchange about the adverse event with the patient and/or family. Similarly, in twelve out of twenty-two instances was the health facility said to provide some form of reparation and/or support. This includes both counselling and other kinds of clinical treatment, ex gratia payments to cover travel, and the like, and improvements made to procedures and clinical processes.

Consumer Accounts of Adverse Events: An Overview

Bringing together issues raised by consumers about their experiences with Open Disclosure, table 2.16 draws attention the following issues:

1. full apologies are made by staff other than those originally involved in or present at the adverse event;

2. staff are happier disclosing less serious adverse events with the consequence that serious adverse events may not be handled according to minimal Open Disclosure standards;

3. the patient liaison person acts as buffer between the health organisation and the clinical professionals on the one hand, and the patient and family on the other hand, limiting the support available for patients and families to social-emotional support; this obviates tangible involvement on the part of clinical professionals in disclosure, reparation and learning from the incident and from the consumer;

4. disclosure may be initiated by staff employed in sites other than that where the adverse event occurred without such staff recognising the need for appropriate Open Disclosure, thereby burdening patients and family with distressing information *and* with the task of acting on that information without the benefit of clinical, professional or organisational experience and support;

5. alongside patients, family members play a crucial role in ensuring that clinical staff take the disclosure of unexpected clinical outcomes seriously, by initiating requests for information, demanding explanations, insisting on disclosure and filing complaints.

The table (2.16) below sets out the details of the individual interviews under the following ten headings:

1. Consumer interviewee number (+ pages in transcript & identity/age of the interviewee)
2. What were the details of the adverse event?
3. Did Open Disclosure take place, and was it Low or High Level Open Disclosure?
4. Was an apology offered, and, if yes, was it partial or full?
5. Was there internal or external adverse event notification?
6. What is the estimated severity of the adverse event?
7. What is the estimated severity of the adverse event as seen by the consumer?
8. Was the outcome of Open Disclosure process judged to be successful?
9. Was there an offer of reparation?
10. Was contact possible with the clinician(s) most closely involved in adverse event?

Table 2.16: Analysis of the patient and family member interview transcripts

Con-sumer interviewee (pages in trans-cript)	What was the adverse event? Did it have a clear cause?	Did Open Disclosure take place? Was it Low or High Level Open Disclosure?	Apology? (Was it partial or full?)	Internal or external notification?	Severity estimate?	Severity seen by pt?	Outcome of OD process judged to be successful?	Was there reparation?	Was contact possible with clinician(s) most closely involved in incident?
1 (1-14) 29 yo female	Pregnant woman induced, started vomiting, received (in her judgment) too little clinical attention for some hours, then suddenly taken to theatre for an emergency caesarean, but the baby dies. Conflicting accounts offered: one clinician claims there was clinician-caused vaginal golden staph infection, but this was denied by others.	Yes, high "And it wasn't until after the [complaints body] had done their formal investigation that I finally got notified, it was about a week later, that [PSO] from [hospital] actually rang me and said, 'We need to talk to you. We need to have an Open Disclosure." (p. 9)	Yes, full [staff blame other clinicians? Backflip?; "… the first meeting was she apologised. She told us that I didn't get the care that I deserved, that you know, I should have been monitored, I should have been this and I should have been that. Then when I handed her the birth certificate that said staphlococcal coriamianitis she backtracked and say, 'No, no, no. We knew that there was something else wrong. There was nothing we could have done. It came on so fast, you know, nothing could have saved it' rah..rah…rah..rah. And that to me seemed like she just completely and utterly was not sorry any more. Just completely and utterly did a backflip and blamed the infection fully rather than saying, 'Well, it was a contributing factor that both of them led to his death.'" (p. 8)	External [Complaints body]	High	high	No: not everyone open; Yes: changes made to hospital procedure.	Flights to city yes, financial support with IVF no	Yes, but doctor only person present of the team present at OD meeting.
2 (14-21) 58 yo female	Older lady is administered anaesthetic overdose; she feels strange following operation, but only receives disclosure of the incident 2 months after the operation.	Yes, high "a lovely lady there who organised this meeting with the head of the anaesthesia department, the head nurse and, I can't remember her name just off the top of my head, but she was such a lovely lady and the three of us were there in the room. We had organised this meeting a month ahead of time, and it was then that I learnt what had actually happened." (p. 15)	Yes, full "It was the nurse's fault because of the way the dosage is given and they told me that they had put in place measures that will not allow this type of thing to happen again." (p. 18)	External [GP (check up)]	Medium high	high	No, Meeting too delayed, subsequent distrust.	Measures put in place to make sure it never happens again (p. 19)	No (nurse absent from OD meeting).
3 (21-31) 36 yo female	Baby is given twice the amount of antibiotics following previous dose not being documented, loses hearing. Baby 'grunts' following birth but this is not immediately diagnosed. Patient receives conflicting accounts: one clinician claims blood got into the baby's lungs as a result of earlier intervention.	Yes, low level ('pop in') "that night that's when that doctor came up to me and said that he had been overdosed and that it was most likely that he failed the hearing test because of that drug, and, yeah, I was devastated." (p. 22)	No apology, but clinicians accepted that nurses were responsible. "We've got no idea. They wouldn't even tell us. All the doctor said was the person was very upset and, yeah, some of them even quit their jobs after they've made a mistake." (p. 29)	Internal [treating clinician]	High/medium high	High (once realised extent of incident)	No, Formal meeting too delayed, conflicting advice from different paediatricians (grunting due to baby swallowing blood after placenta ruptured).	Some financial support, but not enough to cover disability costs and challenges later in life.	No (nurses absent from OD meeting).

Table 2.16: Analysis of the patient and family member interview transcripts (cont'd)

Cons (pages in trans-cript)	What was the adverse event? Did it have a clear cause?	Did Open Disclosure take place? Was it Low or High Level Open Disclosure?	Apology? (partial/full)	Internal or external notification?	Severity estimate?	Severity seen by pt?	Outcome of OD process judged to be successful?	Was there support? Rectification?	Was contact possible with clinician(s) most closely involved in incident?
4 (31-44) 49 yo male	Motorbike accident patient has a spinal injury that is not diagnosed due to partial x-ray of the spine.	Yes, high.	Yes, full. "One thing I will say, um, is that the doctor, the patient safety officer um, apologised profusely." (p. 39)	External [GP check up]	High/ medium high	high	No. "I decided to do it [sue] because I am going to pay for this later." (p. 40); "You know, that apology was really great, at the time, [but] it's not going to help me in future if I have to cease work or… or whatever." (p. 42)	Some financial support, but not enough given potential future expenses; "They did arrange for me to… see an orthopaedic specialist to view the x-rays of my spine, because I had never seen them and had never wanted to see them, uh, while I was still in hospital. Um, and they arranged that, so… you know, I suppose whatever support I may have asked for, they probably would've provided." (p. 35)	Yes. "… they were very open and said that if I had any questions, you know, feel free to come back to them, you know, if I, questions occurred to me later on." (p. 35)
5 (45-51) 27 yo male (fiancée of pt)	There is disagreement between doctors during a birth. This explained as having to do with understaffing. No real harm caused.	Yes. "Uh we had two. We had one, um, just before they were starting the investigation. And then a couple of months later when the investigation was finished, we had another one which was just sort of a wrap up." (p. 48)	No apology. ("That's what the meeting was supposed to be about, but it was just a big defense mechanism for them. There wasn't much admission of anything that went wrong, they tried to." (p. 47)	External [Pt complaint]	Medium low	low	No. "One of the doctors that was in there [OD meeting], he even tried to defend the other doctor, trying to use the wrong scissors." (p. 47)	Counselling offered.	Yes.
6 (51-61) 70 yo male	Patient advises nurse to change surgery side before operation; she does and wrong-side surgery results. While patient says "I caused it." (p. 54), the hospital admits it needs to investigate its procedures.	No. "No I wasn't called at the hospital, they just asked me for my view, over the phone." (p. 55)	No apology. "No it was my [patient's] fault." (p 55)	Internal [treating clinician]	Medium low	Low ('his fault')	Yes.	Yes. Operation offered to rectify; "And they rang me back later and just said, well… the outcome was that they just have to tighten up on procedure, and when I come back in again, you would probably find you're gonna be asked a lot of questions, the same questions by different people." (p. 55)	Yes.
7 (61-80) 69 yo female	When a stent sheath is withdrawn from patient's groin, her blood pressure drops rapidly, and is administered a metaramine overdose.	Yes, low level (dr coming to bedside)	Yes, full. "Well, um, the doctor came and they, they apologised for, he said there'd been a mix-up in the catheter … He came and apologised a few times." (p. 62); "Well, I had to press for it, to get the information I wanted." (p. 68)	Internal [treating medical clinician]	High	High	No. "You know, I've had to wait all that extra time to get the, the analysis report before I could find out. Nobody would tell me why this drug wasn't, I asked repeatedly, 'Why wasn't it checked? Why wasn't it checked?' Nobody could tell me." (p. 70)	Limited support (husband can't fly with pt to Brisbane for operation).	No. "The nurses didn't come and see me. They just came, it was just the two doctors that kept coming to the bedside." (p. 65)

Table 2.16: Analysis of the patient and family member interview transcripts (cont'd)

Cons (pages in trans-cript)	What was the adverse event? Did it have a clear cause?	Did Open Disclosure take place? Was it Low or High Level Open Disclosure?	Apology? (partial/full)	Internal or external notification?	Severity estimate?	Severity as judged by pt?	Outcome of OD process judged to be successful?	Was there support? Rectification?	Was contact possible with clinician(s) most closely involved in incident?
8 (80-87) 26 yo female	Woman has an emergency caesarean due to prolapsed cord, but because the alarm went off in wrong area operation was delayed.	Yes, high level.	No apology. "I got along with all the health care professionals. I thought they were *very* professional and very positive experiences with all of them. I didn't feel negative about any of my interactions with any of the health professionals. It was all really good." (p. 83)	Internal [treating medical clinician & midwife]	High/ medium high.	High.	Yes. "I think the midwife spoke to me about it. There are lots of people that spoke to me about it. I couldn't really put a number on it. But I don't think … probably just the midwife in detail. I don't think anyone really spoke to me about it in detail." (p. 81)	Procedure improved/rectified. "I know they did tell me that they rectified the problem and that they've done a test, like a mock test to make sure it's going off correctly, and that." (p. 86)	Yes. "One thing that maybe I would have liked is for the surgeon that did my caesarian, maybe to speak to me about that side of it 'cause no-one really talked to me about that side of it" (p. 82)
9 (87-96) 28 yo female	Student midwife and junior doctor attend to birth and doctor provides inappropriate rectal surgery causing incontinence needing repeated surgery.	Yes, low level ('popped in').	Yes, partial apology. "Er, I mean…from what I can remember, I was quite sort of upset at the time. They were basically…the whole thing it seemed like they were covering their tails, basically. They haven't….The doctor at the time did apologise but no-one's really taken responsibility for it." (p. 88); "I would like to have an apology…a sincere apology, that, 'yes, we shouldn't have put you in that position.'" (p. 91)	Internal [treating surgeon]	Medium high.	High.	No. "I'll be seeing a lawyer … I just wanted someone to say 'I'm sorry.'" (p. 91)	No.	No, senior doctor only attends OD meeting, and he is unable to explain the AE to the patient's satisfaction.
10 (96-100) 59 yo female (daughter of pt)	Patient had a mild stroke and went into a hospital for rehab physio; he fell out of his wheelchair and ended up with pneumonia in ICU where he died shortly after.	Family refused OD due to family conflict and suspected whitewash.	Yes, partial apology. "The only thing they really admitted to was losing the document and that procedure is being looked at. […] They apologised for our [loss]." *But not for what happened to your father?* "No, they did not take any blame except for the power of attorney document [..]. So, there is three pages of excuses". (p. 99)	Internal [Patient Safety Officer]	Medium high.	High.	No.	No, little support offered.	No.
11 (100-101) mother of 23 yo male	23 yo man attempts suicide after being giving a prescription of 400 pills. He ends up in a nursing home.	Yes, low.	No. "No [they didn't apologise]. It wasn't their fault." (p. 101)		Medium high.	High.	Yes.	Nursing home costs covered by public purse.	Yes. "I actually liked that everyone that was involved with my son was there." (p. 100)
12 (102-104) 61 yo male	Patient given wrong plasma.	Yes, low. ("So, they came over and told us what had happened." (p. 102)	Yes, full. "… telling us the procedure they have done and apologising about what happened" (p. 103); "Yes, they did apologise. Both from [hospital 1] and [hospital 2]." (p. 104)	Internal [Doctors during ward round]	Medium high.	High "To me it was very serious."	Yes. "It was very useful" (p. 103)	"Royal treatment" following adverse event.	Yes. "So, they came over and told us what had happened." (p. 102)

Table 2.16: Analysis of the patient and family member interview transcripts (cont'd)

Cons (pages in transcript)	What was the adverse event? Did it have a clear cause?	Did Open Disclosure take place? Was it Low or High Level Open Disclosure?	Apology? (partial/full)	Internal or external notification?	Severity estimate?	Severity seen by pt?	Outcome of OD process judged to be successful?	Was there support? Rectification?	Was contact possible with clinician(s) most closely involved in incident?
13 (104-107) Wife of 61 yo male (12)	Patient given wrong plasma. (pt 12)	Yes, low. ("So, they came over and told us what had happened." (p. 102)	Yes, full. "But I actually had to write to [name institution] to get any feedback from them." (p. 106)	Internal [Doctors during ward round]	Medium high	High.	Yes. "The meeting was somewhat useful. They couldn't let us know what was going to happen to his body and what the consequences would be."; "I think there was not a lot I liked about the meeting at all. What I liked about the meeting was that they said they would make sure that they would review the procedures […] and the hospital to identify how this could have happened, that was probably it."; "I didn't like the fact that they were in suits and you know like it was 'we're going to fix this because we're the hierarchy' that sort of thing" (p. 105)	"The support of 'Hospital in the home' was marvellous because they were monitoring him as well as me. And they were a very good service support for me as well. Because if anything goes wrong they are there. I just have to ring them." (p. 106)	Yes.
14 (107-110) 50-ish female	Patient had gallbladder surgery and suffered 8 months severe pain post-op. Because suture wasn't tight enough she developed a hernia. Different surgeon operated on the hernia.	Yes, low. [No OD other than with Hospital Liaison person].	No. "I actually spoke to a lawyer. I was so peeved off, that's how bad I was." (p. 109); no letter and no apology.	Internal/external [Second surgeon stated there had been an error, Husband files complaint]	Medium high	High (lots of pain)	No. "I actually spoke to a lawyer. I was so peeved off, that's how bad I was." (p. 109)	Hospital pays for hernia operation; patient given a choice of three surgeons to correct surgery.	No (original surgeon did not make contact or attend OD meeting). "I felt very belittled there. I was given morphine there every time I went and was told you will be right to go home." (p. 109)
15 (110-119) 38 yo female (step mother of pt)	Young man run over by car, and during his 10 hour operation a Hep-C-infected piece of equipment was used.	Yes, high. ("But they were very very good. Like, they sort of sat there very quietly after they'd told us and let us process it all. Um, and… then they said to us, do you have any questions and we did, you know, like we had lots of questions. And they were very good. They answered all of our questions" (p. 115)	Yes, full. "They told us what had happened" (p. 111)	Internal. [Clinicians themselves, 'couple of days later' after op'n]	Medium high	Low (int'wee), high (mother)	Yes. "I liked the fact that it was never a rigid thing. You could, you felt comfortable with these people, um… they spoke to you… not like you were an idiot, they spoke to you like you were a person." (p 117)	Support from social workers, QC, nurses, doctors; process improved. "They, they looked after him very very well." (p. 111)	Yes.

Table 2.16: Analysis of the patient and family member interview transcripts (cont'd)

Cons (pages in transcript)	What was the adverse event? Did it have a clear cause?	Did Open Disclosure take place? Was it Low or High Level Open Disclosure?	Apology? (partial/full)	Internal or external notification?	Severity estimate?	Severity seen by pt?	Outcome of OD process judged to be successful?	Was there support? Rectification?	Was contact possible with clinician(s) most closely involved in incident?
16 (119-135) 64 yo female (wife) and 40-ish daughter)	Patient has cancer in the leg. He is supported by only 1 nurse (while notes say he needs 2 at all times); he falls, breaks his leg. He has an operation 24 hrs later, and dies 3 weeks after that from a blood clot. Family is on-site in the hospital when agency nurse drops patient and announces doctor is needed; doctor comes to treat patient but has to leave 'for more serious case'.	Yes, high.	Yes, full from agency nurse, but then partial apology from other staff. ".. they admitted that they made a mistake" (p. 125).	External. [Fam asked for OD, hospital did not respond, fam rang, hospital said case was closed; nurse advises fam to go to complaints].	High/ Medium high	high	No. "It wasn't, it wasn't enough at the time." *Intwr: Would it have been 'good enough' if they had said, 'Look, we, ar, we've looked into the case and we recognise that the problem is that agency nurses don't read the notes and from now on we'll …'.* "No. Never ever heard that ever. Even when we had the meeting, with the head honchos, and can I just say that they have actually filed our complaint and put it away. That we've, they thought we had already had a meeting and we hadn't. They thought that that nurse, that the head, ar, officer in charge of relations, um, [name], they thought that because we, we talked to her the next morning, that that was sufficient." (p. 127)	Patient moved to smaller hospital for further care (family: 'to free up bed in bigger hospital').	Yes.
17 (135-142) 54 yo female (mother of 29 yo female pt)	Young woman suicides after several previous attempts following discharge. Her family is refused information about the case and is denied answers to questions about the woman's mental diagnosis.	No. (meeting granted, but not a disclosure meeting)	No. "… well the head of the department you know couldn't fault ah what occurred during the course of the-the consultation and more or less said that um [patient name] was advised to seek help from drug and alcohol rehab-rehabilitation" (p. 137)	External. [Fam complaint.]	High	high	Yes. "I think we felt that we were you know treated quite well apart from the head of the department who, he said to us that, um, it is everybody's responsibility to keep themselves alive." (p. 137); No. "So I didn't receive an opportunity to follow up with my diary and try to understand the whole-what led to this event" (p. 138)	No, no support analyzing pt diaries to establish cause of depression & suicide and inform family of risk for other fam members	Yes. Head of Dept offers meeting.

Table 2.16: Analysis of the patient and family member interview transcripts (cont'd)

Cons (pages in trans-cript)	What was the adverse event? Did it have a clear cause?	Did Open Disclosure take place? Was it Low or High Level Open Disclosure?	Apology? (partial/full)	Internal or external notification?	Severity estimate?	Severity seen by pt?	Outcome of OD process judged to be successful?	Was there support? Rectification?	Was contact possible with clinician(s) most closely involved in incident?
18 (142-155) 61 yo daughter of 88 yo female pt)	Older patient is taken to the toilet by two young nurses; she is left alone and falls when she tries to get off the toilet. She breaks her hip which cannot be operated on. She dies 3 weeks later.	Yes, high. "Well, no, well yes and no. Mum had died by this time. By the time I'd put in the formal complaint and they got round to actually doing a meeting, mum had died in the meantime. But my sister and I went up to Brisbane to the meeting." (p. 147)	Yes, full. (by doctor who cries). No (by nurse). "… they said that in the meeting that she [nurse who left pt] was very remorseful." (p. 148)	External-internal. [Other patients alert family; nurse discourages complaint, dr encourages complaint, Fam make complaint]	Medium high	High.	Yes. "Um, well, open and honest and they told me how the young girl was so remorseful, and that they're going to put a woman in to talk to the young nurses". (p. 154)	No. "Yeah, oh, they said that in the meeting that she was very remorseful." (p 148)	Yes. New rule disseminated through hospital. Lot of attention from staff.
19 (155-170) 40-ish daughter and husband of 85 yo female pt)	Patient goes into hospital for physio on Friday, and he falls out of bed after making a family phone call. He is not discovered for some time, during which his breathing gets worse. Family claims he was given insufficient fluids and medication on Saturday. He dies on Sunday.	No. Formal meeting refused by family due to fam conflict, suspected and whitewash.	Yes, full (from one doctor). No (other doctor). "He also stated and apologised to us that she'd slipped between cracks" (p. 157), "No, we made an appointment with him. He went overseas the following week and I rang up his secretary that week he was away. I didn't realise he was away and I said, 'I would like to make an appointment with Dr B because, ar, there's a lot of questions unanswered'." (p. 162)	External [Fam query]	High	High.	No.	No.	No (disclosure did not involve those most closely involved).
20 (171-179) daughter of 93 yo pt	Patient is discharged from hospital despite daughter's protests that she is not well enough. Patient gets sick during the 300km car trip home, suffers from dehydration and dies.	Yes by QC, not by clinical team.	Yes, full (by Quality Coordinator, not by clinicians).	External [fam complaint]	High	High.	No.	No.	No (no disclosure from those most closely involved).
21 (180-185) 52 yo male	Patient given saline overdose following alcohol-related collapse.	Yes, by treating doctor.	No.	Internal [clinical team]	Medium high/ medium low	Low.	Immaterial to patient. Incident and subsequent care resolved his alcoholism.	Yes. Offer of clinical services.	Yes.
22 Mother of 17 yo male	Patient has unsuccessful spinal operation.	Yes, by member of the clinical team.	No.	Internal [clinical team]	Medium high/ medium low	High.	No.	Offer of further surgery (refused due to lack of trust).	No (doctor 'had moved on').
23 84 yo male	Patient's colonoscopy is done with unsterilised equipment.	Yes, by members of the clinical team.	Yes, full.	Internal [clinical team]	Medium high/ medium low	Low.	Yes.	Yes. Check-ups carried out to assess impact.	Yes.

2.5.7 Patients' and family members' reservations about Open Disclosure

As interview statement cited above show, consumers were not unanimous in their appreciation for the way in which Open Disclosure was conducted. Indeed, some consumers expressed misgivings about how they had been communicated with by hospital staff. It is not surprising, of course, for a new and innovative practice advocated in recent policy to display some degree of 'lag' in implementation, and for Open Disclosure communication skills to spread among staff. What is noteworthy about our findings however is that the patients and family members who are entirely satisfied with how their adverse events were handled were in the minority. While most interviewees expressed relief upon being openly told about the adverse event in the Open Disclosure meeting, few patients and family members recounted their experiences without touching on (perceived) problems and shortcomings. We have outlined the reasons for this exhaustively above. Here we note some final considerations about why disclosure is not experienced positively by patients and family members:

- staff fail to recognise there is escalating dissatisfaction on the part of the family and/or patient;

- staff change their position or view on what happened, thereby exacerbating uncertainty and potentially engendering suspicion;

- the health facility moves patients to neighbouring hospitals (due to deterioration or improvement) without adequate Open Disclosure continuity and involvement in the adverse event history of staff at the second facility;

- family members are denied access to clinical-medical information pertaining to the patient's care (on grounds of privacy legislation);

- the health care facility representatives determine whether closure has been achieved rather than the family or patient.

Overall, the interviews suggest the following inverse proportion: the less the health care system is responsible for the adverse event, the better it is deemed to support those harmed, and vice versa: the more the system is (or staff working in the system are) at fault, the less supportive it (they are) is of consumers, and the less open it is (they are) to consumers. This notwithstanding, none of the patients and family members express regret at participating in Open Disclosure. While thirteen out of twenty-three patient/family interviewees judge their Open Disclosure experience not to have been successful (or not successful enough), only in a minority of cases do they report not having experienced any benefit at all from participating in this process.

3 ANALYSIS OF THE HEALTH CARE PROFESSIONALS' QUESTIONNAIRE SURVEY DATA

3.1 Executive Overview

Survey responses (health care professionals only) show the following:

1. **Survey responses (total 80 surveys; response rate 74%) show that health care professional respondents are in agreement that Open Disclosure is of benefit:**

   a. Respondents strongly agree that Open Disclosure benefits health care staff and health care services.

   b. Respondents strongly agree that Open Disclosure benefits patients and families.

2. **Health care professional respondents also agree that Open Disclosure:**

   c. Imposes an emotional burden;

   d. Imposes a resource burden; but it

   e. Has advantages that outweigh its emotional and resource costs.

3. **Health care professional respondents are uncertain about:**

   f. Whether Open Disclosure will ultimately be detrimental to professionals' or organisations' reputation;

   g. When, how and with whom to enact Open Disclosure.

4. **Nursing and medical survey respondents differ on the following points**:

   h. Nursing staff may be more burdened than medical staff by the emotional impact of Open Disclosure.

   i. Medical staff may be more conscious (than nursing staff) of unexpected outcomes not being communicated fully and appropriately to consumers.

3.2 Survey Data – Methods and Findings

3.2.1 Survey Data Analysis

An Open Disclosure questionnaire survey for health professionals was developed for this evaluation and validated by scientific research committees (subcommittees of Human Research and Ethics Committees) and the Survey Resource Group in Canberra. The questionnaire survey tool was piloted in three Victorian sites and slight changes made to the tool. The questionnaire survey was administered to the same group of health professionals that was involved in the Open Disclosure interviews, and they were approached as part of the same (interview) process with the request to fill out the questionnaire survey. In total, 108 health professionals were asked to complete the questionnaire survey. The response rate for this questionnaire was high. A total of 80 questionnaire surveys were completed[31], giving a response rate of 74%.

The survey for health care professionals is comprised of three parts: Part 1 contains demographic and work related questions. Part 2 asks questions about staff experiences of doing Open Disclosure. Part 3 asks about Open Disclosure policies and practices in respondents' organisations.

3.2.2 Survey Data Findings - Questionnaire Part One: Basic demographics

Professional background

As shown in Figure 3.1, 45 questionnaires were completed by staff with a nursing background (58%), 32 by staff with a medical background (37%), 2 by staff with an allied health background (2%) and 1 by a Human Resources employee (1%).

Figure 3.1: Percentage Of Survey Questionnaires Completed Per Profession

---
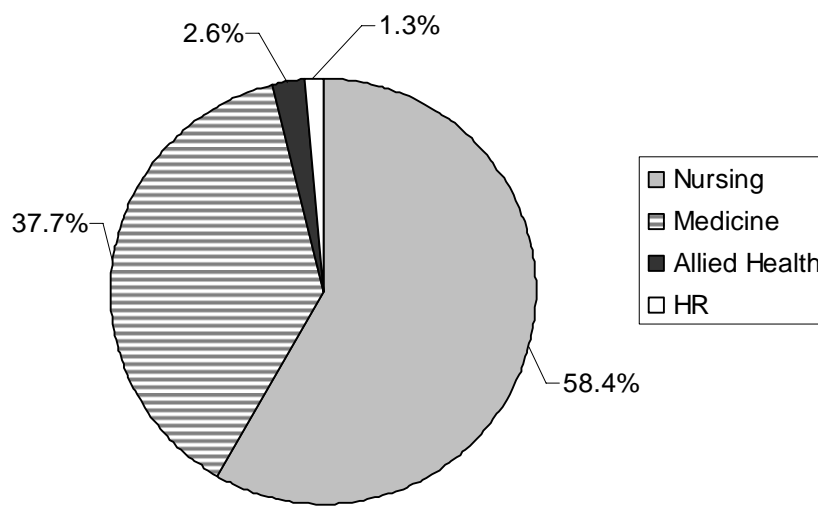
[31] Two surveys were excluded from the analysis because their responses were incomplete.

Further details about the survey respondents are provided in table 3.1. The table shows respondents have a high level of health care experience (average of 24 years), many of them have a considerable (average 66%) administrative-managerial load, the majority (51%) work in metropolitan hospitals, and the highest percentage of survey responses (just over 46%) came from Queensland.

Table 3.1: Health Professional Respondents' Demographics And Background

Category	Respondents' demographics and background
Gender	52% of respondents are female; 47% male.
Age	63% are below the age of 50.
Working experience in health care	The average time the respondents have worked in the health care sector is 24 years, ranging from 3 to 42 years, with 7.6% being in health care less than 10 years and 31.6% for 30 years or more.
Management versus clinical duties	The average time the respondents spent their time with management duties is about 66% compared to 33% with clinical duties. 30% and 2% of respondents spend 100% of their time on management and on clinical duties, respectively. 43% spend more than 50% on management duties.
Type of hospital	The majority of respondents (51 %) work in metropolitan hospitals, 32% in regional and 16% in rural facilities.
State	About 46% completed questionnaires were received from Queensland, 21% from Victoria, 16% from South Australia and 16.3% from New South Wales (see Figure 2.2 below).

Figure 3.2: Percentage Of Survey Questionnaires Completed Per State
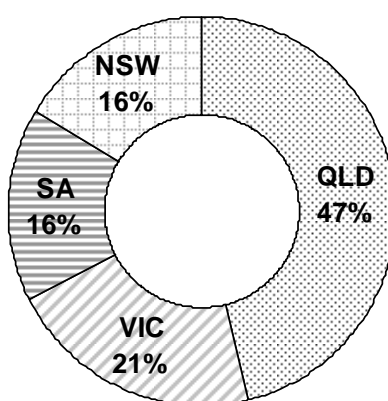
Queensland also had the highest response rate with nearly 75% of health professionals completing the survey. New South Wales had the lowest response rate with about 56% returning the survey.

Sixty-two of the 77 respondents (77%) have received Open Disclosure instruction. Of these 62 respondents, 91% attended a structured presentation or course. In addition to attending a structured course or presentation, 15% of respondents indicated that they have also undertaken other types of training such as self-directed reading and/or online and CD-based instruction. When asked if the training provided them with the skills to take part in an Open Disclosure session, 56 (93%) agreed or strongly agreed. No one disagreed (Table 3.2).

Table 3.2: Respondents' Open Disclosure Training And Open Disclosure Experience

Category	Respondents' experience and training
Open Disclosure Training	77% of respondents (62 out of 77) have undertaken training in Open Disclosure
Experience Doing Open Disclosure	87% of respondents attended an Open Disclosure session with a patient and family member(s)

With regard to having participated in Open Disclosure meetings, the overwhelming majority (87%) of respondents claim having experience doing Open Disclosure (Table 3.2). When asked how many Open Disclosure sessions respondents had attended, 46% answered one to two; 35% answered between three and nine, and 18% answered ten or more. Of those that have attended an Open Disclosure session, 44% have never led a session, 23% led between one and two sessions and 16% have led ten or more sessions[32].

3.2.3   Survey Data Analysis - Questionnaire Part Two: Health Professionals' Views of Consumers' Responses and of Their Own Experiences

This part of the questionnaire explored staff perceptions about consumers' and clinicians' experiences with Open Disclosure. Participants were asked to indicate their agreement or disagreement with statements about Open Disclosure. Answer categories in the form of a Likert scale were provided ranging from strongly agree, agree, uncertain to disagree and strongly disagree. The questionnaire statements were grouped under the following categories:

1.   Health Professionals' Views of Patient (or Family) Responses to Open Disclosure, and

---

[32] NB: the percentages listed do not distinguish between High Level Open Disclosure (for high severity adverse events) and Low Level Open Disclosure (for low severity adverse events).

2. Health Professionals' Views on How Clinicians Themselves Experience Open Disclosure.

1. Health Professionals' Views of Patient (or Family) Responses to Open Disclosure

Nine statements were grouped under this category. There was overwhelming agreement in response to the following statements (Table 3.3):

Table 3.3: Health Professionals' Views About Patient And Family Responses To Open Disclosure: Percentage Of Respondents In Agreement

Survey Statement	% agreement
Overall I think patients' well-being benefits from Open Disclosure	96%
Patients appreciate receiving information through Open Disclosure	92%
The information is given in a way that the patients seem to understand	90%
Patients seem to appreciate being honestly informed through Open Disclosure	88%
Patients' families appreciate receiving information through an Open Disclosure session	82%

Health professionals surveyed were divided about whether *'Patients become angry when informed about adverse incidents'*. 39% agreed or strongly agreed, however, 37% of respondents disagreed or strongly disagreed and the remaining 23% were unsure. The pattern was different with regard to their view on whether families tend to become angry when incidents are disclosed to them. Perhaps reflecting the unpredictable nature of people's responses to incidents, 63% agreed or strongly agreed that families become angry and 25% disagreed or strongly disagreed (refer to Figure 3.3).

The majority of respondents disagreed or strongly disagreed that '*Open Disclosure practices reduce patients' faith in the health care organisation*' (77%), while 15.0% of respondents were unsure.

Figure 3.3: Health Professionals' Views About Whether Families And Patients Become Angry When Informed Of Adverse Events
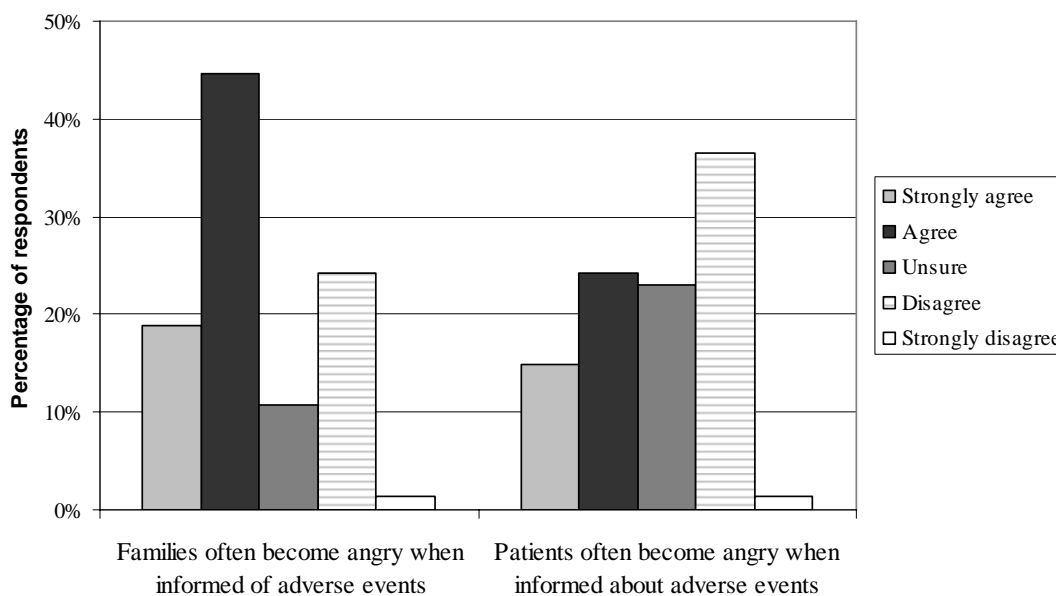
Of significance is that 75% of respondents disagreed or strongly disagreed with the statement that 'O*pen Disclosure causes patients and their families unnecessary distress'*. Given the earlier finding that Open Disclosure tends to be seen as upsetting, agreement with the statement that 'Open Disclosure does not cause unnecessary stress' suggests that respondents do not regard the intensity of emotions generated by Open Disclosure as futile and unnecessarily stressful. Put differently, the emotional intensity of Open Disclosure may be seen to produce positive rather than negative outcomes.

2. Health Professionals' Views on How They Themselves Experience Open Disclosure.

Eight statements were grouped under this category. All were responded to with high levels of agreement. There was overwhelming agreement with the statement '*I feel satisfied with the outcome of the Open Disclosure sessions I have attended'* (90%; see Table 3.4). There was overall agreement with the statement *'I am in favour of Open Disclosure of all adverse events to patients'* (81%).

Table 3.4: Health Professionals' Views On Their Own Open Disclosure Experiences

Survey Statement	Strongly agree / agree	Unsure	Strongly disagree / disagree
I feel satisfied with the outcome of the Open Disclosure sessions I have attended	90% (67)	6% (5)	2% (2)
I am in favour of Open Disclosure of all adverse events to patients	81% (65)	11% (9)	7% (6)

Figure 3.4: Health Professionals' Concern About Litigation And Personal Reputation If Involved In An Adverse Event Requiring Open Disclosure
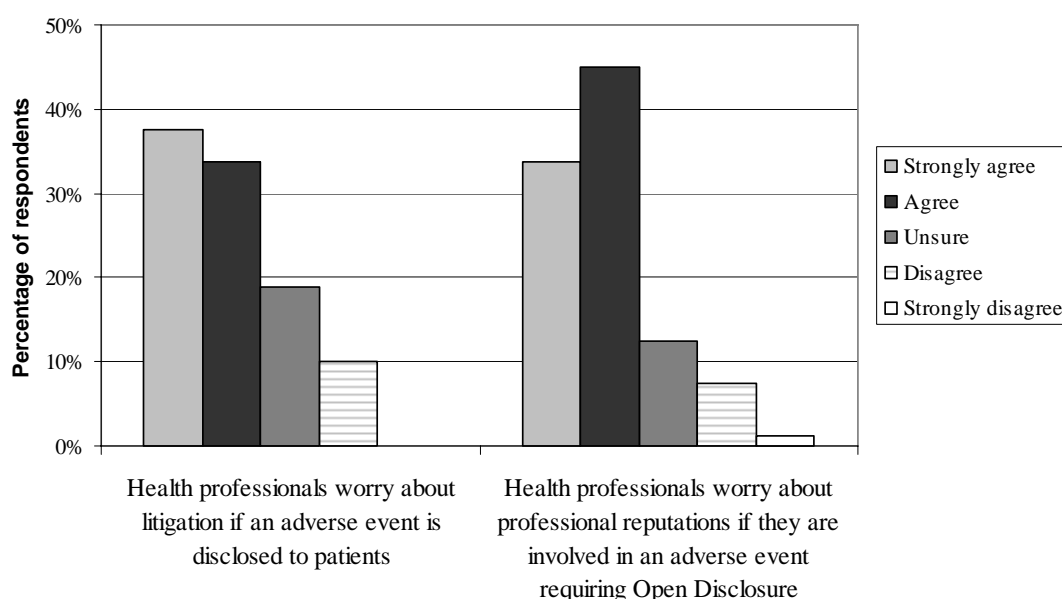
Statements which were responded to with agreement but which also elicited uncertainty include *'Health professionals worry about litigation if an adverse incident is disclosed to patients'* (71% agreement; 18% unsure) and *'Health professionals worry about their reputations if they are involved in an adverse incident requiring Open Disclosure'* (78% agreement; 13% unsure; see figure 3.4). Here, respondents articulate a tension here between colleagues' and the wider organisation's reserved stance towards Open Disclosure and respondents' own support for the policy and their positive practical experience.

The survey statement *'In my experience Open Disclosure reduces litigation'* was responded to with agreement by 55% of respondents, while 41% expressed uncertainty. This comparatively low level of agreement and high level of uncertainty (in the context of this survey's findings) may be due to the limited period of time that Open Disclosure has in fact been part of frontline clinical practice in Australia, rather than to employees' doubt that Open Disclosure will impact on litigation levels. This is certainly an issue that deserves further research investigation.

Figure 3.5: Health Professionals' Views On The Degree Of Distress Caused For Them By Open Disclosure
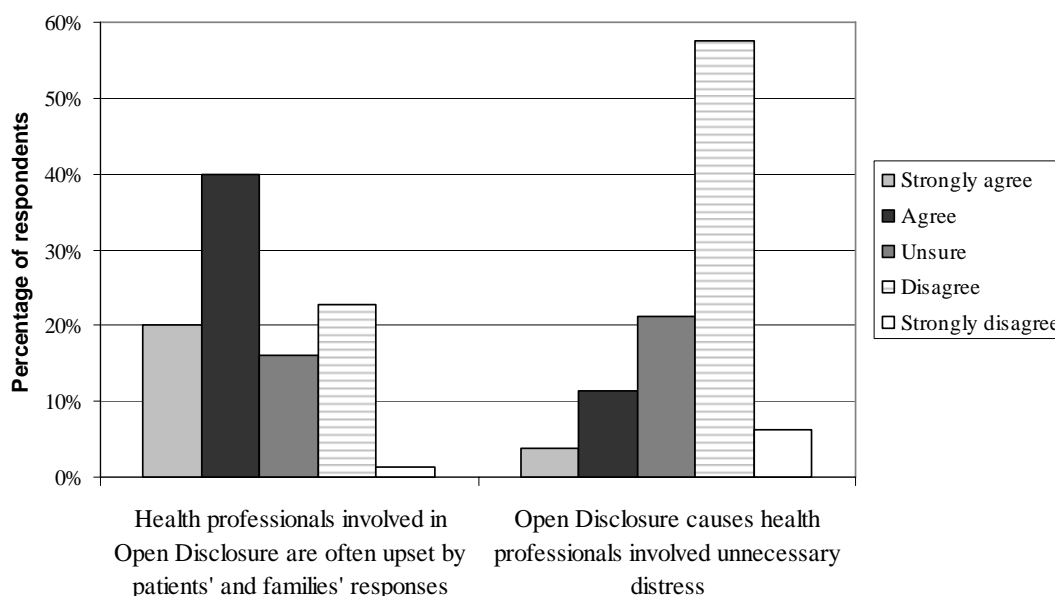
More than half (60%) of respondents agreed or strongly agreed with the statement that *'Health professionals involved in Open Disclosure are often upset by the Open Disclosure session'* (figure 3.5 above). These responses point to a degree of apprehension with regard to the emotional impact of Open Disclosure on staff. When asked if '*Open Disclosure causes health professionals involved unnecessary distress',* however, 63% disagreed. As already noted above, Open Disclosure is seen to be emotionally challenging, but at the same time Open Disclosure is seen to produce worthwhile outcomes.

3.2.4 Survey Data Analysis - Questionnaire Part Three: Health Professionals' Views on Organisational, Policy and Process Factors Pertaining to Open Disclosure

Eight statements were grouped under this category. Perhaps not surprisingly, 95% of respondents agreed that *'The organisation where I work supports an Open Disclosure policy'* and about 25% of respondents indicated that *'The organisation where I work provides education for staff in Open Disclosure practices'*. All of the sites surveyed were Open Disclosure pilot sites in most of which some form of training had been initiated.

1. Health Professionals' Views on Organisational and Policy Factors Pertaining to Open Disclosure

Two tensions affect respondents' answers about organisational and policy factors. First, respondents' answers diverge with regard to their views on Open Disclosure principle and Open Disclosure practice. For practice, about 20% of respondents were unsure if *'Only*

117

severe adverse incidents are openly disclosed in my organisation', with 56% disagreeing and 20% agreeing with this statement. When it comes to principle, 81% of respondents are in favour of Open Disclosure of all adverse incidents to patients. This divergence between views about *what is done* and about *what should be done* points to respondents' awareness of a 'lag' between policy and practice, and to their support for Open Disclosure generally. Support for Open Disclosure as principle is evident from respondents' (strong) agreement (82%) with the statement that *'In my experience Open Disclosure leads to improvement in the quality of health care delivered'.*

Second, tension is evident between health professionals' experience that *'The outcomes of the Open Disclosure sessions I have attended are satisfactory for the organisation'* (82%), and health organisations nevertheless being seen to harbour apprehensions about the effect of Open Disclosure: *'The organisation is fearful that Open Disclosure will lead to bad publicity'* with 48% disagreeing, 27% agreeing and 23% being unsure. This tension reappears when we consider health professionals' interview responses: staff have positive experiences doing Open Disclosure, but they are concerned at the limited spread of this practice.

These tensions notwithstanding, 72% of respondents agreed or strongly agreed that *'Health professionals involved in Open Disclosure sessions receive strong support from hospital managers'.* As the interview data analysis confirms, this may link in with managers' regarding Open Disclosure as an opportunity for enhancing staff-management relationships. When respondents are asked whether *'Health professionals involved in Open Disclosure sessions receive strong support from their colleagues'*, their confidence is lower: 61% agreed or strongly agreed, meaning that as many as 39% felt unsure or disagreed about receiving support from colleagues when disclosing adverse events.

Figure 3.6: Views On The Degree Of Support Received From The Organisation And From Colleagues
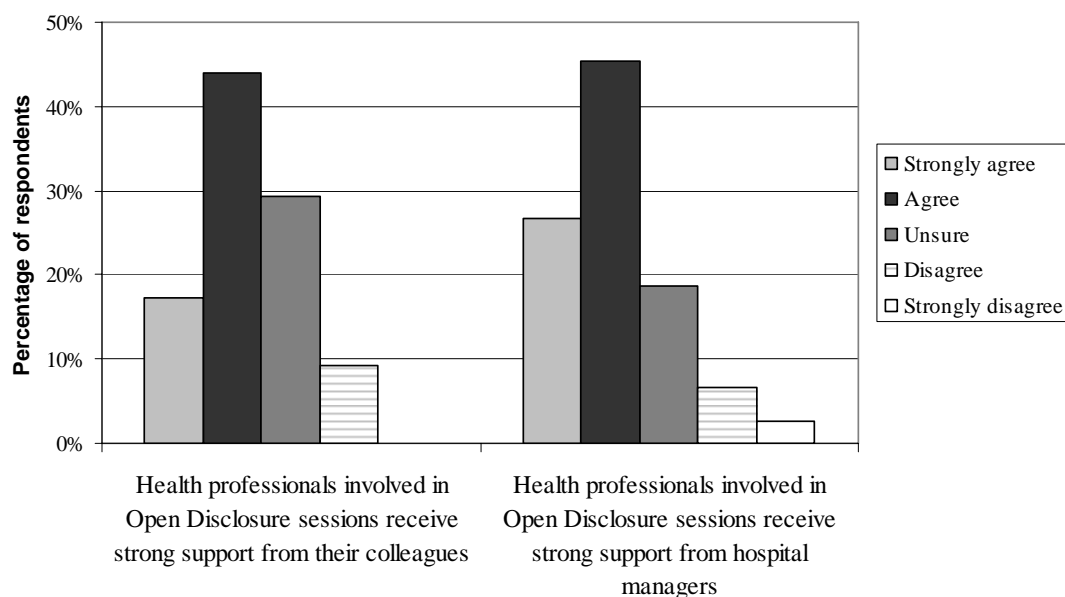
2. Health Professionals' Views on Open Disclosure as Process

Fifteen questions were grouped under this category. There was overwhelming agreement in response to survey statements about the practices of explaining the adverse event, apologising, and taking responsibility[33].

Table 3.5a shows there is overwhelming agreement among staff surveyed that explanations are given accurately and sympathetically, that an apology is made, and that information about the incident is shared with the patient and family members.

Table 3.5a: Health Professionals' Views On Open Disclosure As Process

Survey Statement	% agreement
The explanation given of what has happened to the patients is accurate	97%
The explanations are given sympathetically	98%
An apology is made to the patient	96%
The harm that the patients have experienced is acknowledged by the health professional leading the session	97%
If responsibility for the harm done to patients is highly evident, this responsibility is acknowledged by health professionals in attendance	83%

Table 3.5b further confirms these positive views: health professionals regard the way that Open Disclosure is conducted as near exemplary (table 3.5b).

Table 3.5b: Views On Open Disclosure As Process

Survey Statement	% agreement
The patients have the opportunity to ask questions	100%
The consequences of the event are clearly explained to the patients	93%
The patients are told that steps are taken to avoid adverse incidents occurring again	97%
An offer is made to share with the patients the findings of any further investigation into the cause of the specific incident	89%
The patients are told what steps are being taken to manage the event	96%
A support person for the patient is present (or readily available)	86%

---

[33] As seen, our analysis of patient and family interviews revealed a less positive picture of how Open Disclosure is conducted in practice. Health professionals (legitimately) regard their uptake of Open Disclosure as an important advance on traditional practice. However, we may in fact be in a 'grey space' where Open Disclosure is enacted without as yet meeting patients' and family members' expectations. It is important, we suggest therefore, that health professionals' uptake of Open Disclosure be supported (not least due to overwhelmingly positive responses from all stakeholders), but at the same time mechanisms be put in place for gauging and improving consumers' overall service satisfaction (Parakasuraman, Zeithaml, & Berry, 1985).

Equally, with regard to the timing of Open Disclosure, most respondents regard their organisations as promptly arranging Open Disclosure (68% in agreement). A comparable proportion (64%) also agrees that *'The patients are invited to an Open Disclosure meeting within a reasonable timeframe following the incident',* with only 12% disagreeing and 24% being unsure. This finding too needs to be contextualised with the experiences of patients and family members discussed above.

Figure 3.7: Views Of How Promptly Organisations Arrange Open Disclosure Meetings
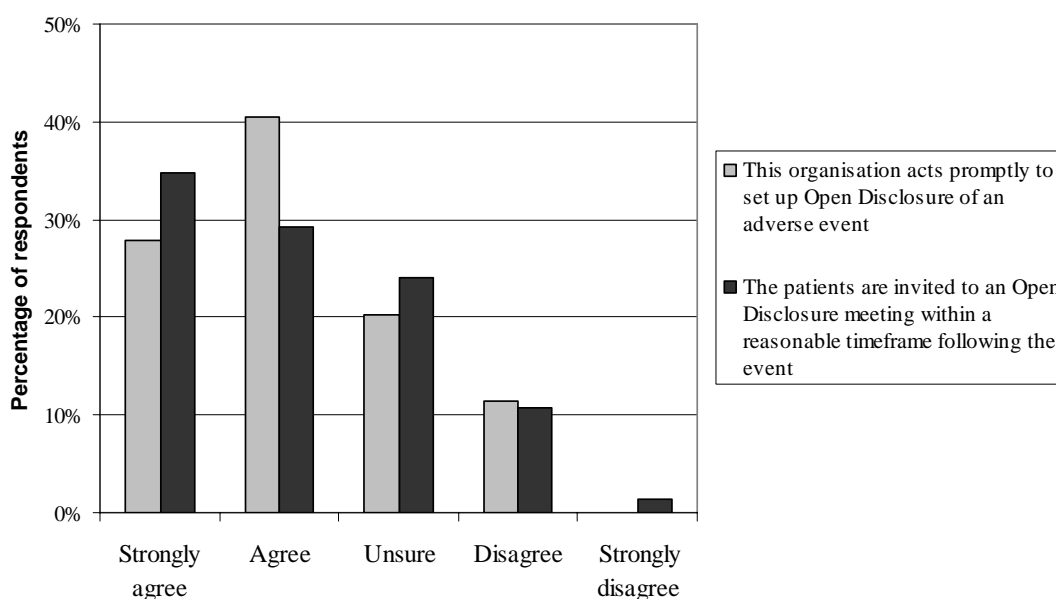
In response to the statement *'The health professionals who explain the events are known to the patient'*, 53% agreed or strongly agreed, 31% disagreed and the remaining 15% of respondents were unsure. That is, just over half of all respondents agree that those who are likely to have had involvement in the adverse event meet with the patient and/or their family to explain what happened. Foreshadowing our consumer interview analysis presented below, this figure is not likely to be inflated, but may rely on instances of Low Level Open Disclosure (i.e. addressing low severity adverse events) rather than High Level Open Disclosure (i.e. for high severity adverse events).

Similarly, the statement *'Patients are not informed about less severe adverse incidents involving their care and treatment'* met with 56% (strong) disagreement and only 18% agreement. 25% were unsure. Here, a slight majority of respondents confirms that the

patient is likely to be appropriately informed about low severity adverse events occurring during their care[34].

Finally, 79% of respondents agreed with Open Disclosure being '*structured as an ongoing, iterative process'* as opposed to being a one-off event (20% were unsure about this, but none disagreed). This points to staff accepting that Open Disclosure is a complex and demanding process that relies on ongoing feedback from all stakeholders for how it unfolds. Here, too, however, it becomes evident that it is important to contextualise these survey responses with health professionals' and consumers' interview statements about these matters. The lag between espoused views (as expressed in surveys) and enacted positionings (as displayed in interviews) becomes evident when we turn to the rather more nuanced meanings conveyed in semi-structured talk.

3.2.5   The Influence of Professional background: Differences in views of and experiences with Open Disclosure between medical and nursing staff

This section outlines the differences in views of and experiences with Open Disclosure between the medical and nursing profession. The professional background referred to here relates to the initial training/profession of the respondents. It however does not refer to their current position. A patient safety officer might have trained as a nurse before moving on to become a patient safety officer. In the following analysis this patient safety officer is considered to belong to the nursing profession[35].

About 58% of questionnaire surveys were completed by nursing staff and about 38% by medical staff. As table 3.6 below shows, medical staff respondents tend to be male, and nursing staff respondents female. Both professions have an average of more than 24 years experience in health care and for some respondents a considerable percentage of their work is devoted to managerial duties. Overall, nursing staff tend to spend more time on management duties than medical staff do.

---

[34] Patients' and family members' interviews analysed above confirmed that low severity adverse events tend to pose limited problems in terms of their disclosure. However, their interviews also suggested that disclosure of high severity adverse events can resemble low level disclosure in that it is done with insufficient procedural formalisation. As the consumer interviews indicated, this poses a risk: a serious adverse event is disclosed but it is done in a way that may not be attuned to consumers' sense of interpersonal dignity and social expectation.

[35] This classification differs from the one utilised in the interview data analysis section, where a 'patient safety officer' and a quality coordinator are categorised as 'Support Personnel', irrespective of clinical background.

Table 3.6: Medical And Nursing Staff Respondents' Demographics And Background

Category	Medical and nursing staff respondents' demographics and background
Gender	81% of medical staff are male; 73% of nurses being female
Age	Both medical and nursing groups have a similar age distribution with 62% and 63% of medical and nursing staff being below 50 years old, respectively
Working experience in health care	None of the medical respondents have worked in health care less than 10 years, compared with 11% of nursing staff. The majority (56%) of medical staff have worked longer than 20 years in health care and 25% more than 30 years. A higher percentage (34%) of nursing staff stayed in health care longer than 30 years
Management versus clinical duties	Nursing staff tend to spend more time on management duties than medical staff do: 13 % of nursing staff spend up to 50%, 86% more than 50% with 37% 100% on management duties. Almost half (46%) of the medical staff respondents spend up to 50% on management duties, with 15% being a 100% occupied with management duties

Medical staff tend to have more experience with attending and leading Open Disclosure sessions than do nursing staff. Almost every medical staff respondent (93%) has been involved in an Open Disclosure session with a patient and family member. Of those, 41% attended between 1 and 2 sessions and 24% attended 10 or more sessions. About 35% indicated that they have not led an Open Disclosure session and 14% led between 1 and 2 sessions. In comparison, a slightly lower percentage of nursing staff (84%) have been involved in Open Disclosure sessions. Half of those respondents specified that they have attended 1 or 2 sessions, and 13% say they attended 10 sessions or more. 1 in 2 (51%) nursing staff respondents have not led an Open Disclosure and 2 in 6 (31%) between 1 and 2 sessions.

Table 3.7: Medical and Nursing Staff Respondents' Open Disclosure Training And Open Disclosure Experience

Category	Respondents' experience and training
Open Disclosure Training	About equal percentages of medical (78%) and nursing staff (75%) have been trained in Open Disclosure
Experience Doing Open Disclosure	93%and 84% of medical and nursing staff respondents attended an Open Disclosure session with a patient and family member(s)

3.2.6 Health Professionals' Views Of Patient (Or Family) Responses To Open Disclosure

There was little to no difference between how respondents from medicine and nursing backgrounds responded to statements relating to how clinicians understand patients' and/or family members' experiences of Open Disclosure. However, there were divergent views on the following four statements. These are discussed below.

Difference One: Patients become angry when informed about adverse events

One in every two medical staff respondents (50%) disagreed that *"Patients become angry when informed about adverse events"*, with 21% expressing uncertainty. For their part, nursing staff tend to *agree* that patients become angry (47%), with 25% expressing uncertainty (figure 3.8).

This difference may be explained by nurses who work at the patient's bedside becoming a target of patients' and family members' distress and anger.

Figure 3.8: Medical And Nursing Staff Respondents' Views About Whether Patients Become Angry When Informed About Adverse Events

Patients become angry when informed about adverse events
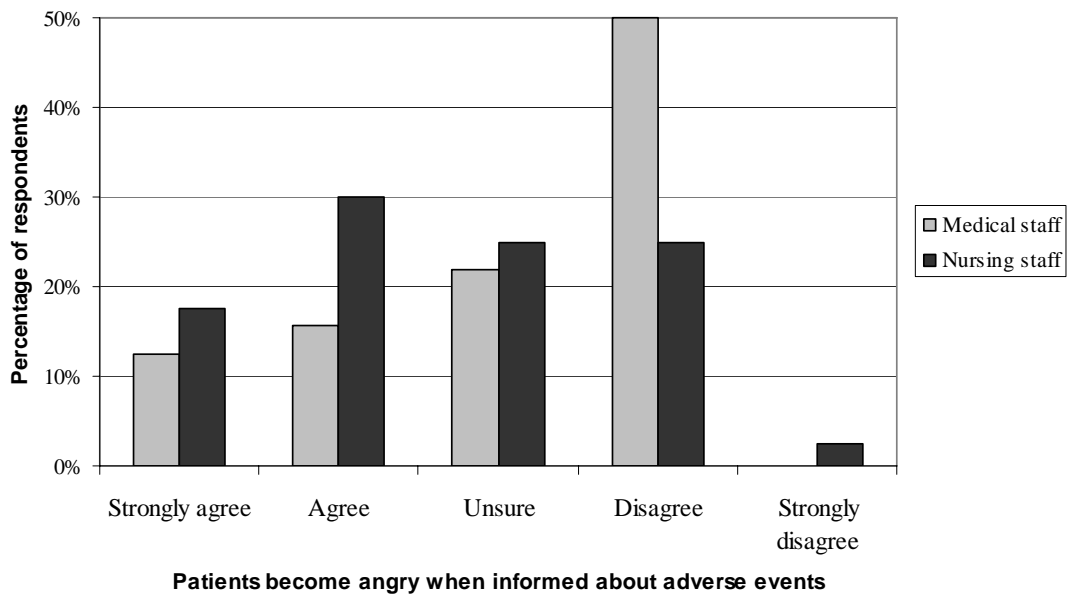
Difference Two: Families become angry when informed about adverse events

Nursing staff also strongly support the statement that *"Families become angry when informed about adverse events",* with 3 in 4 nursing staff (77%) agreeing. A high percentage – but not as high - of medical staff (46%) also agreed with this statement. This difference may again have to do with the professional's proximity to bedside dynamics.

Figure 3.9: Medical And Nursing Staff Respondents' Views About Whether Families Become Angry When Informed About Adverse Events

Families become angry when informed about adverse events
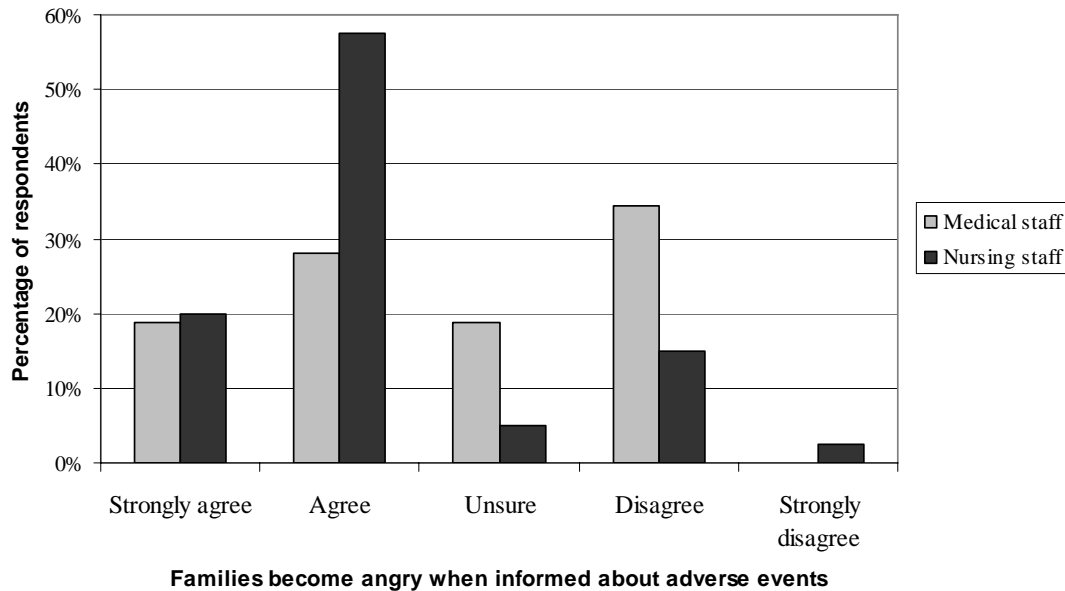
Difference Three: Open Disclosure practices reduce patients' faith in their health professionals

Medical and nurses staff have different views on the statement *"Open Disclosure practices reduce patients' faith in their health professionals"*. About 10% of nursing staff supported the statement, 20% were uncertain with 70% disagreeing. In contrast, 90% of medical staff disagreed. It may again be that medical staff, thanks to their position, role and mobility, are less susceptible to patients' and families' negative feelings than are nurses.

Difference Four: Open Disclosure causes patients and their families unnecessary distress

None of the medical staff respondents agreed that *"Open Disclosure causes patients and their families unnecessary distress"*. This compares to about 10% of nursing staff being in favour of the statement. This is a marginal difference.

The majority (81%) of medical staff disagreed with the statement that *"Open Disclosure causes patients and their families unnecessary distress"*. This percentage is higher than that expressed when doctors are asked if *"Open Disclosure causes health professionals involved unnecessary distress",* where 71% disagreed. Nursing staff responses show that 73% disagreed with the statement that patient and their families are caused unnecessary distress, compared with 55% disagreeing that health professionals are caused unnecessary distress (refer to the section below). Here too a professional-background difference is manifest, with nursing staff placing greater emphasis on the emotional burden of Open Disclosure.

3.2.7 Health Professionals' Views On How Clinicians Themselves Experience Open Disclosure

Again, medical and nursing staff respondents shared similar views on most of the statements relating to their experiences with Open Disclosure. Leaving those similarities aside (they have been addressed in Section 2.2.3 above), we will focus the analysis here on three noteworthy differences.

Difference One: Open Disclosure causes health professionals involved unnecessary distress

A quarter (24%) of nurses agreed that *"Open Disclosure causes health professionals involved unnecessary distress"*, compared to only 3% of medical staff agreeing (table 3.10).

Figure 3.10: Medical And Nursing Staff Respondents' Views About Whether Open Disclosure Causes Health Professionals Involved Unnecessary Distress
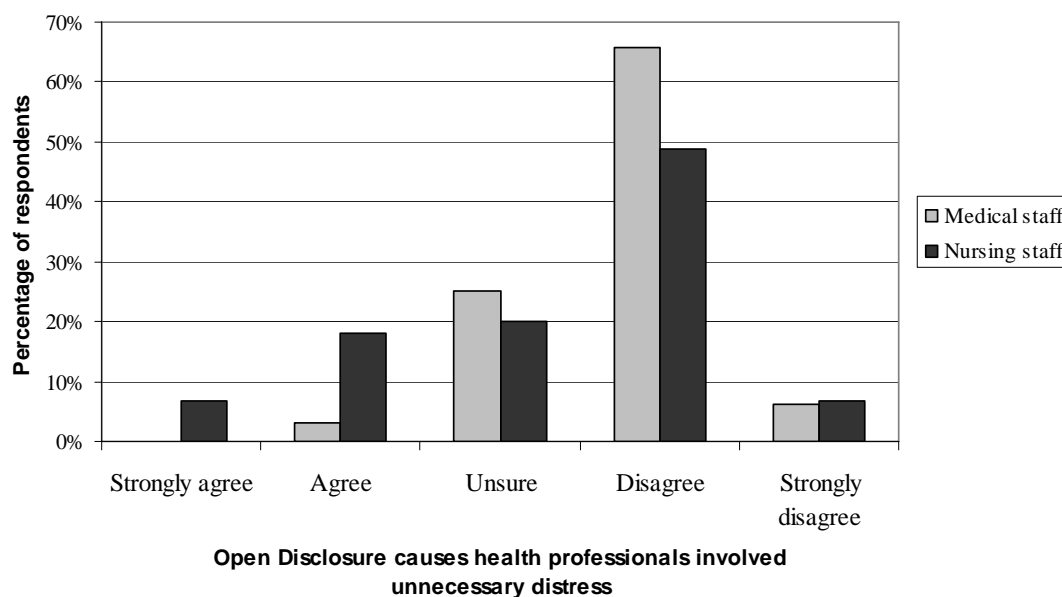
Nursing staff responses seen thus far suggest nurses experience a greater burden than do their medical counterparts in dealing with the emotional intensity of Open Disclosure. This is further evident when considering that the majority of nurses (61%) agreed that '*health professionals involved in Open Disclosure are often upset by patients' and families' responses'* (see table 3.5 above). By the same token, nursing staff tend to feel more supported by their colleagues and their hospital managers than do medical staff (see below).

Difference Two: Health professionals involved in Open Disclosure are often upset by patients' and families' responses

The majority (56%, 61%) of medical and nursing staff agreed that *'Health professionals involved in Open Disclosure are often upset by patients' and families' responses'.* This shows nurses to feel slightly more susceptible to negative responses from consumers than do doctors.

Difference Three: Health professionals involved Open Disclosure sessions receive strong support from their colleagues

When asked if *"Health professionals involved in Open Disclosure sessions receive strong support from their colleagues"*, about half of the medical staff respondents agreed and 40% expressed uncertainty. This compares with 65% of nurses supporting the statement and 21% expressing uncertainty. This difference suggests that while nurses experience a greater emotional burden following disclosure of adverse events, they also provide each other with better peer support.

In contrast, respondents in both groups were in favour of the statement that *'Health professionals involved in Open Disclosure receive strong support from hospital managers'*, with 68% of medical respondents and 75% of nursing respondents agreeing. We know from the interview data that, without senior management support, staff have little faith in Open Disclosure.

3.2.8 Health Professionals' Views on Organisational and Policy Factors Pertaining to Open Disclosure

Medical and nursing staff have expressed similar views in the eight statements about organisational and policy factors. However, there are a few minor differences worth commenting on (table 3.8).

Table 3.8 shows that nurses have slightly more faith in support from health managers than do doctors, and that nurses at the same time have greater fear that Open Disclosure may lead to bad publicity. These two differences confirm our earlier emphasis on nurses' being attuned to the social network structures and dynamics surrounding Open Disclosure. This

carries a cost of course, in so far that for nurses, management, frontline staff and consumer reactions to Open Disclosure may be less mitigated by interpersonal distance and everyday mobility.

Table 3.8: Medical And Nursing Staff Respondents' Divergent Views On Statements On Organisational And Policy Factors

Statement	Medical and nursing staff responses
Health professionals involved in Open Disclosure receive strong support from hospital managers	A slighter higher percentage of nursing staff (75%) agreed than medical staff (68%)
The organisation is fearful that Open Disclosure will lead to bad publicity	A lower percentage of medical staff (44%) agreed compared to nursing staff (53%).
Only severe adverse events are openly disclosed in my organisation	1 in 4 (25%) medical staff respondents agreed compared to 15% of nursing staff
In my experience Open Disclosure leads to improvement in the quality of health care delivered	No medical staff respondents disagreed; 18% expressed uncertainty; 81% agreed. 6% of nurses disagreed and 11% were unsure; 82% (strongly) agreed.

3.2.9 Health Professionals' Views on Open Disclosure as Process

Medical and nursing staff respondents agreed on the majority of statements relating to enacting Open Disclosure as dialogic process (table 3.3 further above). Table 3.9 below outlines a minority of differences in opinion and experiences between nursing and medicine.

The table suggests that doctors have more faith than nurses in explanations given to consumers about adverse events, and that they are more likely to accept responsibility for adverse events. However, and in contrast with this, doctors are less likely to regard Open Disclosure as an iterative process. In light of the differences outlined above showing nurses' higher levels of emotional burden resulting from Open Disclosure, the present responses may be seen to give further weight to the view that doctors may be less inclined to approach Open Disclosure as interpersonal and supportive dialogue and more as a formal information dissemination opportunity consonant with doctors' 'detached concern' (Lief & Fox, 1963).

Table 3.9: Medical And Nursing Staff Respondents' Divergent Views On Open Disclosure as Process

Statement	Medical and nursing staff responses
The consequences of the event are clearly explained to the patients	12% of nurses expressed uncertainty or disagreement; 86% agreed. All medical staff agreed.
If responsibility for the harm done to patients is highly evident, this responsibility is acknowledged by health professionals in attendance	21% of medical staff were uncertain or disagreed with this statement. 12% of nursing staff were uncertain or disagreed with this statement.
Open Disclosure is structured as an ongoing, iterative process"	24% of medical staff were uncertain, compared to 15% of nurses

As figure 3.11 below displays, the majority of nursing staff (62%) disagreed with the statement that *"Patients are not informed about less serious adverse events involving their care and treatment"*. Medical staff also disagreed but to a lesser extent (43%). At the same time, almost one third or 31% of medical staff agreed with this statement, suggesting that medical staff are more conscious (than nursing staff) of unexpected outcomes not being communicated fully and appropriately.

Figure 3.11: Medical And Nursing Staff Respondents' Views About Whether Patients Are Not Informed About Less Serious Adverse Events Involving Their Care And Treatment
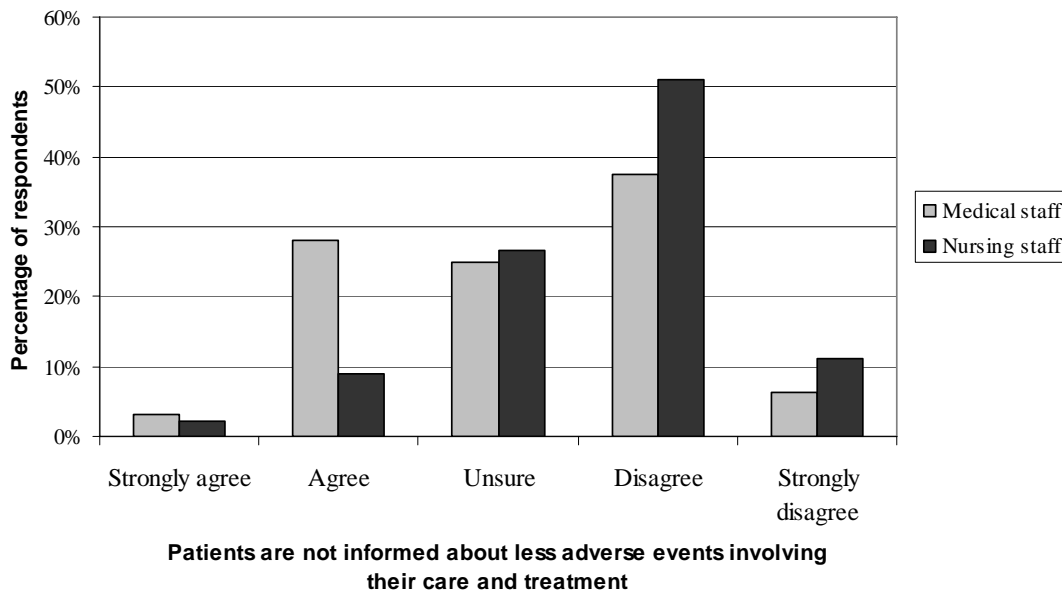
3.3 Concluding Discussion

Acknowledging that these questionnaire surveys were submitted to staff who had volunteered to become involved in Open Disclosure, the survey responses received confirm that Open Disclosure is highly favourably regarded.

The survey results reported are noteworthy for the following three reasons.

1. Taking into account that we were dealing with a self-selected group of health care professionals, the high response rate suggests there is a high level of faith in Open Disclosure on the part of those who completed the survey.

2. Many of the survey responses show high levels of uniformity[36], which further confirms Open Disclosure harbours highly defined advantages and challenges.

---

[36] That is, survey responses group into quite distinct domains of agreement, disagreement and uncertainty across health professional groups, organisational types and jurisdictions.

3. In contrast with these positive assessments of Open Disclosure as practice and as policy, uncertainty is expressed about:

   a. *external* factors, such as the threat of litigation, and loss of personal reputation.

   b. *internal* factors, such as when, how, and with whom to conduct Open Disclosure.

4. Nursing staff may be more burdened than medical staff by the emotional impact of Open Disclosure.

5. Medical staff may be more conscious (than nursing staff) of unexpected outcomes not being communicated fully and appropriately.

We note that these responses may paint an unduly positive picture of how Open Disclosure is enacted and received. When considered in the context of the interviews we conducted (presented and analysed below), the survey responses show more evidence of optimism and enthusiasm than of critical reflection and realistic appraisal. This is no reason to diminish the significance of these reported survey outcomes, however. Given the challenges and delays that policy implementation ordinarily confronts, we do well to recognise that Open Disclosure achieving this level of support in such a brief period of time in the pilot sites (since implementation in 2006) is nothing short of remarkable.

4   OPEN DISCLOSURE – AN INNOVATIVE POLICY

4.1   What Open Disclosure offers

As our report has shown, both health care staff and patient and family member interviewees regard Open Disclosure in mostly positive terms. Even if specific aspects of the process could and should be improved, overall Open Disclosure is seen as harbouring the promise of if not actually realising openness and honesty. To emphasise this point, let us consider two further quotes from the many that support this practice, one from a clinician and one from the patient/family interviews:

> *"Well, all my experience with [Open Disclosure] is positive. It is contributing to the culture thing, it is about getting it off people's chest thing, there is no dealing of hidden agendas, there is no feelings of [distrust], there is true transparency."*
> [Nursing Manager 89-155]

> *"Before March I blamed the hospital, I blamed myself, I blamed everybody. Like, the guilt was just so raw with me. My own guilt and the guilt that I'd let my son down, and the blame that I needed to pass on to the hospital, and all of that. Since the Open Disclosure I know for a fact that there has been measures put in place so that this doesn't happen again and I've also been in contact with legal since then. The Open Disclosure for me itself actually lifted a great weight off my shoulder. I didn't feel like it was about guilt any more. It was about acceptance. This happened which shouldn't have happened but it did and I have to accept that and move on."*
> [Cons 1, 7]

The majority of interviewees support Open Disclosure. There was not one interviewee among the 131 health care staff that we spoke to who had reservations about Open Disclosure, and of the 23 consumers we interviewed not one regretted having been invited to an Open Disclosure meeting. While health care staff were keenly attuned to the risks of Open Disclosure (Section 2.4.5 above) and consumers are very aware of the shortcomings in current practice (Section 2.5.7), most interviewees were also able and willing to articulate benefits.

Drawing on both the clinician and the patient/family interview data, we finish this section with the following comments on the benefits of Open Disclosure (table 4.1).

Table 4.1: Benefits of Open Disclosure

	Benefits of Open Disclosure	Relevant Interview Quotes
1	**Open Disclosure may provide closure.** Open Disclosure can help consumers move on from an incident.	*"Well, clearly, the big thing is closure for, an attempt at closure. You're probably never going to get a hundred percent closure but you at least get people to be able to get back to moving on with their lives, not stuck in a time warp about an incident and becoming bitter and twisted which can have an effect for the rest of their lives."* [Support Personnel 29-205] *"The guilt that I felt because I was his mother I was the person who was supposed to look after him so [you felt you let him down]. Yes, and the Open Disclosure process that we finally had been through has been beneficial for me in the fact that I don't feel as much guilt now."* [Cons 1, 3]
2	**Open Disclosure may assist healing**. Open Disclosure can ensure that the patient trusts the organisation and the clinical staff. This trust is central to improving patients' healing process	*"Well, health care is a trust game. ... If you undermine the trust, you undermine the therapeutic relationship which is important for the patients as well as it is for the comfort of the staff. If they don't feel like they can trust it's much harder for them to get better."* [Medical Manager 33-86] *"Well, I didn't know what was happening or what is the worst thing that could have happened to me. They explained the possibility of dialysis, and they also explained that all the cells in my body would change within 90 days or so. That made me feel better and they reassured me that I was going to get better."* [Cons 12, 104]
3	**Open Disclosure may lower complaint levels.** One health care staff interviewee makes mention of anecdotal evidence that there has been a reduction in complaints following the introduction of Open Disclosure.	*"Yes. I think it's been successful ... Certainly from one of the health service's perspective ... that has had huge success in terms of one of their areas and overall in the hospital [name] was saying that their complaints have gone down 42% which is amazing but whether that just relates to this or not who's to know without doing more evaluation."* [Support Personnel 78-81]

Table 4.1: Benefits of Open Disclosure (cont'd)

	Benefits of Open Disclosure	Relevant Interview Quotes
4	**Open Disclosure may improve organisational culture.** Interviewees comment on how Open Disclosure: 1. strengthens staff's willingness to learn from adverse events; 2. encourages a culture of honesty; 3. enhances the management-clinician relationship; 4. improves how people speak about each others' work and their clinical outcomes.	*"To start with when it first occurred they both wanted to resign and leave and never nurse again, and they're now still working so I think it certainly helped them as well and they, the error occurred because of a practice that was happening in that it wasn't a standard that we would have accepted and they've actually been the change agents in changing that practice in that facility. So they not only benefited from it, they learned from it and they're now teaching others."* [Support Personnel 67-37] *"Well, I think inherently, the whole concept of a more transparent organisation, I think it makes for a healthier organisation."* [Medical Manager 29-170] *"I initially had a few issues with my staff simply looking at me as a manager and saying whose side are you taking, sort of thing. … I think, but all this is gone now."* [Nursing Manager 87-152] *"Open Disclosure stops that tittering that happens about things [the corridor talk] … certainly for the junior staff that sort of, 'He is an idiot because he did this'."* [Medical Manager 86-52]
5	**Open Disclosure can integrate consumers' perspectives and experiences into the (re)design of services** (Bate & Robert, 2007).	*"Another thing that's a benefit, um the … the information you get, from the patient's perspective, before you actually commence your [Root Cause] analysis, you can actually use it in your analysis sometimes, 'cause you're getting their version of events as well, so that … that helps with the um, analysis sometimes."* [Support Personnel 34-149] *"Yeah, he came up a few, a couple of weeks back, and he said that they're reviewing all their procedures in Townsville and double checking what happened. See, my question was, if I was given this, ar, injection, why wasn't it checked and double checked before it was administered. Um, that was my, it's been my question all along, you see. And this is what I wanted to get across to Dr AJ, he's the administrator. Anyway, he found out that it hadn't been checked and everything, and it came out in the HEAPS report, so now they're going to have, they're all being educated on this aromine, the drug that I was given."* [Cons 7, 69]

Table 4.1: Benefits of Open Disclosure (cont'd)

	Benefits of Open Disclosure	Relevant Interview Quotes
6	**Open Disclosure may lead to much better relations with patients and family members**:	*" … when you actually saw that it worked on occasion, you actually got letters of thank you, you know from people who, you'd told horrible stories to about things that you had done to them or their families, um, you know, so, um, so that enabled us to continue to do it."* [Nursing Manager 32-76-7] *"Well, it's helpful as a voice for me. I don't have a voice because I'm just a one here and one there. Um, so I think, and the ladies that I've spoken with, and the lady that helped me here, has given me I suppose you'd call it reassurance that something's been done and that people are listening to people like me."* [Cons 2, 19]

4.2 Open Disclosure – What is needed in the future

Interviewees regard Open Disclosure as a significant turning point in the provision of health care. They sense that Open Disclosure cannot be rolled back, that it will spread rather than recede, and that it will become a standard part of providing health care services. This sense of 'turning point' links in with a number of proposals to realise a carefully structured roll-out and to obviate inappropriate Open Disclosure practices (table 4.2).

Table 4.2: What is needed in the future

	What is needed in the future	Relevant Interview Quotes
1	**Make available awareness training before asking staff to participate in Open Disclosure**.	*"So now we're at this risky stage where we're sort of thinking well we can't you know, we've taken the lid of this box, you can't go and stuff it all back in. We're now thinking what we need to do is roll out more comprehensive, more awareness training for people so that they know when they might get into trouble, and strategically training up some [staff] early catching them before they've needed to disclose."* [Medical Manager 47-86]

Table 4.2: What is needed in the future (cont'd)

	What is needed in the future	Relevant Interview Quotes
2	**Expose medical and nursing students to education about Open Disclosure**.	*"I think that undergraduates need to know about it. I think it needs to be built into our undergraduate program, with the understanding that there are highly trained people who will help you. You need to tell them before you do anything."* [Support Personnel 75-98]
3	**Compensate for the dearth of (High Level) Open Disclosure opportunities by enabling those skilled in Open Disclosure to meet regularly, or by making on-line Open Disclosure resources available**.	*"I think we would all benefit from learning from our experiences for a few more years yet. Having a forum where facilitators could come together, debrief and perhaps reinvigorate their training as we learn more about it."* [Support Personnel 75-98] *"… you almost like it to have it online, so that people can, you know, if they've got say, half an hour free … you can say okay … just hear what this group have done, you know,[how they've] experienced Open Disclosure."* [Medical Manager 36-131]

4.3 Open Disclosure – Questions remaining

There are some matters that we have not been able to resolve or deduce recommendations for. These matters include the following (table 4.3).

Table 4.3: Questions remaining

	Questions remaining	Relevant Interview Quotes
1	**What can clinicians and Open Disclosure support staff commit to paper?** Staff working on Open Disclosure cases need to keep notes about the case. These notes may include conjectures about what happened and who was involved, as well as refutations of particular understandings and approaches to the case. These notes constitute 'soft information': they are dynamic in that their content changes and serves only as a temporary heuristic and mnemonic for staff. They are not 'hard information' that they are confident of and willing to publicise. Given there is (Discovery, Freedom of Information and Privacy) legislation that enables people to request such 'soft information', it may be advisable to review the legislative provisions relating to Qualified Privilege so as to provide certainty to clinicians about the applicability of statutory Qualified Privilege to all aspects of the Open Disclosure process, including pre-meeting documentation. Such as review could investigate the possibility of enacting specific legislative provisions relating to Open Disclosure, much like those currently in existence for Root Cause Analysis under s20Q of the Health Administration Act 1982 NSW and ss71-74 of the Health Care Bill 2007 SA. Alternatively, such information could be classified as the clinician's personal notes and therefore their personal property[37].	*"It structures that meeting using that form. But you've got to be careful what you write in case it is FOI-able. So you would never include some things in a meeting."* [Support Personnel 28-196] *"I would see that [pro-forma] document as a working document. It's not the document I would say should be the FOI-able component of Open Disclosure. [But] I don't think it's protected. I think it probably does have some concerns because we don't know where that document sits in FOI land or its disclosurable-type status. Some places don't use it or write on it [for that reason]."* [Support Personnel 28-196]

---

[37] Unlike with Root Cause Analysis, there are currently no specific Qualified Privilege legislative provisions in relation to the Open Disclosure process. Open Disclosure could of course be considered to come under the general legislative privileges covering 'Quality Activities'. When these legislative provisions are next reviewed (August 2008 for the New South Wales Root Cause Analysis provisions) the Review could consider the merits of having specific legislative recognition of Open Disclosure under Qualified Privilege, and the review could take into account the dynamics and details of the Open Disclosure process, including the status of pre-Open Disclosure notes. The Review could consider enacting sections specifically pertaining to Open Disclosure as it has done for Root Cause Analysis, on grounds that the Root Cause Analysis section be mirrored by an Open Disclosure section. Equally, the general Qualified Privilege and Quality Activity section could be reviewed to incorporate all incident management activities, rather than have separate provisions for Root Cause Analysis and Open Disclosure. For its part, Root Cause Analysis is covered under section S20Q (1): "A person who is or was a member of a RCA team and the relevant health service organisation for which the RCA team was appointed are neither competent nor compellable: a) to produce any document in his or her or its possession or under his or her or its control that was created by, at the request of and solely for the purposes of the RCA team, or b) to divulge or communicate any matter or thing that came to the notice of a member of the RCA team as such a member. (2) Subsection (1) does not apply to a requirement made in proceedings in respect of any act or omission by a RCA team or by a team member of a RCA team as a member". S20R states: "A notification or report of a RCA team under s20O is not admissible as evidence in any proceedings that a procedure or practice is or was careless or inadequate".

Table 4.3: Questions remaining (cont'd)

Questions remaining	Relevant Interview Quotes
On the other hand, if Open Disclosure attracts Qualified Privilege (as quality improvement process), this could contravene the ethos of openness with which staff are to approach adverse event information. This, in turn, could risk Open Disclosure by restricting it in terms of who has access to such information. No-fault legislation differs in that it provides staff with the certainty that proof of fault will not lead to litigation.	
2 **Who can be invited to the Open Disclosure meeting(s)?** Patients and family members set much store by being allowed to invite people to Open Disclosure meetings to support them. Staff interviewees have made comments about it being difficult to know where to draw the line between personal support and other kinds of support, and this impacting in different ways on the dynamics of the Open Disclosure meeting. For example, staff interviewees talk about consumers bringing friends who are lawyers and people who are local politicians. As a guiding principle, who can be invited to the Open Disclosure meeting should be informed by the aims of Open Disclosure itself: the provision of factual information to the patient, the expression of an apology and the explanation of the consequences of the adverse event to the patient. The relevant parties are therefore the patient, associated clinicians and the patient's caregiver and/or next of kin. Lawyers and politicians have means other than Open Disclosure of accessing information for reasons outside of the stated aims of Open Disclosure: FOI, Discovery, and published reports[38].	*"I think the onus on management is to invite the next of kin… and give them a semi-open offer to bring with them whoever they choose. Having said that, you've then got to be careful about issues such as privacy … I attended [an Open Disclosure meeting] recently, where there was no family member present but there were significant friends … who didn't have closure following a death, and they wanted information that they had no right to had because they weren't relatives."* [Medical Manager 9-58]

---

[38] Open Disclosure is not compulsory mediation or even a collaborative law process. The major aim of Open Disclosure is to provide factual information to the patient, an apology, and outline the medical consequences and future actions. Given that, only the immediate parties (i.e. clinicians, patient and patient support person in the form of the person caring for the patient or next of kin) should attend. To be sure, applying Qualified Privilege to Open Disclosure would nullify the problems generated by having lawyers there (or consumers wanting to tape-record or video the meeting; see below). Privilege would render information obtained in that way inadmissible in court. No-fault would further alleviate these problems. This brings us back to the point above: if the applicability of statutory Qualified Privilege or no-fault to Open Disclosure is made more certain, then such reform would provide certainty that adverse event information does not become an object of litigation (see point 4 below).

Table 4.3: Questions remaining (cont'd)

	Questions remaining	Relevant Interview Quotes
3	**In what ways can or should Open Disclosure meetings be (tape/video) recorded?** Health care staff interviewees are uncertain about the extent to which audio and/or video recordings of the Open Disclosure meeting put them or their organisation at risk. Their main concern is that they 'say the wrong thing' (as can happen; see Table 3.6 above), and that such statement ends up being used against them. Others who are more confident in their attitude towards disclosure have fewer concerns about such recordings. This confidence may depend on experience in doing Open Disclosure meetings. Ultimately, Open Disclosure is not compulsory mediation or even a collaborative law process. The major aim of Open Disclosure is to provide factual information to the patient, an apology, and outline the medical consequences and future actions. To be sure, applying Qualified Privilege to Open Disclosure would nullify the problem generated by consumers wanting to tape-record or video the meeting (or by having a lawyer attend as support person, for that matter). Privilege would render information obtained inadmissible in court. No-fault would eradicate the problem altogether: if the applicability of statutory Qualified Privilege or no-fault to Open Disclosure is made more certain, then such reform would provide certainty that adverse event information does not become an object of (for) litigation.	*"I would not normally [allow tape-recording]. Personally I would not participate in a recorded session … because I think … that it hinders the relationships that you should be forming, the dialogue between yourself and the patients, and if you make a recording, even a good recording, it can't pick up all the nuances that go on. What I have been prepared to do in the past is take minutes of the meeting and provide a draft of the minutes to the family and the patient. So I'm not averse to recording it but I'm against, well I personally wouldn't take part in one with either a tape recorder or a video machine."* [Senior Medical Manager 29-46] *"I think you have to be especially wary of it [tape-recording] and would absolutely insist that, say a recording made locally for us as well, [we'd make] copies of that tape or we'd take away a recording at the same time."* [Senior Medical Manager 29-23]
4	**Should Australia consider introducing no-fault liability?** The issue of no-fault liability has been previously considered in Australia (Kirby, 2000: fn39). It was largely dismissed on grounds of constitutional civil rights and due to the political and legal problem of according special immunities to some professional groups whilst other groups face decreasing immunity. The results of the present empirical study suggest however that there may be a need to revisit no-fault, particularly given the (growing) complexity of adverse events, the resource-challenged nature of health care work, and the limited training staff are given to deal with organisational and communicative complexities.	*"'Yes, we know people make mistakes, yes we acknowledge that ninety-nine percent of mistakes are innocent mistakes caused by a variety of factors that are generally outside the control of the individual and if you self-report, then you cannot be disciplined in any way, shape or form in relation to that error', and it's embedding into that system the culture of 'Yes, we're highly skilled professionals, but yes, we do make mistakes and we actually need to learn and act on those mistakes, and not blame."* [Support Personnel 35-6]

Table 4.3: Questions remaining (cont'd)

Questions remaining	Relevant Interview Quotes
Further support for no-fault liability is that the 'reporting culture' and disclosure of incidents in health organisations improves. In New Zealand, for example, no-fault liability has been found to increase reporting of adverse events, and is on that basis argued to improve safety, quality, accountability and public value (P. Davis, Lay-Yee, Scott, Briant, & Schug, 2003).	

4.4 Conclusion

This concludes our report, but not the work. It is clear that Open Disclosure has inspired many frontline staff, but also that it is not yet embedded into clinicians' everyday practices. Work needs to be done on how patients and family members regard Open Disclosure and on informing clinicians about what patients and family members find important. Work needs to be done on extending openness into other domains, such as informed consent and outcomes reporting. Work needs to be done on training staff in communicating with and listening to their patients and their families.

Open Disclosure provides an opportunity for realising patient-centredness in a way that may re-invest health with Public Value (Moore, 1995): consumers becoming engaged in improving health services by being given the opportunity to speak about their care from their perspective; consumers speaking with those involved in adverse events and thereby understanding the pressures clinicians are under, and consumers becoming allies in health care provision and medical treatment by being listened to by those who care for them.

We regard Open Disclosure as an innovative policy: it pre-empts complaints and litigation by encouraging staff to tell the truth. It is a 21st century policy that gives up on old-world oppositions between professional experts and the lay public; between risk management and truth, and between economics and ethics. As several health care staff interviewees said, 'there is no going back'. We can now only move forward towards more ubiquitous disclosure, and towards more realistic engagement with the full array of complexities, achievements and shortcomings that characterise health service delivery.

APPENDIX A: A SUMMARY OF THE FINDINGS: THE INTERVIEWS

Findings: Health Care Staff Interviews

In total 131 interviews were conducted with health care staff between January and November 2007.

1. Analysis of the interview data confirms that health care staff support Open Disclosure:

   b. all of the 131 health care staff interviewed, without exception, expressed approval of the Open Disclosure initiative, confirming the high percentage approval expressed in the questionnaire survey responses

   c. Open Disclosure enhances relationships not just with consumers but also among health care staff themselves

   d. Open Disclosure is challenging because (particularly in the case of severe adverse events) it requires ongoing attention to how the various stakeholders see and experience responses and initiatives

2. The interview data reveal staff are uncertain about:

   a. how to decide whether to conduct Open Disclosure, and if so, whether it should be High or Low Level Open Disclosure

   b. their colleagues' support of their disclosure of adverse events

   c. colleagues' skills in disclosing adverse events

   d. the meaning of 'disclosure of unexpected outcomes'

      1. for most interviewees it is clear that Open Disclosure involves apologising, but for some the apology is not intrinsic to Open Disclosure

      2. for many interviewees it is clear that Open Disclosure moves clinicians' attention to the needs of the patient, but for others it remains defined as a process of medical-technical information dissemination, of explaining the occurrence of 'known risks', and in some instances, of justification of decisions taken and actions carried out

3. Pre-planning encompasses the following tasks (table 3.4 below):

   a. Understand the adverse event, which involves:
   b. Establishing the (nursing, medical, allied health and administrative-managerial) facts of the adverse event
   c. Deciding whether the adverse event requires High Level Open Disclosure or Low Level Open Disclosure

   d. Establishing whether the adverse event needs to be reported to the Coroner or Crown Solicitor

   e. Establishing whether there are any legal, insurance and financial implications (such as ex-gratia payments) and related information that needs to be gathered beforehand

   f. Assemble the team, which involves:

1. Establishing a reliable team of clinical and/or administrative-managerial staff who can be drawn on for urgent High Level Open Disclosure meetings

2. Enquiring into staff attitudes towards and feelings about the adverse event

3. Determining who of the clinical staff to invite to the Open Disclosure meeting and to what extent it is necessary to involve them in a separate pre-planning meeting

4. Deciding whether the person most closely involved in the incident should be invited to come to the Open Disclosure meeting

5. Negotiating with staff who are attending the Open Disclosure meeting the disclosure strategy that is to be adopted; this planning needs to be done without risking the meeting's authenticity

6. Devising a strategy for junior staff who are involved in adverse events: whether they should be protected from confronting victims of (particularly serious) harm and talked to separately, or whether they should be invited to observe the Open Disclosure process, providing the Open Disclosure sessions are carefully selected so they are likely to benefit from observing them

i. Assess the dynamics of the patient/family, which involves:

1. Finding out details about the patient's and family's reactions to the unexpected outcome

2. Determining who of the patient's family should be invited to the meeting

3. Identifying a family member as the single spokesperson and contact person; this is important to obviate different family members conducting unrelated conversations with staff

ii. Plan the disclosure, which involves:

1. Planning language to use and practising how to apologise given the specifics of the adverse event (without jeopardising the authenticity of the meeting)

2. Preparing a strategy for and position on how to record the Open Disclosure meeting and whether to share that record with the patient (family)

3. Arranging a suitable space for the Open Disclosure meeting; such space may need to be an isolated one in case privacy is needed for the expression of emotions; it needs to be one that has easy access and exit, one where there are no dangerous unattached (throw-able) objects, and one that has a low table with tissues and water (or tea) for everyone

4. Determining when disclosure of adverse event information is not appropriate or needs to be deferred

iii. Decide how to interface Open Disclosure with other Incident Management processes, which involves:

1. Deciding on how to interface Open Disclosure with Root Cause Analysis

2. Deciding to what extent to involve consumers in these investigation processes

4. Doing Open Disclosure encompasses (table 3.6 below):

   i. Excellence in Communication
      1. Saying sorry sincerely
      2. Active (reflective) listening
      3. Dealing with complex patient and family dynamics
      4. Determining the cultural appropriateness of Open Disclosure in situation where one deals with patients and families with culturally and linguistically diverse backgrounds
      5. Ensuring Open Disclosure avoids conflicting and/or unverifiable accounts
      6. Deciding how the desired level of privacy and confidentiality affects the use and dissemination of disclosure information

   ii. 'Organisational Citizenship
      1. Distinguishing between conventional ways of dealing with 'known risks' and the openness and no-blame ethos of Open Disclosure
      2. Managing staff who are most closely involved in the incident and support their needs
      3. Taking responsibility for addressing and resolving unexpected outcomes even if those outcomes were not produced by one's own unit, department or facility

5. Interviewees expect that frontline staff will behave in the following ways to realise Open Disclosure:

   b. Approach 'complications' and 'known risks' as adverse events potentially requiring Open Disclosure
   c. Make themselves available for pre-planning and conduct of Open Disclosure meeting(s)
   d. In cases where they were closely involved in the incident, consider and discuss with others the possibility of attending the Open Disclosure meeting(s) and the implications of doing so
   e. Skill themselves in eliciting from patients (and family members) perceptions and feelings to establish whether the disclosure satisfies their needs and expectations
   f. Show in what they do and say that disclosure communication is integral (not peripheral) to their clinical-professional role and skills
   g. Acknowledge that Open Disclosure requires learning from the adverse events that is not purely technical and systems-based, but also team-based, interpersonal, and even personal, in so far as that each disclosure inevitably reshapes the patient-clinician relationship

6. Interviewees propose the following strategies for following up Open Disclosure meetings:

   h. Patient-oriented follow-up strategies
      i. Make sure that the patient and the family spokesperson can contact a designated staff member

      ii.   Send out a letter out to the patient (and family) within 48 hours that summarises the Open Disclosure discussion and, if there was one, the plan that was agreed on

      iii.   Offer the possibility of additional Open Disclosure meetings

      iv.   Be pro-active in organising additional Open Disclosure meetings

      v.   Ensure the follow-up meeting(s) are appropriately timed

   i.   Staff-oriented follow-up

      i.   Involve staff in a factual debrief

      ii.   Involve staff in an emotional debrief (following an adverse event and/or an Open Disclosure meeting)

   j.   Organisation-oriented follow-up

      i.   For staff in charge of Open Disclosure, liaise with those engaged in Root Cause Analysis

      ii.   Systematically record the Open Disclosure process, and keep records in pre-allocated places (The conduct of Open Disclosure follow-up processes will benefit from a well-developed in-house adverse event register)

      iii.   Arrange monthly meetings among those involved in doing Open Disclosure (A Community Advisory Committee involvement is recommended to signal progress of Open Disclosure roll-out in the organisation and publicise the level of its success to members of the community)

7.   Interviewees see the following as constituting success factors:

   k.   Communication success factors

      i.   Staff are proficient in Active Listening or Reflective Listening

      ii.   Staff display and enact sincerity

      iii.   Staff maintain good inter-disciplinary communication and relationships

   l.   Service success factors

      i.   Clinicians have a pre-established rapport with the patient (and family)

      ii.   Bereavement counselling is available for patients and family members

      iii.   Minimal chance exists that there will be conflicting accounts of adverse events

      iv.   Staff enact restorative justice

   m.   Organisational success factors

      i.   Staff training and general roll-out of Open Disclosure is arranged

      ii.   Medical staff participate in Open Disclosure training

      iii.   The organisation has efficient staff support measures in place

      iv.   Incident management is effective and supportive; that is:

        1.   Organisational-structural prerequisites (incident reporting, investigation and feedback) have been put in place

        2.   Rapid turn-around of and access to adverse event information occurs through the health service's incident reporting system

        3.   Staff self-report adverse events

        4.   Service-internal notification outweighs external notification of adverse events

        5.   Reassurance is given that reporting will not incur blame on the part of the health service or colleagues

6. Staff are familiar with the types of adverse events that require Open Disclosure

7. A 'single adverse event desk'[39] has been set up

8. Interviewees propose the following as constituting challenges:

    n. Internal challenges

        i. Emotional challenges

            1. Multi-cultural sensitivity is crucial and resource-intensive

            2. Staff may not sufficiently appreciate the emotional labour that is needed for Open Disclosure

            3. Open Disclosure can exacerbate the clinician-patient (family) relationship

        ii. Technical-administrative challenges

            1. The resource requirements of Open Disclosure may exceed what clinicians and/or organisations can provide

            2. Clinicians need to engage more in work process mapping, design and research-based feedback

            3. Primary and tertiary care are misaligned in their communications with the patient

    o. External challenges

        i. Consumers may mobilise Freedom of Information and/or Discovery legislation to force the release of health and clinical information

        ii. Outside institutions (the media, agenda-driven bodies) promote and demand blame

Summary of the Findings: The Consumer Interviews

1. The interviews reveal that:

    a. Thirteen out of twenty-three consumer interviewees judge their Open Disclosure experience not to have been successful (or not successful enough)

    b. Few consumers express regret about participating in Open Disclosure

    c. Only in a minority of cases do consumers report not having experienced any benefit at all from participating in Open Disclosure

2. **Patients and family members express appreciation about:**

    a. Being informed about who (which staff) plays what role in Open Disclosure

    b. Being given a sincere apology

    c. Being attentively listened to

    d. Staff approaching Open Disclosure as an information dissemination exercise *and* as a grief management process

    e. Being allowed to make contact with those most closely involved in the adverse event if that desire is there

    f. Having the open disclosure meeting conducted with an appropriate level of respect for cultural and linguistic diversity

---

[39] Such a 'desk' encompasses a pre-determined set of people who share access to a location where relevant information and documentation are securely stored.

g. Being enabled to plan ahead, and supported in conceptualising their practical, personal and emotional needs in the future

h. Organisations showing they can learn and have learned from their adverse event and will or have put processes in place to prevent similar events from occurring again

3. Consumers express concern about Open Disclosure in so far that:

b. The patient and/or family is not always involved in determining the severity of an adverse event

c. The patient and/or family are not always allowed sufficient time to pre-plan for Open Disclosure (and prepare questions and statements, as well as to come to terms with the consequences and meaning of the harm done)

d. Open Disclosure meetings are not always scheduled appropriately, attended punctually, or given enough time

e. Patients and family members are not always supported in ensuring that a patient/family support person is present during the Open Disclosure meeting(s)

f. Apologies may be offered by staff other than those originally involved in or present at the adverse event

g. Serious adverse events may not be handled according to minimal Open Disclosure standards

  i. disclosure of high severity adverse events can resemble Low Level Open Disclosure in that it is done with insufficient procedural formalisation

  ii. disclosure of high severity adverse events is insufficiently attuned to consumers' sense of interpersonal dignity and social expectation

h. A patient liaison person or patient safety official acts as buffer between the health organisation and the clinical professionals on the one hand, and the patient and family on the other hand

  i. support personnel limit the support available for patients and families to social-emotional support

  ii. reliance on support personnel risks organisations not achieving tangible involvement on the part of clinical professionals in disclosure, reparation and learning from the incident and from the consumer

i. There may be an inverse relation between severity of the incident and facilities' approach to Open Disclosure with consumers' interviews suggesting that

  i. the less the health care facility regards itself to be responsible for the adverse event, the better it is deemed to inform and support those harmed

  ii. the more the system is (or staff working in the system are) seen to be at fault, the less likely it is (they are) to be supportive of consumers, and the less open it is (they are) to consumers

j. The health care facility representatives determine whether closure has been achieved without appropriately involving the family or patient

4. Consumers articulate the following risks presented by Open Disclosure:

a. Staff fail to recognise there is dissatisfaction on the part of the family and/or patient as a result of how the disclosure is done, exacerbating rather than improving relationships

b. Staff change their position or view on what happened without adequate explanation, thereby creating uncertainty

c. Staff contradict one another, thereby exacerbating uncertainty

d. The health care facility moves patients to neighbouring hospitals (due to deterioration or improvement) without adequate Open Disclosure continuity and involvement in the adverse event history of staff at the second facility

e. Family members are denied access to clinical-medical information pertaining to the patient's care (on grounds of privacy legislation)

f. Disclosure may be initiated by staff employed in sites other than that where the adverse event occurred without such staff recognising the need to take appropriate steps to ensure Open Disclosure occurs, thereby burdening patients and family with distressing information *and* with the task of acting on that information (alerting the original health care facility) without the benefit of clinical, professional or organisational experience and support.

APPENDIX B: THE OPEN DISCLOSURE EVALUATION – TENDER SPECIFICATIONS

Table: Project design and quality / performance criteria

	A Phase descriptions	B Criteria indicating progress and success	C Where reported in this document?
Phase 1 30 March 2007	The first phase (55 days) encompassed the planning and organising of the project, including applying for Ethics approval from relevant institutions, developing and piloting the survey questionnaire, identifying and arranging (phone-conferenced) meetings with stakeholders (clinicians, patients, carers) at main sites to negotiate the details of the project, and planning visits to case study sites.	1. Ethics applications submitted to Health departmental Human Research Ethics Committees across Australia, and to UTS, UoM and UQ HRECs 2. Ethics approval obtained from UTS, UoM and UQ Human Research Ethics Committees, and from relevant health departmental agencies 3. questionnaire survey developed, piloted and validated 4. meetings arranged with stakeholders at sites 5. ethnographic case study sites contacted	Appendix C Appendix B Survey appended in Appendix D Appendix A Appendix A/B
Phase 2 31 May 2007	The second phase (60 days) centred on administering the questionnaire surveys, meeting with and interviewing stakeholders.	1. questionnaire surveys administered and reasonable response rate achieved 2. representative number of stakeholders interviewed at sites or by phone 3. Open Disclosure sessions observed and recorded	Section 2: Survey Data Analysis Appendix A; Section 3 Appendix A/B
Phase 3 29 June 2007	The third phase of the project (30 days) encompassed data analysis. This involved processing the survey questionnaire information, interpreting and triangulating multiple data sources, formulating project recommendations and suggestions, and producing an interim report.	1. survey data processed and interview and questionnaire data analysis completed 2. outcomes from interview and observational studies triangulated with survey data 3. initial project recommendations formulated for interim report, delivered 29 June 2007	Section 2: Survey data analysis Section 3: Interview data analysis; Appendix E (survey result tables) Section 0: Executive Summary
Phase 4 30 November 2007	The fourth and last phase of the project included further data collection, data analysis, report writing, negotiating draft versions of the report with the commissioning agency, and finalising the project report for submission.	1. draft version of report submitted to commissioning agency for comment on *30 November 2007* 2. final report submitted 3. draft of academic paper prepared	1. Submitted 30 November 2007 2. 3. First paper attached in Appendix.

APPENDIX C: THE OPEN DISCLOSURE EVALUATION – Interview Details

This section provides details of those respondents and their sites whose data form the basis of this report. The data collection proceeded as follows. To date, 154 interviews have been conducted, 24 in NSW, 33 in Victoria, 68 in QLD and 29 in SA. In total, 23 interviews were conducted with patients and family members (15 patients and 8 family members) and 131 interviews with health professionals.

Figure A.1: Number Of Interviews Conducted In Each State
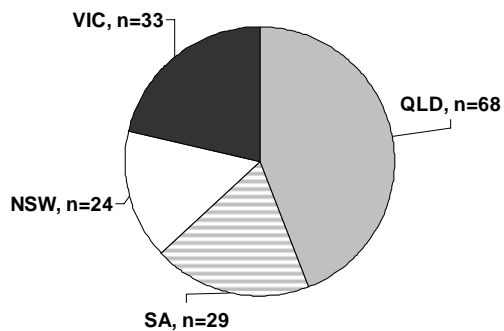
Figure A.2: Total Number Of Interviews Conducted
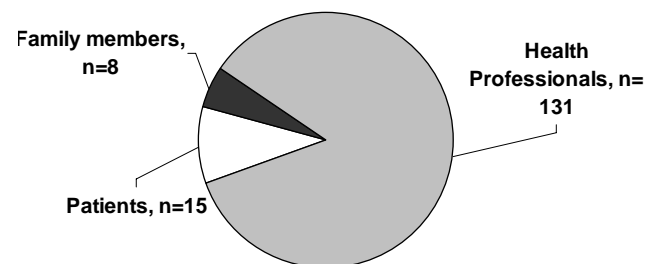
A full table of interviews conducted is presented below. The family member interviews ranged from 11:21 minutes to 39:15 minutes; the patient interviews from 15:08 minutes to 59:54 minutes; the health professional interviews from 13:00 minutes to 1:58:33 hour. More than half of the interviews (81) were conducted over the phone and 73 interviews face-to-face.

Table A.1: Number Of Interviews Conducted At Open Disclosure Pilot Sites

Facility[40]	# of nursing interviews	# of medical interviews	# of patient/family interviews	# of interviews clinician managers/admin	TOTAL
Interviews conducted in Victoria					
Hospital 1		2			**2**
Hospital 2	2	3	3		**8**
Hospital 3	2	6		1	**9**
Hospital 4	1		2		**3**
Hospital 5	1	1		2	**4**
Hospital 6	1	1		4	**6**
Interviews conducted in South Australia					
Hospital 7	2	7		3	**12**
Hospital 8	4	2	2	1	**9**
Hospital 9	3	1		3	**7**
Interviews conducted in Queensland					
Hospital 10				3	**3**
Hospital 11		5	2	2	**9**
Hospital 12	2	1	3	4	**10**
Hospital 13		2		2	**4**
Hospital 14		8	3	11	**22**
Hospital 15		1	7	6	**14**
Hospital 16		1		4	**5**
Interviews conducted in New South Wales					
Hospital 17				5	**5**
Hospital 18	1	2		5	**8**
Hospital 19		2	1	2	**5**
Hospital 20	1			1	**2**
Hospital 21		4			**4**

[40] These facilities have been de-identified for reasons of confidentiality.

APPENDIX D: ETHICS SUBMISSIONS

This section sets out the ethics applications that have been approved, those that were not approved and those that were significantly delayed.

Approvals

In total, 28 Human Research Ethics Committees have approved the National Open Disclosure Evaluation Study:

- o Victorian sites include:
    - The Alfred Hospital, initial approval granted 2nd January 2007, approval withdrawn on 20th March 2007, approval re-instated on 27th August 2007
    - Barwon Health, 12th December 2006
    - Northeast Wangaratta, 15th December 2006
    - St Vincent's Hospital, 8th March 2007
    - West Gippsland, 2nd June 2007
    - Eastern Health, 9th July 2007

- o Tasmanian sites include:
    - Southern Tasmania Health, 8th March 2007

- o South Australian sites include:
    - Flinders Medical Centre, 28th February 2007
    - Lyell McEwin Hospital, 28th May 2007
    - Children's, Youth and Women's Health Service, 2nd June 2007

- o Queensland sites include:
    - Cairns, 1st March 2007
    - Rockhampton, 20th June 2007
    - Townsville, 24th April 2007
    - Bundaberg, 23rd April 2007
    - University of Queensland, 5th May 2007
    - Princess Alexandra Hospital; Queen Elizabeth II Hospital, 24th April 2007
    - Uniting Health Care, 6th June 2007
    - Royal Brisbane and Women's Hospital, 10th September 2007

- o New South Wales sites include:
  - Prince of Wales Hospital, 14th February 2007
  - Wollongong Hospital, 13th April 2007
  - Nepean Hospital, 3rd May 2007
  - Dubbo Base Hospital, 19th April 2007
  - Wyong Hospital, 29th March 2007
  - Royal North Hospital, 19th April 2007
  - Manning Base Hospital, 22nd May 2007
  - Griffith Base Hospital, 15th May 2007
  - Liverpool Hospital, 22nd June 2007
  - University of Technology, 20th February 2007

Sites where our ethics applications have not been approved

- Our ethics application to Wodonga Human Research Ethics Committee was not approved on the grounds that (correspondence of 9th May 2007): "the internal site researcher may have a conflict of interest by being expected to be both observer and active participant in the organisation of the Open Disclosure project, and also possibly being involved in post-sessions supporting staff".

- Our ethics application to ACT Health Human Research Ethics Committee was not approved because the research team was unable to obtain information from ACT Health and inform to the HREC committee about the Canberra hospital site where the project would take place (correspondence of 15 June 2007).

- Our ethics application to Sydney South West Area Health Service (Royal Prince Alfred Hospital zone) was not approved on 19th September because the committee felt that the evaluation was premature given that the Open Disclosure process had not yet commenced in the Sydney South West Area Health Service.

- Our ethics application to North Coast Area Health Service was not approved on 1st September 2007 because the research team was unable to address issues the committee had asked to be addressed before the study could be approved. The research team was further unable to secure management support because the Open Disclosure process had not yet commenced in that Area Health Service.

Delayed ethics submissions

Submission of ethics applications to the following sites were delayed and therefore abandoned due to problems affecting the identification of internal investigators or the need to obtain management approval: Bendigo Healthcare Group, Southern Health, Goulburn Valley and the four sites in WA.

APPENDIX E: ABBREVIATIONS AND DEFINITIONS USED

Abbreviations

ACQSHC	Australian Commission for Quality and Safety in Health Care
OD	Open Disclosure
QH	Queensland Health

Glossary of terms used in this report and their definitions[41]

Adverse event	An **incident** in which harm resulted to a person receiving care.
Attitude	A taken-as-given way of thinking and talking, often evolved over years of socialisation and education.
Communication	Practices of meaning and sense making which are to some degree standardised. Communication usually occurs when there is a difference affecting what people do, know, believe, or want to happen, and this difference is to be resolved through symbolic exchange (compare: **interaction**).
Conflict	A kind of interaction or communication which is motivated by excess **difference** whose resolution remains unachieved.
Context	The sphere of the taken-for-granted. Context includes kinds of knowing as well as physical dimensions which make up 'setting'.
Control	A mode of communication and/or interaction oriented towards determining what others do and say (compare: **power**).
Culture	The configuration of attitude and meanings which together can be seen to be definitive of 'what people are' or 'where people come from'. Culture can be seen as a 'state' or something people possess, while it appears more fruitful to regard it as a performance, or process.
Difference	Difference is an informational-communicational imbalance: some know or have different things compared to others and people's attempts to resolve such differences involve **communication** as a form of symbolic exchange. Some differences may be incommensurable, and no amount of communication may be able to resolve it. Much here depends on people's stances or **attitudes** as to whether they are interested in bridging difference.
Discourse ethics	This term references the view that people's ethical stance is not arbitrary to *the way* they conduct themselves in interaction, and to *how* they communicate. The focus here is on the process of communication itself, besides what is talked or written about, or its substance. Discourse ethics manifests in terms of specific speaking rules that are imposed on the communication event. For example, people shall not be interrupted; no two people shall speak at once, respectful language shall be used, and so forth.
Ethnography	A technique used for describing what human beings do in selected settings, usually comprising 'participant observation', field notes, narrative accounts, interviews, and the like (cf. transformative ethnography).

---

[41] Some of these definitions have been adopted from the Australian Council for Safety and Quality in Health Care Shared Meanings project glossary.

Ethos	A set of values or **attitudes** that govern what people do, believe, feel or say.
Evaluation	The systematic examination of a policy, program or project aimed at assessing its merit, value, worth, relevance or contribution.
Face-to-face	Communication which takes place in situations of co-presence (where two or more people are present in time and space).
Formative Evaluation	Evaluation conducted during a course of a policy's, program's or project's life, with the aim to help in its development and improve it, assess process rather than outcomes (cf **summative** evaluation), and provide detailed, diagnostic answers rather than concise and unambiguous answers (cf summative evaluation).
Incident	An event or circumstance which could have or did lead to unintended and/or unnecessary harm to a person, and/or complaint, loss or damage.
Information	A kind of **communication** which has somehow been displaced from people's concerns in the 'here and now', so as to embody a more distant, general and sometimes abstract significance.
Interaction	The actions which people can engage in when aiming to accomplish a task (e.g. passing bags of sand along a chain of people in case of a flood). Communication is a specialised kind of interaction (compare: **communication**).
Interactive evaluation	Evaluation will provide information about the delivery and implementation of a program, selected component or activity (Owen & Rogers, 1999).
Interests/ concerns	Issues which (can) motivate people's communications and/or interactions, and which rate highly in terms of people's sense of rightness, truth, or well-being.
Liability	Liability is the result of committing a breach of legal responsibility, duty or obligation. It means being answerable and chargeable for the breach of responsibility, duty or obligation. Liability can be civil or criminal, depending upon the nature of the responsibility, duty or obligation. For example, liability may arise from provisions in a contact, from professional negligence, through obligations and duties imposed under statute law, as well as from equitable obligations and duties such as a breach of fiduciary duty.
Miscommuni-cation	An effect of the way(s) in which we have structured, or failed to structure, our communications with others. At a simple level, miscommunication may include minor errors, like forgetting information that is not absolutely crucial or central to the work, as well as major errors, which affect the quality and outcomes of the work. Seen from a systemic or organisational level, miscommunication is a term which can be applied (as a form of critique) to what workers may perceive as 'routine' aspects of how they work; for example, conveying crucial information 'off the top of people's heads' creates risks in so far as issues are easily forgotten or get 'skewed' in the process of communication; speaking to people without writing down what is said; not speaking to people who ought to have been spoken to; using single paper copies of documents crucial to the work process, and so on. Miscommunication, then, besides uttering statements that are inaccurate, also encompasses statements arising from inappropriate assumptions about the use of different modes of communication.
Open Disclosure	An open, consistent approach to communicating with patients when things go wrong in health care. This includes expressing regret for what has happened, keeping the patient informed, providing feedback on investigations and the steps taken to prevent a recurrence of the adverse event.
Patient centredness	Patient centredness has been characterised as requiring a biopsychosocial perspective, seeing the 'patient-as-person', sharing power and responsibility, establishing the therapeutic alliance, and conducting being the doctor 'as person' (Stewart & Martinez-Lucio, 1998).

Positioning	The way in which we see ourselves as relating to others, and how this translates in what we say, how much we (presume to be able to) say, how we say it, and so on. Some people are known as arrogant: their positioning is predictably dismissive of others' views and feelings. Other people are known as considerate: their positioning is more often than not observant of others' concerns.
Power	In traditional accounts, power is the means through which some people can get others to do things which they would otherwise not do. This is its 'negative' definition. In more recent accounts, a more 'positive' definition has been put forward: power is the totality of actions that contributes to the realisation and maintenance of a practice, social institution, or productive organisation. In this latter view, power is less about the authority some have over others, as about the productivity or products which a community of people can be seen to be responsible for and implicated in. This kind of productivity involves mobilising not merely what individuals can do, but what materials and technologies can do. Power, then, is a complex of people, their practices, their levels of experience and contribution, and all the various ways in which their skills are technologised and spatialised (compare: **control**).
Practice	A term which references a particular and relatively routinised and ritualised way of doing or saying.
Practice improvement	An approach to work that is anchored in routines of measuring, analysing, intervening and observing of the effects of the change intervention, with the aim of enhancing outcomes.
Risk management	Risk management centres on the attempt to minimise risks in organisations. Recent approaches to risk management prefer to regard risk as capital, in order to deploy risk as a source of organisational learning.
Speech genre	This is a particular way of structuring our spoken communications with others: 'ward rounds' are a speech genre, and so are 'family conferences'. **Open Disclosure** is also a speech genre, albeit an inchoate one.
Standard	A standard sets out specifications and/or procedures designed to ensure that a material, product, method or service is fir for the purpose and consistently performs the way in which it was intended
Suffering	Suffering involves experiencing anything subjectively unpleasant, which may include: pain, malaise, nausea and/or vomiting, loss, depression, agitation, alarm, fear, grief or humiliation.
Summative evaluation	Evaluation conducted at the end of a policy's, program's or project's life to assess the overall effectiveness and to certify outcomes in concise and unambiguous terms (cf **formative** evaluation).
Systematisation	The **practice** of formally mapping the broad outlines of what we do, in an attempt to see how what we do on a day-to-day basis measures up against our impressions and expectations about the outcomes and quality of what we do. In effect, systematisation start with notation, through which we engender reflexivity and change. In general, communication relies on systematising how we exchange meanings. Social life, in that sense, is conditional upon a modicum of systematisation for people to be able to enact it and predict its unfolding.
The floor	This is a technical socio-linguistic term for 'the space where we (assume the right to) speak': 's/he always assumes a right to the floor over others'. Someone who 'takes the floor more than others' may not be speaking according to the rules put forward within **discourse ethics**.

APPENDIX F: THE QUESTIONNAIRE SURVEY

UNIVERSITY OF TECHNOLOGY SYDNEY

OPEN DISCLOSURE SURVEY FOR HEALTH PROFESSIONALS

Instructions:

You are invited to complete the following questions relating to open disclosure by ticking or circling your response, or by providing comments. There are three sections to the survey.

- Section 1 contains demographic questions and the extent to which you have participated in open disclosure sessions.
- Section 2 has questions about your specific experiences of open disclosure.
- Section 3 involves questions about open disclosure policies and practices in your organisation.

The definition we have applied to open disclosure is the following: honestly telling patients or family members about unexpected harm that occurs as a result of treatment or care, which is not directly caused by a patient's illness or underlying condition.

Please return the survey in the reply paid envelope.

Thank you for your time and support.

Section 1. Demographics

Tick or write your responses where appropriate.

1.What is your professional background?

        Medicine ☐
        Nursing ☐
        Pharmacy ☐
        Other: ☐ Please specify_____

2.What is your gender?

        Male ☐
        Female ☐

3. What is your age? _____ years.

4a. What is your current position in your organisation?
_____

4b. In what type of hospital do you work?
Metropolitan ☐ Regional ☐ Rural ☐

5. How many years have you worked in health care? (since you gained your initial qualification) _____ years

6. What percentage of your present work time do you spend on management duties? _____%

7.What percentage of your present work time do you spend on clinical duties? _____%

8. Have you undertaken any training in open disclosure?
Yes ☐ No ☐
If no, skip to item 12.1.

9.What form did the training take? (tick as many as appropriate)

Structured presentation or course ☐

A colleague explained the process ☐

Online education ☐

CD/DVD education ☐

Self-directed Reading ☐

Other: ☐ Please specify_____

10. The training I received provided me with the skills to take part in an open disclosure of an adverse incident to a patient.

Strongly agree   Agree   Unsure   Disagree   Strongly disagree
☐ ☐ ☐   ☐   ☐

11. Have you ever attended an open disclosure session?

Yes ☐   No ☐

If your answer is 'No' skip to item 13.1

How many sessions have you attended? _____

How many sessions have you led? _____

Section 2. Your experiences of open disclosure

12. Indicate from your typical experience in open disclosure sessions your agreement or disagreement with the following statements. Please circle your response in the most appropriate box.

	Strongly Agree 5	Agree 4	Uncertain 3	Disagree 2	Strongly Disagree 1
12.1 The explanation given of what has happened to the patients is accurate.	5	4	3	2	1
12.2 The consequences of the event are clearly explained to the patients.	5	4	3	2	1
12.3 The information is given in a way that the patients seem to understand.	5	4	3	2	1
12.4 The explanations are given sympathetically.	5	4	3	2	1
12.5 An apology is made to the patients.	5	4	3	2	1

156

	Strongly Agree 5	Agree 4	Uncertain 3	Disagree 2	Strongly Disagree 1
12.6. The harm that the patients have experienced is acknowledged by the health professional leading the session.	5	4	3	2	1
12.7 If responsibility for the harm done to patients is highly evident, this responsibility is acknowledged by health professionals in attendance.	5	4	3	2	1
12.8 The patients have the opportunity to ask questions.	5	4	3	2	1
12.9 The patients are told that steps are taken to avoid adverse incidents occurring again.	5	4	3	2	1
12.10 An offer is made to share with the patients the findings of any further investigation into the causes of the specific incident.	5	4	3	2	1
12.11 The patients are invited to an Open Disclosure meeting within a reasonable timeframe following the incident.	5	4	3	2	1
12.12 The health professionals who explain the events are known to the patient.	5	4	3	2	1
12.13 A support person for the patient is present (or readily available)	5	4	3	2	1
12.14 The patients are told what steps are being taken to manage the event.	5	4	3	2	1
12.15 The patients are told what steps are being taken to prevent a recurrence of the incident.	5	4	3	2	1
12.16 The patients seem to appreciate being honestly informed through open disclosure.	5	4	3	2	1

	Strongly Agree **5**	**Agree** **4**	**Uncertain** **3**	**Disagree** **2**	**Strongly Disagree** **1**
12.17 Patients appreciate receiving information through open disclosure.	5	4	3	2	1
12.18 Patients become angry when informed about adverse incidents.	5	4	3	2	1
12.19 Patients' families appreciate receiving information through an open disclosure session.	5	4	3	2	1
12.20 Open Disclosure is structured as an ongoing, iterative process.	5	4	3	2	1
12.21 Families often become angry when informed of adverse incidents.	5	4	3	2	1
12.22 I feel satisfied with the outcome of the open disclosure sessions I have attended.	5	4	3	2	1
12.23 Health professionals involved in open disclosure are often upset by patients' and families responses.	5	4	3	2	1
12.24 Health professionals involved in open disclosure sessions receive strong support from their colleagues.	5	4	3	2	1
12.25 Health professionals involved in open disclosure receive strong support from hospital managers.	5	4	3	2	1
12.26 The outcomes of the open disclosure sessions I have attended are satisfactory for the organisation.	5	4	3	2	1
12.27 Overall I think patients' well-being benefits from open disclosure.	5	4	3	2	1

Section 3. Open disclosure policies and practices in your organisation

Indicate from your typical experience in open disclosure sessions your agreement or disagreement with the following statements. Please circle your response in the most appropriate box.

	Strongly Agree **5**	**Agree** **4**	**Uncertain** **3**	**Disagree** **2**	**Strongly Disagree** **1**
13.1 The organisation where I work supports an open disclosure policy.	5	4	3	2	1
13.2 The organisation where I work provides education for staff in open disclosure practices.	5	4	3	2	1
13.3 Health professionals worry about litigation if an adverse incident is disclosed to patients.	5	4	3	2	1
13.4 Health professionals worry about their professional reputations if they are involved in an adverse incident requiring open disclosure.	5	4	3	2	1
13.5 The organisation is fearful that open disclosure will lead to bad publicity.	5	4	3	2	1
13.6 Only severe adverse incidents are openly disclosed in my organisation.	5	4	3	2	1
13.7 Patients are not informed about less severe adverse incidents involving their care and treatment.	5	4	3	2	1
13.8 This organisation acts promptly to set up open disclosure of an adverse incident.	5	4	3	2	1
13.9 I am in favour of open disclosure of all adverse incidents to patients.	5	4	3	2	1
13.10 In my experience open disclosure reduces litigation.	5	4	3	2	1
13.11 Open disclosure practices reduce patients' faith in their health professionals.	5	4	3	2	1

	Strongly Agree 5	Agree 4	Uncertain 3	Disagree 2	Strongly Disagree 1
13.12 In my experience open disclosure leads to improvement in the quality of health care delivered.	5	4	3	2	1
13.13 Open disclosure causes patients and their families unnecessary distress.	5	4	3	2	1
13.14 Open disclosure causes health professionals involved unnecessary stress.	5	4	3	2	1

14. Is there anything you would like to change about the way open disclosure is conducted in your organisation? If so, please elaborate.

_____

_____

_____

_____

_____

_____

_____

_____

15. Are there any other comments you would like to make about open disclosure?

_____

_____

_____

_____

_____

_____

_____

_____

Thank you very much for your time and input

APPENDIX G: QUESTIONNAIRE SURVEY RESULT TABLES

Section 1. Demographics

1) What is your professional background?

	Frequency	Percent	Valid Percent	Cumulative Percent
Medicine	32	40.0	40.0	40.0
Nursing	45	56.3	56.3	96.3
Allied Health	2	2.5	2.5	98.8
Other	1	1.3	1.3	100.0
Total	80	100.0	100.0	

2) What is your gender?

	Frequency	Percent	Valid Percent	Cumulative Percent
Male	38	47.5	47.5	47.5
Female	42	52.5	52.5	100.0
Total	80	100.0	100.0	

3) What is your age?

	Frequency	Percent	Valid Percent	Cumulative Percent
20-39 years	17	21.3	25.0	25.0
40-49 years	26	32.5	38.2	63.2
50-59 years	24	30.0	35.3	98.5
Above 59	1	1.3	1.5	100.0
Total	68	85.0	100.0	
Missing	12	15.0		
Total	80	100.0		

4a) In what type of hospital do you work?

	Frequency	Percent	Valid Percent	Cumulative Percent
Metropolitan	41	51.3	51.3	51.3
Regional	26	32.5	32.5	83.8
Rural	13	16.3	16.3	100.0
Total	80	100.0	100.0	

4b) In which state do you work?

	Frequency	Percent	Valid Percent	Cumulative Percent
NSW	13	16.3	16.3	16.3
QLD	37	46.3	46.3	62.5
VIC	17	21.3	21.3	83.8
SA	13	16.3	16.3	100.0
Total	80	100.0	100.0	

5) How many years have you worked in health care?

	Frequency	Percent	Valid Percent	Cumulative Percent
1-9 years	6	7.5	7.6	7.6
10-19 years	15	18.8	19.0	26.6
20-29 years	33	41.3	41.8	68.4
30-39 years	23	28.8	29.1	97.5
More than 39 years	2	2.5	2.5	100.0
Total	79	98.8	100.0	
Missing	1	1.3		
Total	80	100.0		

6) What percentage of your time to you spend on management duties?

	Frequency	Percent	Valid Percent	Cumulative Percent
0%	2	2.5	2.5	2.5
1%-49%	19	23.8	23.8	26.3
50%-99%	35	43.8	43.8	70.0
100%	24	30.0	30.0	100.0
Total	80	100.0	100.0	

7) What percentage of your time do you spend on clinical duties?

	Frequency	Percent	Valid Percent	Cumulative Percent
0%	26	32.5	32.5	32.5
1%-49%	23	28.8	28.8	61.3
50%-99%	29	36.3	36.3	97.5
100%	2	2.5	2.5	100.0
Total	80	100.0	100.0	

8) Have you undertaken any training in Open Disclosure?

	Frequency	Percent	Valid Percent	Cumulative Percent
Yes	62	77.5	77.5	77.5
No	18	22.5	22.5	100.0
Total	80	100.0	100.0	

9) What form did the training take?

	Frequency	Percent	Valid Percent	Cumulative Percent
Structured presentation or course	46	57.5	76.7	76.7
A colleague explained the process	4	5.0	6.7	83.3
Self-directed reading	1	1.3	1.7	85.0
Course and self-directed reading	6	7.5	10.0	95.0
Course and a colleague explained the process	2	2.5	3.3	98.3
Course, online education, CD and self-directed reading	1	1.3	1.7	100.0
Total	60	75.0	100.0	
Missing	20	25.0		
Total	80	100.0		

10) The training provided me with the skills to take part in an Open Disclosure session

	Frequency	Percent	Valid Percent	Cumulative Percent
Unsure	4	5.0	6.7	6.7
Agree	36	45.0	60.0	66.7
Strongly agree	20	25.0	33.3	100.0
Total	60	75.0	100.0	
Missing	20	25.0		
Total	80	100.0		

11a) Have you attended an Open Disclosure session?

	Frequency	Percent	Valid Percent	Cumulative Percent
Yes	63	78.8	87.5	87.5
No	9	11.3	12.5	100.0
Total	72	90.0	100.0	
Missing	8	10.0		
Total	80	100.0		

11b) How many Open Disclosure sessions have you attended?

	Frequency	Percent	Valid Percent	Cumulative Percent
1-2	28	35.0	46.7	46.7
3-9	21	26.3	35.0	81.7
10 or more	11	13.8	18.3	100.0
Total	60	75.0	100.0	
Missing	20	25.0		
Total	80	100.0		

11c) How many Open Disclosure sessions have you led?

	Frequency	Percent	Valid Percent	Cumulative Percent
0	26	32.5	44.1	44.1
1-2	14	17.5	23.7	67.8
3-9	9	11.3	15.3	83.1
10 and more	10	12.5	16.9	100.0
Total	59	73.8	100.0	
Missing	21	26.3		
Total	80	100.0		

Section 2. Your experiences of open disclosure

12.1) The explanation given of what has happened to the patients is accurate

	Frequency	Percent	Valid Percent	Cumulative Percent
Unsure	2	2.5	2.7	2.7
Agree	35	43.8	46.7	49.3
Strongly agree	38	47.5	50.7	100.0
Total	75	93.8	100.0	
Missing	5	6.3		
Total	80	100.0		

12.2) The consequences of the event are clearly explained to the patients

	Frequency	Percent	Valid Percent	Cumulative Percent
Disagree	3	3.8	4.0	4.0
Unsure	2	2.5	2.7	6.7
Agree	30	37.5	40.0	46.7
Strongly agree	40	50.0	53.3	100.0
Total	75	93.8	100.0	
Missing	5	6.3		
Total	80	100.0		

12.3) The information is given in a way that the patients seem to understand

	Frequency	Percent	Valid Percent	Cumulative Percent
Disagree	1	1.3	1.3	1.3
Unsure	6	7.5	8.0	9.3
Agree	39	48.8	52.0	61.3
Strongly agree	29	36.3	38.7	100.0
Total	75	93.8	100.0	
Missing	5	6.3		
Total	80	100.0		

12.4) The explanations are given sympathetically

	Frequency	Percent	Valid Percent	Cumulative Percent
Unsure	1	1.3	1.3	1.3
Agree	28	35.0	37.3	38.7
Strongly agree	46	57.5	61.3	100.0
Total	75	93.8	100.0	
Missing	5	6.3		
Total	80	100.0		

12.5) An apology is made to the patient

	Frequency	Percent	Valid Percent	Cumulative Percent
Disagree	1	1.3	1.3	1.3
Unsure	2	2.5	2.7	4.0
Agree	25	31.3	33.3	37.3
Strongly agree	47	58.8	62.7	100.0
Total	75	93.8	100.0	
Missing	5	6.3		
Total	80	100.0		

12.6) The harm that the patients have experienced is acknowledged by the health professional leading the session

	Frequency	Percent	Valid Percent	Cumulative Percent
Disagree	1	1.3	1.3	1.3
Unsure	1	1.3	1.3	2.7
Agree	30	37.5	40.0	42.7
Strongly agree	43	53.8	57.3	100.0
Total	75	93.8	100.0	
Missing	5	6.3		
Total	80	100.0		

12.7) If responsibility for the harm done to patients is highly evident, this responsibility is acknowledged by health professionals in attendance

	Frequency	Percent	Valid Percent	Cumulative Percent
Strongly disagree	1	1.3	1.4	1.4
Disagree	3	3.8	4.1	5.4
Unsure	8	10.0	10.8	16.2
Agree	30	37.5	40.5	56.8
Strongly agree	32	40.0	43.2	100.0
Total	74	92.5	100.0	
Missing	6	7.5		
Total	80	100.0		

12.8) The patients have the opportunity to ask questions

		Frequency	Percent	Valid Percent	Cumulative Percent
	Agree	19	23.8	25.3	25.3
	Strongly agree	56	70.0	74.7	100.0
	Total	75	93.8	100.0	
	Missing	5	6.3		
Total		80	100.0		

12.9) The patients are told that steps are taken to avoid adverse events occurring again

		Frequency	Percent	Valid Percent	Cumulative Percent
	Unsure	2	2.5	2.7	2.7
	Agree	31	38.8	41.3	44.0
	Strongly agree	42	52.5	56.0	100.0
	Total	75	93.8	100.0	
	Missing	5	6.3		
Total		80	100.0		

12.10) An offer is made to share with the patients the findings of any further investigation into the causes of the specific event

		Frequency	Percent	Valid Percent	Cumulative Percent
	Disagree	3	3.8	4.0	4.0
	Unsure	5	6.3	6.7	10.7
	Agree	32	40.0	42.7	53.3
	Strongly agree	35	43.8	46.7	100.0
	Total	75	93.8	100.0	
	Missing	5	6.3		
Total		80	100.0		

12.11) The patients are invited to an Open Disclosure meeting within a reasonable timeframe following the event

	Frequency	Percent	Valid Percent	Cumulative Percent
Strongly disagree	1	1.3	1.3	1.3
Disagree	8	10.0	10.7	12.0
Unsure	18	22.5	24.0	36.0
Agree	22	27.5	29.3	65.3
Strongly agree	26	32.5	34.7	100.0
Total	75	93.8	100.0	
Missing	5	6.3		
Total	80	100.0		

12.12) The health professionals who explain the events are known to the patient

	Frequency	Percent	Valid Percent	Cumulative Percent
Disagree	22	27.5	31.0	31.0
Unsure	11	13.8	15.5	46.5
Agree	23	28.8	32.4	78.9
Strongly agree	15	18.8	21.1	100.0
Total	71	88.8	100.0	
Missing	9	11.3		
Total	80	100.0		

12.13) A support person for the patient is present (or readily available)

	Frequency	Percent	Valid Percent	Cumulative Percent
Strongly disagree	1	1.3	1.3	1.3
Disagree	3	3.8	4.0	5.3
Unsure	6	7.5	8.0	13.3
Agree	27	33.8	36.0	49.3
Strongly agree	38	47.5	50.7	100.0
Total	75	93.8	100.0	
Missing	5	6.3		
Total	80	100.0		

12.14) The patients are told what steps are being taken to manage the event

	Frequency	Percent	Valid Percent	Cumulative Percent
Disagree	1	1.3	1.3	1.3
Unsure	2	2.5	2.7	4.0
Agree	31	38.8	41.3	45.3
Strongly agree	41	51.3	54.7	100.0
Total	75	93.8	100.0	
Missing	5	6.3		
Total	80	100.0		

12.15) The patients seem to appreciate being honestly informed through Open Disclosure

	Frequency	Percent	Valid Percent	Cumulative Percent
Disagree	2	2.5	2.7	2.7
Unsure	7	8.8	9.3	12.0
Agree	29	36.3	38.7	50.7
Strongly agree	37	46.3	49.3	100.0
Total	75	93.8	100.0	
Missing	5	6.3		
Total	80	100.0		

12.16) Patients appreciate receiving information through Open Disclosure

		Frequency	Percent	Valid Percent	Cumulative Percent
	Unsure	5	6.3	7.8	7.8
	Agree	26	32.5	40.6	48.4
	Strongly agree	33	41.3	51.6	100.0
	Total	64	80.0	100.0	
	Missing	16	20.0		
Total		80	100.0		

12.17) Patients become angry when informed about adverse events

		Frequency	Percent	Valid Percent	Cumulative Percent
	Strongly disagree	1	1.3	1.4	1.4
	Disagree	27	33.8	36.5	37.8
	Unsure	17	21.3	23.0	60.8
	Agree	18	22.5	24.3	85.1
	Strongly agree	11	13.8	14.9	100.0
	Total	74	92.5	100.0	
	Missing	6	7.5		
Total		80	100.0		

12.18) Patients' families appreciate receiving information through an Open Disclosure session

		Frequency	Percent	Valid Percent	Cumulative Percent
	Disagree	1	1.3	1.3	1.3
	Unsure	12	15.0	16.0	17.3
	Agree	31	38.8	41.3	58.7
	Strongly agree	31	38.8	41.3	100.0
	Total	75	93.8	100.0	
	Missing	5	6.3		
Total		80	100.0		

12.19) Open Disclosure is structured as an ongoing, iterative process

	Frequency	Percent	Valid Percent	Cumulative Percent
Unsure	13	16.3	20.3	20.3
Agree	31	38.8	48.4	68.8
Strongly agree	20	25.0	31.3	100.0
Total	64	80.0	100.0	
Missing	16	20.0		
Total	80	100.0		

12.20) Families often become angry when informed of adverse events

	Frequency	Percent	Valid Percent	Cumulative Percent
Strongly disagree	1	1.3	1.4	1.4
Disagree	18	22.5	24.3	25.7
Unsure	8	10.0	10.8	36.5
Agree	33	41.3	44.6	81.1
Strongly agree	14	17.5	18.9	100.0
Total	74	92.5	100.0	
Missing	6	7.5		
Total	80	100.0		

12.21) I feel satisfied with the outcome of the Open Disclosure sessions I have attended

	Frequency	Percent	Valid Percent	Cumulative Percent
Disagree	2	2.5	2.7	2.7
Unsure	5	6.3	6.8	9.5
Agree	44	55.0	59.5	68.9
Strongly agree	23	28.8	31.1	100.0
Total	74	92.5	100.0	
Missing	6	7.5		
Total	80	100.0		

12.22) Health professionals involved in Open Disclosure are often upset by patients' and families responses

	Frequency	Percent	Valid Percent	Cumulative Percent
Strongly disagree	1	1.3	1.3	1.3
Disagree	17	21.3	22.7	24.0
Unsure	12	15.0	16.0	40.0
Agree	30	37.5	40.0	80.0
Strongly agree	15	18.8	20.0	100.0
Total	75	93.8	100.0	
Missing	5	6.3		
Total	80	100.0		

12.23) Health professionals involved in Open Disclosure sessions receive strong support from their colleagues

	Frequency	Percent	Valid Percent	Cumulative Percent
Disagree	7	8.8	9.3	9.3
Unsure	22	27.5	29.3	38.7
Agree	33	41.3	44.0	82.7
Strongly agree	13	16.3	17.3	100.0
Total	75	93.8	100.0	
Missing	5	6.3		
Total	80	100.0		

12.24) Health professionals involved in Open Disclosure receive strong support from hospital managers

	Frequency	Percent	Valid Percent	Cumulative Percent
Strongly disagree	2	2.5	2.7	2.7
Disagree	5	6.3	6.7	9.3
Unsure	14	17.5	18.7	28.0
Agree	34	42.5	45.3	73.3
Strongly agree	20	25.0	26.7	100.0
Total	75	93.8	100.0	
Missing	5	6.3		
Total	80	100.0		

12.25) The outcomes of the open disclosure sessions I have attended are satisfactory for the organisation

	Frequency	Percent	Valid Percent	Cumulative Percent
Disagree	2	2.5	2.7	2.7
Unsure	11	13.8	14.9	17.6
Agree	41	51.3	55.4	73.0
Strongly agree	20	25.0	27.0	100.0
Total	74	92.5	100.0	
Missing	6	7.5		
Total	80	100.0		

12.26) Overall I think patients' well-being benefits from Open Disclosure

	Frequency	Percent	Valid Percent	Cumulative Percent
Unsure	3	3.8	4.0	4.0
Agree	29	36.3	38.7	42.7
Strongly agree	43	53.8	57.3	100.0
Total	75	93.8	100.0	
Missing	5	6.3		
Total	80	100.0		

Section 3. Open Disclosure policies and practices in your organisation

13.1) The organisation where I work supports an Open Disclosure policy

	Frequency	Percent	Valid Percent	Cumulative Percent
Disagree	1	1.3	1.3	1.3
Unsure	3	3.8	3.8	5.0
Agree	32	40.0	40.0	45.0
Strongly agree	44	55.0	55.0	100.0
Total	80	100.0	100.0	

13.2) The organisation where I work provides education for staff in Open Disclosure practices

	Frequency	Percent	Valid Percent	Cumulative Percent
Disagree	9	11.3	11.3	11.3
Unsure	12	15.0	15.0	26.3
Agree	36	45.0	45.0	71.3
Strongly agree	23	28.8	28.8	100.0
Total	80	100.0	100.0	

13.3) Health professionals worry about litigation if an adverse event is disclosed to patients

	Frequency	Percent	Valid Percent	Cumulative Percent
Disagree	8	10.0	10.0	10.0
Unsure	15	18.8	18.8	28.8
Agree	27	33.8	33.8	62.5
Strongly agree	30	37.5	37.5	100.0
Total	80	100.0	100.0	

13.4) Health professionals worry about their professional reputations if they are involved in an adverse event requiring Open Disclosure

	Frequency	Percent	Valid Percent	Cumulative Percent
Strongly disagree	1	1.3	1.3	1.3
Disagree	6	7.5	7.5	8.8
Unsure	10	12.5	12.5	21.3
Agree	36	45.0	45.0	66.3
Strongly agree	27	33.8	33.8	100.0
Total	80	100.0	100.0	

13.5) The organisation is fearful that Open Disclosure will lead to bad publicity

	Frequency	Percent	Valid Percent	Cumulative Percent
Strongly disagree	4	5.0	5.0	5.0
Disagree	35	43.8	43.8	48.8
Unsure	19	23.8	23.8	72.5
Agree	20	25.0	25.0	97.5
Strongly agree	2	2.5	2.5	100.0
Total	80	100.0	100.0	

13.6) Only severe adverse events are openly disclosed in my organisation

	Frequency	Percent	Valid Percent	Cumulative Percent
Strongly disagree	11	13.8	13.8	13.8
Disagree	34	42.5	42.5	56.3
Unsure	19	23.8	23.8	80.0
Agree	13	16.3	16.3	96.3
Strongly agree	3	3.8	3.8	100.0
Total	80	100.0	100.0	

13.7) Patients are not informed about less severe adverse events involving their care and treatment

	Frequency	Percent	Valid Percent	Cumulative Percent
Strongly disagree	9	11.3	11.3	11.3
Disagree	36	45.0	45.0	56.3
Unsure	20	25.0	25.0	81.3
Agree	13	16.3	16.3	97.5
Strongly agree	2	2.5	2.5	100.0
Total	80	100.0	100.0	

13.8) This organisation acts promptly to set up Open Disclosure of an adverse event

	Frequency	Percent	Valid Percent	Cumulative Percent
Disagree	9	11.3	11.4	11.4
Unsure	16	20.0	20.3	31.6
Agree	32	40.0	40.5	72.2
Strongly agree	22	27.5	27.8	100.0
Total	79	98.8	100.0	
Missing	1	1.3		
Total	80	100.0		

13.9) I am in favour of Open Disclosure of all adverse events to patients

	Frequency	Percent	Valid Percent	Cumulative Percent
Strongly disagree	1	1.3	1.3	1.3
Disagree	5	6.3	6.3	7.5
Unsure	9	11.3	11.3	18.8
Agree	36	45.0	45.0	63.8
Strongly agree	29	36.3	36.3	100.0
Total	80	100.0	100.0	

13.10) In my experience Open Disclosure reduces litigation

	Frequency	Percent	Valid Percent	Cumulative Percent
Strongly disagree	1	1.3	1.3	1.3
Disagree	2	2.5	2.5	3.8
Unsure	33	41.3	41.3	45.0
Agree	31	38.8	38.8	83.8
Strongly agree	13	16.3	16.3	100.0
Total	80	100.0	100.0	

13.11) Open Disclosure practices reduce patients' faith in their health professionals

	Frequency	Percent	Valid Percent	Cumulative Percent
Strongly disagree	13	16.3	16.3	16.3
Disagree	49	61.3	61.3	77.5
Unsure	12	15.0	15.0	92.5
Agree	3	3.8	3.8	96.3
Strongly agree	3	3.8	3.8	100.0
Total	80	100.0	100.0	

13.12) Open Disclosure practices reduce patients' faith in their health professionals

	Frequency	Percent	Valid Percent	Cumulative Percent
Strongly disagree	13	16.3	16.3	16.3
Disagree	49	61.3	61.3	77.5
Unsure	12	15.0	15.0	92.5
Agree	3	3.8	3.8	96.3
Strongly agree	3	3.8	3.8	100.0
Total	80	100.0	100.0	

13.13) Open Disclosure causes patients and their families unnecessary distress

	Frequency	Percent	Valid Percent	Cumulative Percent
Strongly disagree	11	13.8	13.8	13.8
Disagree	49	61.3	61.3	75.0
Unsure	16	20.0	20.0	95.0
Agree	3	3.8	3.8	98.8
Strongly agree	1	1.3	1.3	100.0
Total	80	100.0	100.0	

13.14) Open Disclosure causes health professionals involved unnecessary stress

	Frequency	Percent	Valid Percent	Cumulative Percent
Strongly disagree	5	6.3	6.3	6.3
Disagree	46	57.5	57.5	63.8
Unsure	17	21.3	21.3	85.0
Agree	9	11.3	11.3	96.3
Strongly agree	3	3.8	3.8	100.0
Total	80	100.0	100.0	

APPENDIX H: QUESTIONNAIRE SURVEY - OPEN ENDED RESPONSES

Question 14: Is there anything you would like to change about the Open Disclosure process?

Comment
I think being a bit less dramatic about doing disclosure would make it a lot easier on everyone - it should be treated as part of normal life. Making such a fuss about it ("look at us - we are disclosing!!") makes it much more mysterious than it needs to be.
Yes. It needs to be organisation-wide in training and practice. It needs "clinical champions" throughout the organisation. The trained OD personnel need extra time to do this. It needs to be immediate and at all levels, not just an "OD team" at a later date.
The challenge is to educate staff that Open Disclosure is essential for the benefits of the patients/families and us as a health organisation. There is still a tendency to sweep things under the carpet and a blurred description of what constitute adverse/potential adverse outcome. It is important that we all learn from the many experiences and challenges of conducting OD!
Currently education has been restricted to OD consultants. Brief introductory education given at orientation and HEAPS training. Structured education planning (about 1 hour sessions) required to inform all clinicians of the process and benefits. Other clinicians require more intense training ie. 2 day course offered by PSC.
More clinicians need to be made aware of its value and it should have a structure around it, not ad hoc by people.
Well supported by our executive team.
This is a very timely process that should be regarded as a health procedure. Just like any other health procedure it has risks and benefits and needs to have appropriate training provided […].
I would like it to be routine practice and not names as it is currently.
Unsure of emphasis given in organisation's orientation to new employees - expect would be improved. Unhappy or rather amused at terminology or concept of a "new process" given to what for me and my department has been normal practice for 30 years! It would be nice to have more time for ongoing education and some time for formal training of "trainers".
It is not happening! I did the training - that is the first and last time it has ever been broached. We did a reg information session.
Training of staff
Needs to be part of normal clinical business; NOT a SPECIAL programme.
Difficult to ascertain compliance to Open Disclosure and understanding of Open Disclosure. Providing education has been difficult
More support by the organization for a family that has been caused harm and the ex-gratia payment is not provided.
More timely. More staff especially senior medics educated and involved
Arrangements should be flexible and less prescriptive. One solution is not suitable for all occasions.
Senior medical staff must be more involved where it is left to Registrars and Nurse Managers to resolve and discuss: the patient/client deserves the response from head clinician with ongoing follow-up reassurance. That it is a patient's right to know. If done correctly reduces litigation -->education of the unknown issues regarding ethics, litigation, patients' rights needs to be attended.
Process needs to be "normalised". Immediate disclosure @ point of care, followed up as necessary by a possibly more formal process. Disclosing of all adverse events/errors regardless of level of harm.
More Training and resources for the process
Needs to be formalised and demystified to the "old fashioned" medical practitioners.
No, it is done well. Maybe some more formal training.
More resources to be able to provide education.
I have only been involved with 1 incident - I am unsure of how it is managed.
Ensure costs met for private consultations, investigations, operations etc.
Not at the moment.
One of the very beneficial adjuncts to the verbal meeting is to follow that up with a written piece of correspondence from the hospital to the patient/relatives about the item discussed and the response by the hospital to that/them.

If anything, apply more widely.
Encourage direct and early involvement of caring clinician as soon as possible - delays lead to patient perception of a cover-up.
Increased education for clinical staff would be beneficial. Initiating the process through the position of Executive Director of Medical Services would be more advantageous, rather than via the Patient Safety officers.
Much of the OD focussed on OD training for clinicians. There was no or very little advice or suggested plan for how roll out OD in a large organisation. It was expected or the perception was that the PSO's could just roll it out. No time or resources were available initially (the CD, lanyard swings, posters etc only came online recently). The people doing the education need to be Drs, senior, nurses, not the PSO's and complaint managers/patient liaison etc and yet the staff we trained don't see it as their role. "Someone else more senior should do it."
Education of staff about the process. Briefings prior to and after the meeting.
I think all adverse events that a patient experiences (whether or not the patient is aware of event), should be disclosed to the patient.
Wider range of education activities, eg at orientation or incorporated into appraisals.
Has been working fine in my experience. Very concerned about the development of a "policy" as I think this will ruin current good practice.
We have incorporated Open Disclosure as a normal part of our practice (organisational response) to a sentinel event as well as for other adverse events whether require management at an organisational level. This seems to work well. Open Disclosure is one part of the response to an event and should not be seem as a separate response.
Yes. More practice education and timing for medical staff (especially more senior and prominent staff and support some from managers).
We have adopted the Cognitive Institute method which is quite […]. Timeliness is also still an issue.

Question 15: Are there any other comments you would like to make?

Comment
The effort goes into preparation – the supporting systems need to be in place. Once that is done, the actual disclosure is much easier, and can be done with pretty ordinary skills, provided there is one expert on the team.
I don't think it was right to just choose a small division to trial it. It needs organisation wide acceptance.
I think Open Disclosure gives both parties the opportunity to openly discuss the event and for both to gain an understanding as to why the event occurred and reassure the woman that it has been acknowledged and steps are put in to place to ensure it does not happen again. Both parties gain closure to the event.
Excellent practice that both improves patient trust in health care and leads to positive safety/quality initiatives.
I would like more training.
There is a real need to incorporate debriefing/support sessions for OD trained staff who undertake OD sessions. This is provided for involved clinicians but not necessarily OD officers who may will find the process rewarding but stressful and even traumatic. OD officer peer group review is I think something important to sustainability of an active and engaged OD officer pool.
In regards to question 13.6, 13.7 OD occurs when need flagged for it to occur ie. Incident reported directly for OD. Complaint management, moral obligation. Successful OD is dependant on good communication. Many times OD occurs without formal process →with good outcomes ie as part of clinical disclosure directly by treating team. Rarely able to capture this natural process.
An extremely important issue needs as many staff as possible to understand.
I have attended meetings where incidents and Open Disclosure outcomes have been discussed but I have only participated in one Open Disclosure at this facility. My comment reflects some of my personal feelings about the process. As Open Disclosure becomes the accepted norm I feel the outcomes will be improved.
We need to go forward with eyes open. This is not a panacea. But it is an important element of patient safety.
It should be just part of the way things are done.
I am an invited member of the reference group for the project; my involvement began only 9 months ago when it was realised the group lacked "cross-divisional" representation (from a now "Women's and Babies" section of the hospital). I see my role as providing oversight and critique of the implementation and monitoring of the project.
Understand that "Open Disclosure" is/has been poorly practiced in some specialities. I think this often is due to lack of leadership within departments – units are unaware of it. Non medical staff may likely be not fully aware or even unaware of full explanations given. I feel incensed.

There is a need to inform patient PRIOR to delivery, of their risks, particularly obesity and drug abuse patients. Apologising for events beyond control of the average doctor are unreasonable and do not benefit anyone. Addressing issues such as understaffing and medical input will go a long way to PREVENT adverse issues.
Open Disclosure for everything probably not separate for things which caused harm – makes you more conscious. Makes you to prepare for OD.
1) A sad indictment on society that special programmes like this are needed. 2) You will know that Open Disclosure programme has been successful when there is no need for a special programme! 3) Healthy people, healthy hospitals, healthy societies are only possible when reality is faced (or openly discloses). "Truth fears no question".
I found the QH training (2day) session intimidating and confronting whilst it was realistic (to a degree). I found the "actors" seemed to go "overboard" on their reactions.
QH is developing an excellent program for staff, needs to be further developed for clinicians, however, this will come. I was thrilled to be involved.
We need to learn to speak to the patient. The disclosure involves not ignore and address the families as they speak for the patient. Use correct and understandable language for lay patients and families. Speak the truth.
Open Disclosure should be seen as a cornerstone of trusting relationship between patients and care-givers. Should not be turned into "ritualised" practice. Needs to be balanced by "fair compensation" policy.
It can expose us to unexpected risks but it is still the right thing to do. The political masters need to accept and support it.
Very important! Should be part of medical school and specialty training.
I think it is a good process.
I found it a positive experience with improved care outcomes.
Original education from RACS.
It is/can be a lot of work administratively – it needs to be become not everyone goes home smiling and later some legal action can follow so it does need a reasonable level of executive administrative support.
I think it's an excellent strategy.
Very beneficial to both patients and their families & health care professionals. Support is given to all involved. More education to health professionals would be beneficial.
I believe in the process. It seems to have some benefits for patients and yet not all are satisfied with the process. It needs long term executive support and an implementation plan and resources. If it is only done by the willingness of committed staff already doing a fulltime job its success as a project will be limited. We need to get executive support first, then general education, then training otherwise staff who were trained are not being used early on in the time frame and think it was a waste of time doing the training.
It is a stressful process on staff. More support/education is required
Needs to be more structured. The type/severity of events which prompt an Open Disclosure meeting need to be standardised rather than at the discretion of the health care workers directly involved.
Incorporate as part of normal organisational response to SAC 1 and 2 events. Clinician level disclosure is often sufficient. We have not used our OD peer support group as much as I expected.
Hooray! At last common decency and common sense are promoting after years of medico legal paranoia suggesting to us that you should say "I regret" rather than "I'm really sorry" and "We got it wrong".
I've been very involved in OD since 2002. […] Firstly, "simply saying sorry" is not so simple. Secondly, see OD in the same light as informed consent. It represents a CONTINUUM OF TRUTH which starts from when we first encounter to when we finally depart.

APPENDIX I: INTERVIEW GUIDE FOR HEALTH PROFESSIONALS

UNIVERSITY OF
TECHNOLOGY SYDNEY

OPEN DISCLOSURE QUESTIONS
FOR HEALTH PROFESSIONALS

Before starting the interview I would like to provide you with some background information: a research team from the University of Technology Sydney has recently been commissioned by Queensland Health to evaluate the Open Disclosure pilot program that has been rolled out to 41 health care sites across Australia. This UTS research team will be supported by researchers from the University of Melbourne, and the University of Queensland who will oversee the research in their States. My name is […] and I am from the University of [Technology, Queensland, Melbourne].

This evaluation will seek to provide information about the success of the Open Disclosure pilot. Open Disclosure involves: *clinicians saying sorry to patients and their carers for mishaps they were involved in and informing patients and carers about steps that the organisation will take to rectify the situation and prevent similar mishaps from occurring in the future*.

We are conducting interviews with health professionals and patients and their families who have been involved in Open Disclosure sessions. This is why I am here today: to conduct an interview with you about your views and experiences of Open Disclosure. The interview will take about 30-45 minutes and with your permission I would like to tape the conversation.

1. What is your understanding of OD?
2. Describe to me what the OD process at your organisation entails?
   a. How has the OD Standard been implemented or adapted?
   b. Has the organisation developed an OD response plan?
   c. What types of adverse incidents involve OD?
   d. Who is usually involved in the OD process? Who is the OD Team? Who attends the OD session?
   e. How many people typically are present at the OD meeting? Does this change from the first meeting to subsequent meetings?
   f. How many OD sessions might typically be required for any given case?
   g. Tell me who drives the conversation in the OD meeting? Who says 'Sorry..'?
   h. Is there typically a peer support person for the patient?

3. Are you aware of any type of pre-planning that takes place prior to an OD meeting with the patient/family?
   a. Do those involved determine what to say?
   b. Do those involved anticipate levels of and kinds of emotions to be expected?
   c. Do those involved determine who to invite to the initial OD meeting with the patient/family given the specifics of the case?

4. Describe to me the level, depth and degree of OD Training in your organisation?
   a. Formal training? Informal training? In-house? External?

       b. Is OD Training information-based or mentor facilitated?

       c. How many staff attend OD Training?

       d. How regular is the OD Training?

       e. Has the OD Training been evaluated?

       f. How is information about the process and OD standard disseminated to staff?

5. Are patients/family given the opportunity to record the OD meeting?

6. Is there *any* recording of discussion during the OD meeting – either during or after?

7. Is there any follow-up communication with the patient/family? What?

8. Is there a follow-up Root Cause Analysis? (RCA) If so, who is involved in the RCA? Is the patient/family involved?

9. OD meeting and justice: Tell me about who you seek to advocate justice (as fairness) for?

10. Tell me about any evaluation of the OD process here at this hospital? (not OD Training)

11. What has been your experience in getting clinicians involved in the OD process?

12. What makes the OD process work here at (a) an organisational level (b) a meeting level? Is there a single determinant? How could the process be improved?

13. What do you perceive are the risks associated with OD?

14. What do you perceive are the benefits of OD?

15. What do you think underpins the implementation of the OD Standard here? Why do it?

16. What do you think motivates this organisation to implement the standard?

APPENDIX J: INTERVIEW GUIDE FOR PATIENTS AND FAMILY MEMBERS

UNIVERSITY OF
TECHNOLOGY SYDNEY

OPEN DISCLOSURE QUESTIONS

FOR PATIENTS AND THEIR FAMILY MEMBERS

1. What is your age?
2. What is your gender?
3. Are you the patient, a family member or close friend?
4. What was the main reason why you were admitted to hospital?
5. What were the unexpected harms that occurred to you that led to the OD meetings?
6. When were you first made aware the unexpected harm was done to you?
7. How did you feel when you were told that unexpected harm was done to you?
8. Did you feel that health professionals had been open and honest with you?
9. Did you feel listened to and all your questions answered. Were the answers explained to you in simple English?
10. What supports were you offered and received? What did you need?
11. What notification did you get about the meeting? When, where, duration, attendees, how much notice
12. Were you involved in an RCA and notified of the findings?
13. How serious was the unexpected harm that occurred to you or your relative or friend (very serious, serious, somewhat serious, not serious, not very serious)?
14. How many Open Disclosure meetings have you attended where a doctor or another health worker spoke to you about the unexpected harm that occurred in hospital?
15. What type of health professionals were present at these meetings? (doctor, nurse, pharmacist, other)?
16. How useful did you find the meetings in dealing with harms that occurred to you or your relative or friend?
17. How involved have you felt in relation to health professionals' interactions with you since your unexpected harms were found?
18. Do you see Open Disclosure as a useful approach to acknowledging errors in care to patients and their families? In what ways?
19. Have you found the outcomes of these sessions satisfactory? In what ways?
20. What did you like about these meetings?
21. What did you not like about these meetings?
22. Is there anything you would like to change about the way the meetings were carried out in the hospital for you or for your relative or for your friend?
23. Are there any other comments you would like to make about open disclosure?

APPENDIX K: 1st ACADEMIC PAPER PREPARED FROM THIS RESEARCH

The paper reproduced below has been prepared from this research, with another draft manuscript (focusing on the specifics of learning to apologise using 'real play') close to finishing. The paper below is being presented at the International Communication Association in Montreal, May 2008, and will be submitted (with permission from Queensland Health and the Australian Commission for Safety and Quality in Health Care) as part of a special issue of the *Journal of Language and Social Psychology* on health communication, due out 2009.

Title:

A New Structure of Attention? Open Disclosure of Unexpected Clinical Outcomes to Patients and their Families

Abstract:

This paper presents an inquiry into the enactment of a health policy reform initiative that is being adopted in a number of post-industrial nations: Open Disclosure. Open Disclosure mandates that discussions with patients/family and team staff about unexpected clinical outcomes or 'adverse events' are now no longer ad hoc, individualized and without consequences for how the work is done, but planned, collaborative and leading to system change. We review policy and research literature that describes Open Disclosure as intending to promote 'open and honest' discussions about adverse events with affected patients, families and with staff involved or implicated, while at the same time constraining how these discussions are enacted. We then present an empirical analysis of a corpus of interviews about the impact of Open Disclosure on clinicians' practices. Our article situates Open Disclosure in the context of arguments that health care workers are increasingly expected to do 'emotional labour' with patients and their families. A significant component of the disclosure of adverse events, the data reveal, is that staff need to practise 'reflexive listening' as a means of managing patients' and family members' anger and distress in response to incidents. In exploring the relevance of the 'emotional labour' thesis to the empirical data, the article elaborates two alternative scenarios that such skills and their targeted training entrain. First, the analysis suggests that thanks to the intensity of Open Disclosure interactions, clinicians may be introduced to an affective-interactive space which they were hitherto unaware of and unable to enter. The new practice of reflexive listening may be a means enabling staff to appropriate a more reflexive stance towards themselves, or attain what Thrift calls 'a new structure of attention' (Thrift, 2004a). The often recommended 'partial apology' (cf. Vines, 2005) may only secure 'cheap grace' (Berlinger, 2003) and fail to achieve the emotional dialogue that patients and staff require. Yet the need to manage medico-legal risk results in proceduralised rules for staff. So secondly the analysis suggests clinicians may be empowered by reflexive listening to handle emotional situations; but they now also hold the burden of ethical application of these skills.

A New Structure of Attention? Open Disclosure of
Unexpected Clinical Outcomes to Patients and their Families

Introduction

This article explores the complexity and practical implications of a policy that is gradually being taken up by health departments around the globe. This policy, usually referred to as 'Open Disclosure', is the focal point for a complex array of interests and intents. At minimum, Open Disclosure involves: 1) an explicit statement that an unexpected clinical outcome (or 'adverse event') occurred and a basic description of what happened, 2) an apology or expression of regret, and 3) an investigation of and intervention in work processes in order to prevent recurrences (Gallagher, Waterman, Ebers, Fraser, & Levinson, 2003: 1006). Adoption of Open Disclosure is strongly advocated by those who have deployed it in practice (Woods, 2007), as well as by those for who regard confession and forgiveness as central to recuperating trust into the clinician-patient relationship (Berlinger, 2003). In addition, disclosure of adverse events to patients and families is said to reduce the numbers of patients making complaints and pursuing litigation (Lamb, 2004). In support of this latter argument, some insurance companies have begun to pescribe Open Disclosure in their contracts with health providers (e.g. COPIC, 2004)[1]. However there is also some anxiety about new financial risk due to the chance that Open Disclosure prompt legal cases rather than just averting them, given the large number of incidents that currently remain undisclosed (Studdert, Mello, Gawande, Brennan, & Wang, 2007; but see Wakefield, Jorm, & Ryan, 2007). Nevertheless, governments and policy makers have no option but to reconcile the public's right to know with the dangers and costs incurred by hospitals' growing clinical-technical capability.

Aside from its focus on adverse events, the *tenor* Open Disclosure – honesty between clinicians and patients - is not novel. Thirty years ago in the West open discussions about people's end of life were rare (Glaser & Strauss, 1965). Now, they are the norm (Seale, 2000) in part thanks to medical training focusing on communicative strategies that enable clinicians to break bad news (Buckman, 1992). In a sense, Open Disclosure pushes this practice of sharing medical-clinical knowledge with consumers of health care to the limit: discussions with patients/family and team staff about adverse events are now no longer ad hoc, individualized and without consequences for how clinical processes unfold, but planned, collaborative and lead to carefully evaluated work process changes. Open Disclosure shifts these discussions from the conventional practice of informing patients and family members about the occurrence of a 'known risk' or 'a complication', towards involving health care consumers in discussing and (to a degree) resolving unexpected outcomes, particularly if these include clinical errors and incidents.

Open Disclosure originated in the late 1980s at the Veterans Affairs (VA) Medical Centre in Lexington, Kentucky. Following a string of legal costs and pay-outs totaling more than US$1.5 million (see Kraman, Cranfill, Hamm, & Woodard, 2002), "administrators [there] decided to adopt a more pro-active policy in medical cases that had the potential to result in litigation" (Woods, 2007: 81). Results of the VA Open Disclosure trial appeared to confirm that honesty and organizational risk management are not mutually exclusive (Kraman & Hamm, 1999). The approach has since been refined into detailed policy guidelines across different jurisdictions, including Canada, the U.K. and Australia (e.g. Health Quality Council of Alberta, 2006; National

---

[1] It remains unclear from the COPIC materials, however, whether it is the admission of liability and settlement or the grief management, or both, that lead to the positive results reported to flow forth from Open Disclosure.

Patient Safety Agency, 2005). The Australian *Open Disclosure Standard* is typical, balancing prudent risk managerial with moral and restorative justice (Australian Council for Safety and Quality in Health Care, 2003).Thus, policy makers in a number of countries have begun to mandate that health organizations become involved in revealing and apologizing for clinical-medical shortcomings.

The present article will consider how frontline staff are positioned to engage with this requirement for honesty. Following a review of the literature, the article[2] presents an analysis of interviews done with clinicians involved with 'doing' Open Disclosure with patients and family members. These analyses show that Open Disclosure constitutes a complex set of potentially contradictory demands, including: encouraging clinicians to adopt communication skills (such as 'reflexive listening'); the ethos of not blaming colleagues or the organization; as well as, a personal responsibility to risk manage adverse events for the organization. Our conclusion suggests that the openness Open Disclosure mandates into being suspends clinicians between the institutional apology as merely 'cynical civility' (Vines, 2005), the inclination to engage with and advocate for consumers' anger and distress, and the organizational imperative to ward off or control complaints and litigation.

Open Disclosure: Research and Policy

The central challenge of Open Disclosure is the requirement to disclose information about adverse events to people who are physically injured and psychologically affected by those adverse events. There is both a difficulty of accessing actual instances of Open Disclosure and a dearth of experience among clinicians enacting Open Disclosure according to the recently produced guidelines. Therefore much research reports on how clinicians *would* or *should* respond if finding themselves in the situation of having to share with patients and their families information about adverse events, and how patients (families) *may* respond in return (Chan, Gallagher, Reznick, & Levinson, 2005; Liebman & Hyman, 2004; Mazor, Reed, Yood, Fischer, Baril, & Gurwitz, 2006). Gallagher and colleagues' work is often cited as it reveals disjunctions between what patients expect following incidents and what the doctors involved would be prepared to provide (Gallagher, Garbutt, Waterman, Flum, Larson, Waterman et al., 2006; Gallagher & Lucas, 2005). Among other things, patients' in-principle views about when to deploy Open Disclosure are found to be broader than those of doctors. For these patients an apology is desirable where for doctors apologizing remains a source of (legal) concern; patients expect full disclosure of what happened while doctors would "choose their words carefully", and where patients valued truth and compassion, the doctors valued truth, objectivity and professionalism.

There are however some reports from individuals, such as Woods (2007), who base their findings and advice on personal experience, or on interviews with people who have experienced incidents and their disclosure (Berlinger, 2005). Having been sued as a surgeon, Woods recounts how he was shocked into becoming more attentive to how he communicates with patients. Woods' stance is of interest here, not just because he articulates a strongly moral-philosophical view, but also because his book *Healing words: The power of apology in medicine,* published by the prominent US Joint Commission[3], is now in its 2nd edition and has already been translated into several languages. Woods sees Open Disclosure as in the first instance providing a moral framework for

---

[2] This paper is the first in a series that reports on the national evaluation of Open Disclosure practices in Australia. The research is funded by the Australian Commission for Safety and Quality in Health Care and managed by Queensland Health. Ethics approval was gained from 32 Human Resource Ethics Committees around Australia. Details of these approvals is available upon request.

[3] The Joint Commission is a governmental organization that accredits health services in the USA and provides clinical practice improvement consultancies and resources.

healing a damaged interpersonal relationship. Accordingly, it is crucial for him that the disclosure and the apology are genuine and not beholden to a risk management logic.

> If risk management (that is, claims avoidance) is the primary focus, the end goal, in essence, is to manipulate the provider-patient relationship to the organization's advantage, not because the patient is intrinsically important as individual. As I have noted time and again, risk management benefits cannot be pursued as the reason for apology and disclosure. Rather, risk management benefits naturally ensue as a by-product of maintaining the relationship. (Woods, 2007: 37)

Berlinger's account brings together the experiences of clinicians involved in incidents and of consumers affected by incidents (Berlinger, 2005). Her book seeks to balance acknowledging clinicians' pain and distress following the realization of having contributed to a patient's harm, and patients' right to disclosure and restorative justice. She concludes:

> Physicians may think of themselves as less powerful than injured patients and their families if they have been taught to view such patients and families as angry adversaries and potential litigants. But in the physician-patient relationship, the physician is always the more powerful actor, whether or not she is comfortable with that role. The injured patient, moreover, has been rendered more, not less, vulnerable as a result of his injury. Already vulnerable as the result of illness or other impairment, he has been harmed by those he entrusted to help him. Keeping these uncomfortable truths in mind may help physicians to respond to injured patients and their families with humility and compassion rather than fear and suspicion. (Berlinger, 2005: 102)

For their part, Open Disclosure policy and guidelines inform staff they should disclose within the existing constraints of error management. This is evident in how this documentation privileges the expression of regret ('we are sorry this happened') over the more legally risky 'full apology' ('we are sorry we made an error'). Except for guidelines issued in Alberta (Health Quality Council of Alberta, 2006), jurisdictions require staff to apologize in ways that avoid admitting fault and incurring legal liability. For example, exemplary statements offered in Queensland Health documentation include "I am very sorry for all the distress that you have had as a result of this incident" and "Everyone in this organization is very sorry that this terrible event has happened to you" (Queensland Health, 2006a). Other Open Disclosure Guidelines provide discursive examples of apologies that avoid both legal liability and mutual blame. Thus, "Your husband … was given an injection of penicillin shortly before his death. There were notes in his medical records that he was allergic to penicillin, but the person who gave the injection did not see the notes. We are sorry about this incident" is acceptable, while "The nurse knew your husband … was allergic to penicillin, because it is written all over the notes, but she gave him the injection by mistake that caused him to have an anaphylactic reaction, from which he could not be resuscitated. We are very sorry about this incident" is not (NSW Health, 2007: 11)[4].

---

[4] The second unacceptable example differs from the first in that it encompasses causal specificity ('because'), personalization ('the nurse'), attribution of mental process ('[the nurse] knew'), and a judgment ('by mistake').

A desire for prudent risk management would also appear to underpin much of Open Disclosure guidelines' detailed advice about how to pre-plan and structure incident disclosure, to prevent diverging versions of what happened circulating and causing confusion. Thus, the documentation insists on staff following a sequence of 'moves' that follow on from the opening apology: asking the patient about their experience, answering their questions honestly, informing them about what the organization will do (investigate), and conducting the post-investigation feedback meeting. It is evident however from the emphasis given to it that a crucial component in this sequence is creating space for the patient's (and family members') response. In one set of training materials, for example, the following wording is provided to ensure this happens: "There must be many questions that you would like to ask us. We have as much time as we need so please ask us what you need to know" (Queensland Health, 2006a). This shows that Open Disclosure guidelines, besides constraining the disclosing clinician(s) to particular kinds of language and disclosure moves, also can prescribe handing a modicum of control over the disclosure meeting to the patient (and family) to ensure they can articulate their distress and anger: "Being listened to is an important stage of healing and moving on" and "Being able to tell your story and express your concerns to a considerate and attentive listener is therapeutic" (Queensland Health, 2006a).

These considerations show that adverse event disclosure opens up a complex interactive domain. To be sure, Open Disclosure is inscribed into a carefully designed set of dialogic stages and procedures, but at least one of its components is defined in terms of a shift of control from clinician (organization) to patient (and family). In order to illuminate how clinicians experience and enact the disclosure interaction, let us turn to our analysis of 120 interviews with staff across Australia who have participated in Open Disclosure. As our analysis will show, Open Disclosure is discussed in terms of confronting clinicians with having to resolve the tension between controlling risk and the volatility of in situ interaction.

Data and Methodology

We conducted one hundred and twenty interviews with clinicians who have done Open Disclosure. These interviews were collected as part of a national evaluation of Open Disclosure funded by the Australian Commission for Safety and Quality in Health Care. The interviews were transcribed and discourse analysis (Iedema, 2007) used to …. and results were collated in two reports to provide guidance for Australian policy makers on further recommendations for the implementation of Open Disclosure.. For the purposes of the present paper, the interview data is re-analysed to draw out information about how interviewees talk about Open Disclosure as interactive and affective practice. The data is presented under three headings: pre-planning of the Open Disclosure meeting; saying 'sorry' - navigating between liability and apology, and turning on the power of reflexive listening.

Pre-planning of the Open Disclosure meeting

General advice emphasizes the importance of the Open Disclosure pre-planning meeting which is to take place before staff sit down with the family and the patient to formally disclose the adverse event (Liebman & Hyman, 2004; Queensland Health, 2006b). The purpose of the pre-planning meeting includes: establishing the facts of the adverse event as much as possible, thinking through who was involved in the incident and whether that person or persons should be involved in the disclosure, gathering information about the patient and the family (through the patient liaison officer and other sources), and rehearsing what to say during the open disclosure conference. As the first quote below bears out, an important component of pre-planning is preparing for the emotional dynamics of the patient and family members:

Extract 1 (Patient Liaison Officer [NSW27])

"If there's an actual loss of life, you can bet your bottom dollar, there's going to be a myriad of emotions that all come from, you know, wherever those individuals were in, in that person's life, you know? Um. So you're dealing with a bit of bereavement, uh, in all possibility in those circumstances, so it doesn't hurt to have a little bit of knowledge about how people grieve, that sort of thing. But there's usually, there's usually clues. I mean, if you're going into a situation cold turkey, it would always do you a lot of good if you can talk to some of the staff that have been dealing with that family, because they wouldn't have been left out on their own. They would have had some of the staff dealing with them, they may have had a social worker brought in, or… So you tap into those people that have had interaction, and try and pick up some information from them. If not, it it does boil down to a bit of your old body language and, and try to put yourself in their position I think, and try and understand how they might feel."

Besides trying to envisage patients' and family members' emotions, the pre-planning meeting also needs to assess the attitude of the clinicians whose actions may have contributed to the adverse event, and who may have been asked (by the consumer) to attend:

Extract 2 (Anaesthetist SA [pp])

I talked to the anaesthetist and said that having done the Open Disclosure that I felt that certain things were important and perhaps we could …, he was in agreement that perhaps we could interview that particular way so I did guide it in the sense that I put forward the initial point to saying sorry without taking blame. And then I sort of led him to say to allow the patient to express how she felt. So, we did discuss how it would probably be best to go and if there were incidences where he was starting to butt into what the patient was trying to say I would sort of go and sort of say *Perhaps we get to that later*. Because the problem is sometimes when someone's being involved themselves they want to explain all the time."

Pre-planning for Open Disclosure, then, is a crucial strategy that prepares disclosers for the intensity of grief, distress and anger experienced by consumers, and for the degree of intransigence harboured by colleagues who have trouble 'understanding how they [the patient/family] might feel'. As the following interviewee explains, many of these tactics are now incorporated into daily practice to pre-empt problems:

Extract 3 (RN [Vic 141])

"I mean, years ago our consultants would say, 'Well, make an appointment and if it suits me', you know, that's passé now, you know, for example, the day starts with the night person handing over to the morning team, right, and that includes physiotherapist, liaison nurse, me, you know, a whole lot of people and we start our morning by looking at x-rays with just a quick overview of the patients and then we have a detailed bedside-to-bedside which can take hours, but at that x-ray meeting, that's when I break away and we discuss any incidents that have occurred and, 'What are the family aware of?', 'Do we need to talk to the family?' and then we'll say, 'Well, look, I'm free', the doctor will say, 'Look, what about two o'clock, can you arrange for the family to come in at 2 or 3 or before 5 or whatever', and so that's a common daily activity."

These interview responses show that a lot of groundwork takes place before the Open Disclosure session happens, and that everyday practice may be changing in recognition of the importance of the practice of disclosure. This groundwork is oriented not purely towards establishing the 'facts' of the incident. It is also about appraising or 'qualculating' (Thrift, 2004b) affective responses and intensities on the part of those involved, and possible ways of dealing with them. This involves those leading the disclosure in a complex kind of 'emotional labour' (Hochschild, 1983): preparing oneself for consumers' and colleagues' affects, and devising strategies and discursive maneuvers that may help change their course.

'Saying sorry'

When the Open Disclosure session happens, the affective dynamics presaged in the pre-planning phase are enacted in real time. In some cases, this translates into a pragmatic use of the apology:

Extract 4 (Patient Liaison Officer [NSW 27-31])

"Um, you, you sort of go in and and, you know, obviously you're thanking people for being there blah blah blah, explaining why you're there, and and, and then at that time, it's appropriate for the first, sort of apology, I think. You know, to say, look, you know, I'm really so sorry that we're here under these circumstances or, or whatever, you know. It, it's hard to have a proper script in those situations because you have to evaluate the people that you're dealing with. You have to really make a snap judgment to determine how best to determine the information that you want to give them."

This interviewee intimates the task is manageable, even though patients 'can sense' whether those doing the disclosing are 'pulling wool over their eyes':

Extract 5 (Midwife nurse [SA 70])

"For the most part…I think most patients, most people are fairly sensible people and they know if you're pulling the wool over their eyes. They just want you to be honest and if something's happened they want you to be able to say, 'Look, this has happened. Perhaps it shouldn't have, or for whatever reason, this is what's happened.'"

The next interviewee is more explicit about the tensions that result from having to disclose adverse events, manage legal risk, and be genuine. For this interviewee, Open Disclosure raises a serious ethical dilemma:

Extract 6 (Director of Clinical Governance [NSW 8])

"I know, it's a very hard judgment, but um, this family have grieved, they've understood what's happened, and now we're going to go back to them and say, 'Well, I'm sorry but actually this is what happened', and so it's a tremendously difficult dilemma, ethical dilemma for some of these issues as to what we do. I mean we tend to err on the side of disclosure but …"

This dilemma is exacerbated by having to face up to the anger and distress of victims of adverse events, and having little choice but to 'share their pain':

Extract 7 (Director Health Service [Qld 142])

"…when you're actually there, and in the hot seat, and … and … and explaining, um even though I haven't been directly involved in the incident, but it … it's still a very emotional, draining, stressful situation that you … you actually go through, and, you really have got no idea. When you walk into that meeting, all it's left up to is … is your good communication skills, and um … and you know, and how reasonable is the family that you're dealing with? And again, you could be very reasonable people in normal times, but you know, they're … most people are going through life-altering um change, and it's a crisis, they're in crisis, and um you don't really know how the people are going to react, so … so that's what sharing the pain is about."

By sharing the pain, we surmise, this last interviewee means being genuinely receptive to what patients and family members are experiencing. But how can those doing the disclosing and the apologizing 'share the pain' and not lose sight of the boundaries beyond which one is exposing oneself to legal liability and threat to organizational reputation? This brings us to the third component of our analysis: the space that disclosure creates for patients and family members to take the floor, affectively speaking, and for staff to practise the skill of 'reflexive listening'.

Reflexive listening

As its simulation training emphasizes, Open Disclosure involves the deployment of reflexive listening (Queensland Health, 2006a). Reflexive listening is a technique described in Gerald Eagan's *The skilled helper* (Eagan, 2006), a book that for decades has helped inculcate psychotherapeutic skills in therapists, counselors and clinical psychologists. In the context of Open Disclosure in Australia, reflexive listening is taught by involving trainees and actors in simulating emotional confrontations.

> **Extract 8 (Doctor [SA 34])**
>
> **Interviewee**: "And I would go and say that before I did the course I would go in there and say *Sorry*. I would say *I did*. I would do that and I would take the responsibility and I've just been lucky enough that there hasn't been that serious. But *I did to you*, that is not right and I can see that now. And then I want to explain, I need to tell you what's happened because I feel terrible. And what the process teaches you is that stop thinking about yourself for one minute. It is not all about me. Step back and say 'what about you?'."
>
> **Interviewer**: So, you moved … from a provider focus to patient focus?
>
> **Interviewee**: "Absolutely."

The doctor quoted in extract 8 describes their mind-altering experience of simulating the disclosure of an adverse event scenario with an actor. While this is the strongest statement found in the interview data, many other interviewees confirmed that the main impact the training had on them was 'to learn to be silent' in the face of anger and distress. The person quoted in extract 9 describes how this technique enabled her to deal with one particular patient's anger:

> **Extract 6 (Nursing Manager [Qld 77-8])**
>
> "Um, one of the things they were very angry and it took quite a while for them to just, you know get rid of their anger, um, I guess one of the things that I had learned which I probably wouldn't have done before the training, um, I didn't try and interrupt them or stop them from talking. I didn't try and deflect the blame because they were wanting to blame somebody, they were wanting to know the name of the nurse that was suppose to be looking after him. You know who'd turned their back or, or whatever, um, so you know, for 25 minutes, they ranted and shouted and were very um-scathing of, of the service. Um, I guess at the end of that, when they finally came, they were just getting tired from being so angry, um, I basically said look, I, I really just apologised and said, you're right. …"

Remaining silent creates interactive room for the patient and family members to vent their emotions. As they use the silence to articulate these emotions, they are reassured that their emotions are legitimate, they are enabled to let their emotions run their own course, and they gain the opportunity to re-experience and thereby disentangle themselves from those emotions (Eagan, 2006). Paramount to this process is that reflexive listening on the part of the listener counter-acts the dialogic intensity that speakers' emotions entrain.

But on occasions silence alone will not do. In extract 7, the interviewee recounts how they saw no option but to accept responsibility for what happened under pressure of victims' anger.

> **Extract 7 (Director Health Service [Qld 123-4])**

> "Yeah. And um so he said look, you know, I mean this is not fair, somebody hurt my baby, and you're not going to tell us who it is? You know, we are going to go to Freedom of Information and find out, we can easily find out. So I said look, [name father], I mean the one thing …? I said look, if you really want to blame somebody, I'm very happy for that to happen, you can blame me. I'm the consultant here, looking after the show, I am responsible if something happens, and that's why we are in this room, having this discussion. And that's why I've been honest with you to say it has happened, and we are sorry that it happened. We promise you that we will look into all the things, and as soon as we find out all the lessons we are going to learn from it, we will come back to you and [name mother]. But yes, if you want to blame somebody, you can blame me. And the first time I list this, because we knew the child through the [?] so look, oh no, well it's not fair, you were not involved. I said but yes, I am involved."

In this instance, the clinician bends under pressure of the victim's anger and accepts responsibility. This, they say, produced 'a breath of fresh air':

Extract 8 (Director Health Service [Qld 124])

"And you know, ah it was one of the most dramatic experiences I ever had. As soon as I offered that [statement about taking responsibility for the adverse event] to them, it's almost like there was a breath of fresh air coming into this room, you know, and you really - you could see him physically change, you know? … His tone changed, his body language changed, and he was like saying you know, things like so where … where do we go from here? You know? So that to me, was a very eye-opening experience, very."

Another clinicians describes their experience of how 'venting' can lead to reconciliation:

Extract X (Medical Superintendent [Qld 164])

 "Nonetheless, the opportunity to ventilate for the family, the mum when she went out, [name daughter] was still angry. She was not happy at all, but the mother who had left the room at one stage in the proceedings and, um, I think the mother went out for a fag, so I left her out there for a while then said to [name daughter], when I thought she could have finished her fag, '[name patient], go get your mum', and she came back and the thing sort of rolled on from there. And on the way out [name daughter] said, [name mother] said, after ventilating quite a lot of emotion, 'Mostly I'm really very nice. I'm not always like this.'

These interviewees' comments show that Open Disclosure is considerably more than revealing adverse events to patients and uttering a controlled apology. These interview responses suggest that Open Disclosure is in the first instance an *affective* practice. Clinicians doing the disclosing need to intuit patients', family members' and colleagues' reactions to adverse events; they need to be able to 'read' who among the staff are going to be defensive and intransigent, and the disclosers themselves need to be able to 'sit on their hands' as well as intervene strategically into how these emotional dynamics play themselves out. Indeed, in managing the affective dynamics among the different stakeholders, disclosers are charged with creating what Thrift calls an 'on-demand environment' (Thrift, 2004a).

A New Structure of Attention?

As noted in our overview with which we began our article, Open Disclosure is a complex domain of health reform. Its policy brings together numerous discourses, including clinical medicine, health services reform, legal justice, restorative ethics, risk management, patient safety, incident investigation, clinical quality improvement, and insurance and indemnity pay-out minimization. There are strong tensions among these discourses, and these are left for the frontline employee to resolve while in conference with the victims of incidents. In the knowledge that these meetings can be volatile interactive spaces, Open Disclosure policy and training advise staff to limit their apologies to expressions of regret, and reassure victims that a satisfactory explanation will be

forthcoming, as well clear and realistic change management plans to prevent the incident from reoccurring.

As the interview data demonstrated, however, the affective work that clinicians need to do to realize this practice is considerable. They move precariously among the limits dictated by their lawyers, the proscriptions inscribed into their insurance contracts, the policies put out by health departments and health care organizations, and patients' and family members anger and despair. Open Disclosure counsels against legal advice of the last few decades by adopting the principle of openness, but the way this openness is enacted will determine whether it is promoted to ward off complaints and litigation, or whether it is indeed able to achieve restorative justice for victims. It is at the heart of disclosure as interactive practice that these matters are decided: are disclosers able to deploy their reflexive listening training without mobilizing it for the purpose of silencing victims? Woods, who we cited earlier, has strong views on the matter:

> Authentic listening is not a technique. It is centered in compassion and in a concern for the other person that goes beyond our self-centered needs. Listening authentically is centered in the principle of psychological reciprocity: To influence others, we must first be open to their influence. (Woods, 2007: 119)

Woods is skeptical about attempts to up-skill frontline clinicians in 'error communication' that centres on enunciating 'appropriate apologies' (e.g. Liebman & Hyman, 2004).

> … policies that try to choreograph what providers can and cannot say, as malpractice insurers seem interested in doing … [amount to] an attempt to micromanage the provider-patient relationship – to control communication – and I believe this can paradoxically drive a wedge between two people at a time when it is most critical for honest, respectful, transparent communication and where apology is the norm. As long as organizations continue to treat apology and disclosure as a risk management strategy, instead of an authentic attempt to help providers maintain trust and enhance the provider-patient relationship, they will continue on their path to ineffective results. They will never maximize risk management benefits because their intent is wrong. They're trying to do the right thing for the wrong reason." (Woods, 2007: 37)

Nevertheless, towards the end of his book, Woods sets out discursive examples of what he regards as realizing authentic communication. In situations where clinicians are facing angry patients/families, he recommends that they use language such as that reproduced below (italics in original):

> *I see that you are angry. I would like to take a few minutes to reflect on my performance and how it has led to the current situation. Let me think this over so I can respond thoughtfully and accurately to your concerns and offer an appropriate apology.* (Woods, 2007: 74)

Woods is equally specific about non-verbal body practices and how they play a role in conveying authenticity: *"sit down within touching distance"; "Look at your patient"; "To be effective, your body language must be in synch with your words and tone of voice"*. It would be easy to be critical of this scripted authenticity. But for Woods, we suspect, these discursive recommendations are intended to provide an entry point into what Thrift would call 'a new structure of attention', enabling frontline clinicians to begin to 'hear' patients (families) in ways they have not been able to do before. This reflexive element is at the centre of Woods' book, with the authentic apology functioning as a reconfirmation of the fiduciary morality that underpins the doctor-patient relationship.

On a broader front, it seems undeniable that the adverse event, conventionally regarded as part and parcel of the 'known risks' of health care provision, has now shifted into a space where the public's right to know requires it to be revealed, investigated, turned into learning, and prevented in future. Contributing to this shift in a major way, Open Disclosure is a policy reform initiative that intervenes in the communicative contours of clinicians' obligations to patients and in the interpersonal complexion of their relationships with those who experience adverse events. Open Disclosure tries to spell out what experiences staff are to produce for patients/families following an incident, drawing on and designing affect to restore the service's credibility, control, and confidence. Revealing the inevitable tensions that are at its heart, Open Disclosure is intended to generate an interactive space whose affectivity and intensity are at once deliberately engendered and yet carefully managed by the partial apology and limited disclosure (eg the junior doctor's name is not given).

Framed thus, Open Disclosure is no longer co-extensive with conventional clinical-professional training, where communication ensures that sufficient amounts and appropriate types of information are exchanged to ensure smooth unfolding of the clinician-patient relationship and achieve optimal outcomes for both the service (provider) and the patient. Communication, in the conventional mode, centres on performing emotional labour to achieve pre-circumscribed outcomes: 'a satisfactory explanation', 'release of victims' anger and venting of their grievances', 'reassurance that the organization will take steps to prevent reoccurrence', 'communication follow-up to demonstrate changes made to the service'. Here, of course, the term emotional labour can harbour a utilitarian accusation: emotion is communicatively *produced* to achieve a pre-determined outcome or to satisfy the expectations of others (Taylor, 1998); it is not (meant to be) *experienced* through the immediacy of human co-presence.

But it is here that the interview statements presented above are most revealing. As the interviewees confirmed, their planning of Open Disclosure sessions could never guarantee that the disclosure would go as envisaged. They were clear that they were not able to direct the meetings, come in with pre-scripted lines, or impose their views of what was just, correct and right. Examples demonstrated that the affective intensity of the meetings may override any control the clinicians might want to retain over the interaction. The only tactic left for them was 'to sit on their hands and listen'. In effect, in disclosing incidents they found themselves engaging with patients' and family members' feelings, 'sharing the pain', and creating an acceptable affective outcome for those who had been hurt by their care.

Conclusion

The literature reveals tensions at the heart of Open Disclosure among clinical, legal, indemnity, moral and organizational discourses. The analyses presented above reveal a further tension between the abstract intents of these various discourses and the volatile nature of the in situ interactions that Open Disclosure policy implementation can call forth. Will more litigation be the result, or will the interpersonal intensity of disclosure predispose consumers towards reconciling themselves with the limits of their health care system? Consumers may accept the emotional tokens of sorrow extended to them by staff as valid, or they may reject staff's emotional labour in expectation of a genuine, more tangible apology. Open Disclosure policy privileges the 'partial apology' (cf. Vines, 2005) and thereby risks being granted 'cheap grace' (Berlinger, 2003). However, the intensity of communication that clinicians are having to face, described in some of the interview statements above, makes it difficult to fully reduce this initiative to a 'cynical civility' (Vines, 2005).

Over and above the emotional labour that has conventionally characterized clinical work with patients, clinicians are encouraged and enabled by this health reform to pay reflexive attention to how they engage with others' concerns, feelings, and expectations, without immediately questioning or rejecting their relevance. With this rise in emphasis on communicative ability and reflexive listening, the criteria for clinical success and failure may indeed have begun to shift from technical skill criteria towards communicative acumen: is the clinician able to provide 'patient-centred care', appropriately break bad news, and, now, conduct honest and open discussions with each other and with patients and families about complications and incidents, as well as handle the emotional fall-out from those encounters?

Open Disclosure confronts staff with the consequences of incidents for patients/families, and thereby potentially perturbs existing identities and prevailing communication practices. As argued, Open Disclosure may engender a new structure of attention on the part of clinical professionals, and this may well mark the beginning of a new level of acceptance and insight into the limits of health care on the part of the public. Something like – need more time data to tell yes!. It is true that the Open Disclosure literature contains considerable procedural advice and attention to the constraints of risk management (Cantor, Barach, Derse, Maklan, Wlody, & Fox, 2005; Fein, Hilborne, Kagawa-Singer, Spiritus, Keenan, Seymann et al., 2005; Liebman & Hyman, 2004). Yet in offering this guidance, this literature is nevertheless united on what is at issue here: "physicians and other health care professionals [have to] develop an awareness of the communication skills most likely to be useful during disclosure conversations" (Liebman & Hyman, 2004: 24). For our subjects Open Disclosure interactions engendered real emotions and risk; this new affective space could not be predictably controlled and there was tension between procedural requirements and the ethical obligations introduced by reflexive listening. Our analysis therefore uggests new communication awareness extends from knowing facts and formal constraints to being heedful to the dynamics of affect-charged social interaction. [5]

---

[5]

References

Australian Council for Safety and Quality in Health Care (2003). Open Disclosure Standard: a national standard for open communication in public and private hospitals following an adverse event in health care. Canberra: Commonwealth of Australia.

Berlinger, N. (2003). Avoiding Cheap grace. *Hastings Center Report*, 33(6), 28-36.

Berlinger, N. (2005). *After harm: Medical error and the ethics of forgivenness* Baltimore: Johns Hopkins Press

Buckman, R. (1992). *How to break bad news: a guide for health care professionals* Baltimore: The Johns Hopkins University Press

Cantor, M.D., Barach, P., Derse, A., Maklan, C.W., Wlody, G.S., & Fox, E. (2005). Disclosing adverse events to patients. *Joint Commission Journal on Quality and Safety*, 31(1), 5-12.

Chan, D.K., Gallagher, T.H., Reznick, R., & Levinson, W. (2005). How surgeons disclose medical errors to patients: A study using standardized patients. *Surgery*, 138(5), 851-858.

COPIC (2004). COPIC's 3R's Program. *COPIC Newsletter*, 1(1).

Eagan, G. (2006). *The Skilled Helper: A Problem-Management and Opportunity-Development Approach to Helping* New York: Brooks/Cole

Fein, S., Hilborne, L., Kagawa-Singer, M., Spiritus, E., Keenan, C., Seymann, G., Sojania, K., & Wenger, N. (2005). A conceptual model for disclosure of medical errors. *Advances in Patient Safety*, 2(2005), 483-494.

Gallagher, T.H., Waterman, A.D., Ebers, A.G., Fraser, V.J., & Levinson, W. (2003). Patients' and physicians' attitudes regarding the disclosure of medical errors. *Journal of the American Medical Association*, 289(8), 1001-1007.

Gallagher, T.H., & Lucas, M.H. (2005). Should we disclose harmful medical errors to patients? If so, how? *Journal of Clinical Outcomes Management*, 12(5), 253-259.

Gallagher, T.H., Garbutt, J.M., Waterman, A.D., Flum, D.R., Larson, E.B., Waterman, B.M., Dunagan, W.C., V.J., F., & Levinson, W. (2006). Choosing your words carefully: how physicians would disclose harmful medical errors to patients. *Archives of Internal Medicine*, 166(August 14-28), 1585-1593.

Glaser, B., & Strauss, A. (1965). *Awareness of Dying* London: Weidenfeld and Nicholson

Health Quality Council of Alberta (2006). Disclosure of Harm to Patients and Families: Provincial Framework. Calgary: Health Quality Council of Alberta.

Hochschild, A.R. (1983). *The Managed Heart: Commercialisation of Human Feeling* Berkeley: University of California Press

Iedema, R. (2007). Essai: On the materiality, contingency and multi-modality of organizational discourse. *Organization Studies*, 28(6).

Kraman, S., Cranfill, L., Hamm, G., & Woodard, T. (2002). Advocacy: the Lexington Veterans Affairs Medical Center. John M. Eisenberg Patient Safety Awards. *Joint Commission Journal for Quality Improvement*, 28(12), 646-650.

Kraman, S.S., & Hamm, G. (1999). Risk management: Extreme honesty may be the best policy. *Annals of Internal Medicine*, 131(12), 963-967.

Lamb, R. (2004). Open disclosure: The only approach to medical error. *Quality and Safety in Health Care*, 13(2004), 3-5.

Liebman, C.B., & Hyman, C.S. (2004). A Mediation Skills Model To Manage Disclosure Of Errors And Adverse Events To Patients. *Health Affairs*, 23(4), 22-32.

Mazor, K., Reed, G., Yood, R., Fischer, M., Baril, J., & Gurwitz, J. (2006). Disclosure of Medical Errors: What Factors Influence How Patients Respond? *Journal of General Internal Medicine*, 21(7), 704-710.

National Patient Safety Agency (2005). *Being Open: Communicating patient safety incidents with patients and carers.* Available from: http://www.npsa.nhs.uk/site/media/documents/1456_Beingopenpolicy1_11.pdf. Accessed on: 24 September 2007.

NSW Health (2007). Open Disclosure Guidelines. Sydney: NSW Health.

Queensland Health (2006a). Queensland Health Open Disclosure Peer Support Training. Brisbane: Queensland Health.

Queensland Health (2006b). Queensland Health Incident Management Policy. Brisbane: Queensland Health.

Seale, C. (2000). Changing patterns of death and dying. *Social Science and Medicine*, 51, 917-930.

Studdert, D.M., Mello, M.M., Gawande, A.A., Brennan, T.A., & Wang, Y.C. (2007). Disclosure of medial injury to patients: an improbable risk management strategy. *Health Affairs*, 26(1), 215-226.

Taylor, S. (1998). Emotional labour and the new workplace. In P. Thompson, & C. Warhurst (Eds.), *Workplaces of the future* (pp. 84-103). Basingstoke: Macmillan.

Thrift, N. (2004a). Intensities of feeling: Towards a spatial politics of affect. *Geografiska Annaler*, 86B(1), 57-78.

Thrift, N. (2004b). Movement-space: the changing domain of thinking resulting from the development of new kinds of spatial awareness. *Economy and Society*, 33(4), 582-604.

Vines, P. (2005). Apologising to avoid liability: Cynical civility or practical morality? *Sydney Law Review*, 27(3), 483-505.

Wakefield, J., Jorm, C., & Ryan, C. (2007). Open Disclosure: Details matter - A Response to Studdert et al 2007. *Health Affairs*, 26(3), 903-904.

Woods, M.S. (2007). *Healing words: The power of apology in medicine*. Oakbrook Terrace, Ill.: Joint Commission on Accreditation of Healthcare Organizations.

APPENDIX L: TEAM PERSONNEL - BRIEF BIOGRAPHICAL STATEMENTS

Professor Rick Iedema – Coordinator of the Project

> ***BA (Liverpool, U.K.), MA & PhD (Syd)***
> ***Professor of Organizational Communication***
> ***Associate Dean (Research), Faculty of Humanities and Social Sciences***
> ***University of Technology Sydney***

Prof Rick Iedema's contribution to the study of clinical communication in hospitals is internationally recognized across the areas of organization studies, health care quality and safety and health services research and discourse analysis. In partnership with colleagues, he has attracted over $8 million in peer-reviewed funding over the last 8 years. His research success includes Principal Chief Investigator roles on three 3-year ARC Discovery grants that attracted above-average funding, and co-Chief Investigator roles on three ARC-SPIRT/Linkage funded projects, two NHMRC projects, a National Breast Cancer Foundation project, and a Clinical Excellence Commission project. He acts as 'Expert of High International Standing' for the Australian Research Council and reviews grants for the Danish Research Council for the Humanities and for the Singaporean National Research Foundation. He has published over 100 peer-reviewed articles, book chapters, full-length conference papers and book reviews in international, high-ranking journals across different disciplinary domains, including *Organization Studies, Social Science and Medicine, British Medical Journal, Health Services Management Research, Communication and Medicine, Discourse and Society, Text* and *Visual Communication.* Rick's work has attracted several invitations to present international keynotes and contribute articles to state-of-the-art publications such as encyclopaedias, handbooks and journal special issues. His research targets how doctors, nurses, allied health staff and managers communicate about the organization of their hospital work, and inquires into whether and how clinicians' communications realize the intent of 21st century hospital reform initiatives. Rick has taken overall carriage of the Open Disclosure Evaluation project; he has interviewed stakeholders, and had oversight of data analysis, report production and publication of results.

Associate Professor Elizabeth Manias

> ***BPharm, M Pharm, RN, MNStudies, PhD***
> ***Associate Professor, School of Nursing, University of Melbourne***

A/Prof Elizabeth Manias is a registered nurse and pharmacist who has made a sustained contribution in medication safety, interpersonal and organisational communication, and consumer participation. Her work has examined the complex communication processes about how clinical care is carried out by examining different perspectives and the complexities of the dynamic environment in which communication takes place. She has extensive experience and expertise in undertaking hospital ethnographic research and evaluation studies in hospitals and universities. To date, she has received over $1.4M of competitive research funding from diverse sources, including ARC and NHMRC. She has also obtained competitive funding from government sources including the Victorian Department of Human Services, the Nurses' Board of Victoria and the previous Australian Council for Safety and Quality in Health Care to support her work. She is the author or co-author of 7 textbooks, 7 book chapters, 65 peer-reviewed research journal articles, 8 multimedia medication programs, and numerous other publications. Her work has attracted invitations to present at national and international conferences, to provide consultancies with key international organisations (e.g. the Medicines Council of the United Kingdom), and to contribute papers to high quality publications including journal special issues, chapters in books and position statements. A/Prof Manias's work upholds the importance of

translating findings into practice, and in disseminating knowledge generated in creative and diverse ways. For instance, she developed a medication management education module for nurses who wish to be endorsed as nurse practitioners in the state of Victoria. She was the leader of the team that negotiated the successful tender from the Department of Human Services to develop this module. The team subsequently produced comprehensive guidelines for quality teaching and learning about medications, which were to be implemented by all Victorian Universities. She is also a co-author of the highly successful textbook, *Fundamentals of Pharmacology,* which is in its 5th edition. This is the prescribed medication education textbook used in most Australian and New Zealand University Schools of Nursing. It is also used in Asia, South America and the United Kingdom. The textbook won two prestigious awards in The Australian Awards for Excellence in Educational Publishing in 2004. These Awards are the premier event for acknowledging excellence and creative innovation in textbook publishing. In 2005, she was awarded the prestigious Mona Menzies Award by the Nurses Board of Victoria, in view of her exemplary contribution to health care. Her understanding of current health care trends and emerging needs is shaped through active membership on key committees. On a state government level she is a member on two health committees: the Victorian Medicines Advisory Committee and the Victorian Medication Safety Committee, which provide advice on medicine-related issues. On a national level she is a member of the Royal College of Nursing Australia Quality Use of Medicines Network, which develops position statements on nurses' roles in medication management, and makes recommendations to commonwealth bodies on patient safety in medication use. Her role has been to supervise Allison Williams, interview stakeholders, and contribute to data analysis.

Professor Desley Hegney

RN, Cert. Occ. Health Nursing (Sydney), DipNursEd (ACAE), BA (Hons) (UNE), PhD (Southern Cross), FRCNA, FCN (NSW), FAIM

Director, Research Practice Development Centre, The University of Queensland and Blue Care, Professor of Rural and Remote Nursing [Sister E Kenny Chair] – University of Southern Queensland, University of Queensland, Toowoomba Health Service District, Director, Centre for Rural and Remote Area Health, Director, Australian Centre for Rural and Remote Evidence Based Practice

Professor Desley Hegney's major research interest has been in the area of primary health care nursing – particularly rural nursing and practice nursing. She was the inaugural president of the Association for Australian Rural Nurses Inc., and the foundation Editor of the Australian Journal of Rural Health (1992-2003). Her research into the role and function of the rural nurse in Australia described for the first time the generalist advanced practice role of rural nurses in Australia. Her work has since been replicated in Canada. Desley is a foundation member of the executive of the ICN Rural and Remote Area Nursing Network, formed in Canada in 2004. Her contribution to the profession includes membership of: The Queensland Nursing Council's Steering Committee for the Scope of Nursing Practice (including the Decision Making Framework); the Queensland Health Ministerial Advisory Board on Rural Health; the Queensland Health Ministerial Taskforce for the Recruitment and Retention of Nurses; and Deputy-Chair of the National Rural Health Alliance. Desley is currently on the Editorial Boards of The Journal of Rural and Remote Health (online); the Rural Nursing Journal (published online in the USA) and the Australian Journal of Advanced Nursing. Desley is an experienced researcher, attracting funding totally $2.5 million in the last five years and has published extensively from these research projects. Desley has given approximately 45 invited and keynote addresses in the last five years and is also an experienced teacher. Desely developed the Graduate Certificate and Masters of Advanced Nursing Practice (Rural and Remote) at the University of Southern

Queensland. This was the first rural and remote nursing nurse practitioner program to be accredited in Australia. Her role has been to supervise data collection at the Brisbane site and contribute to data analysis.

Dr Anthony Tuckett

Senior Lecturer, University of Queensland, PhD

Anthony Tuckett was the 2001 Centaur Doctoral Fellow and a 2005 Honorary Fellow at the School of Nursing, University of Queensland. Anthony has published widely on the topic of truth-telling in health care.

Donella Piper

Barrister/Solicitor High Court of NSW, PhD Candidature (Public Participation in Health Care Decision-Making)

Donella Piper is currently a PhD Candidate at the Centre for Clinical Governance located within the Faculty of Medicine at the University of New South Wales. The topic of her thesis is "*The Role of Legislation in Facilitating Community Participation in Healthcare Governance : NSW Health a Case-study.*" She is a Legal Practitioner of the Supreme Court of New South Wales (Practising Certificate Class A) and Barrister and Solicitor of the High Court of Australia. She has practised primarily in commercial law matters, including providing corporate governance advice to entities and conducting legal compliance audits. Donella was a Director New England Area Health Service (NEAHS) from July 2002 - July 2004. During the term of her appointment she was Chair of the NEAHS Clinical Ethics Committee and a member of the NEAHS Medical and Dental Appointments Committee. Donella has lectured in law at UNE School of law (1996-2004) and Flinders University of South Australia (1996-97) in a variety of subject including legal ethics and professional conduct, equity and trusts, contract law, introduction to business law, property law, corporations law, constitutional law and criminal law. Her role has been to contribute legal advice.

Suyin Hor

BPsych Hons (UNSW), MEd (by Research, UNSW)

Su-yin is a post-graduate researcher with a background in psychology and training in psychological research methods, with experience designing and conducting an Australia-wide study with gifted primary school students, using both quantitative and qualitative survey data for her Masters research in Education. Su-yin is currently undertaking research for her PhD with the Centre for Clinical Governance Research as part of a wider ARC Discovery Grant: 'Anchoring preventive health care to positive learning', using ethnographic methods to study how clinicians act and interact with each other, in learning from and preventing adverse events, near misses, critical incidences and error. Her role has involved transcribing interview sound files.

Nadine Mallock

BHI, MHI (Health Informatics)
Researcher, Australian Council for Health Care Standards

Ms Nadine Mallock is a Research Officer at the Centre. She has a background in Health Informatics and is currently completing an economics degree. Ms Mallock has extensive experience in administering and analysing questionnaires, searching databases and the Internet, managing projects, writing reports and liaising with health care key stakeholders. She is/or has been working on a wide range of projects including the evaluation of Point of Clinical Care Systems, knowledge management, the development of a health sector impact evaluation tool, diversity management and defining the public health workforce. In 2002, Ms Mallock was part of the Clinical Practice Improvement Training Program evaluation team. Her role has been to organise and coordinate aspects of the Open Disclosure study.

Dr Allison Williams

B.App.Sc.(Nsg.), Monash University Grad. Dip. Adv.Nsg.(Clin. Nurse Ed.), LaTrobe University, Master of Nursing, LaTrobe University, PhD, The University of Melbourne
Research Fellow, School of Nursing, The University of Melbourne

Allison Williams is a Research Fellow at the School of Nursing, The University of Melbourne, Australia. Allison has a strong interest in enhancing standards of professional practice and health care delivery. Her research interests relate to disease management and symptom control in people with chronic disease states. She is interested in issues concerning informed consent and open disclosure in relation to medicine self-management and has a successful grant as Principal Researcher in the ARC Linkage Australian Postdoctoral Research Fellowship (Industry) investigating medicine adherence from the consumer's perspective. Her role has been to interview stakeholders.

Dr Ros Sorensen

BSocWrk, PhD (UNSW)
Senior Lecturer, School of Nursing, University of Technology Sydney

Ros Sorensen is Senior Lecturer in the Faculty of Nursing, Midwifery & Health and researcher in the Centre for Health Services Management. She teaches in a range of subjects related to health service organisation and management. Her research interests and activities lie in health policy development and implementation, health service governance and accountability, managing clinical processes in clinical workplaces and health service organisations, and understanding the personal and professional dynamics in managing change. She has authored over twenty publications in the field of health service organisation and change management and delivered over twenty presentations nationally and internationally in the field. Her role has been to interview stakeholders.

Dr Sue Brownhill

Research Fellow, Faculty of Humanities & Social Sciences, University of Technology Sydney
PhD

Sue Brownhill has extensive experience in social scientific research methods. Sue's role on the project has been to deduce themes from the interview data, using grounded theory.

Dr Bruce Perrott

BCom, MBA, PhD (UNSW)
Senior Lecturer, School of Marketing, Faculty of Business, University of Technology Sydney
Bruce Perrott's interests lie in the area of strategic management. He is concerned with how business and marketing strategies are formulated, formalised and managed through the implementation process. His current focus relates to the impact on electronic marketspace developments on business and marketing strategy and marketing/business strategy in health care. Bruce teaches in the areas of Marketing strategy; Marketing management; New product management; Electronic business projects; and Marketing strategy for electronic business. His research areas include Electronic marketing; transformation; management education for electronic business; and migration into electronic business. Her role has been to interview stakeholders.

A/Prof Hermine Scheeres

MA (Syd), DipEd (Syd Teach Coll), GradDipTESOL (SCAE), PhD (UQ)
Associate Professor, School of Adult Education, University of Technology Sydney
Hermine Scheeres has worked in higher education; technical and further education and secondary education in Australia, England, Mexico and Argentina. Her current positions include: Co-ordinator of the BA Organisational Learning and the Grad Dip Literacy and Numeracy. She is a member of UTS Academic Board, Deputy Chair of the Board of the Faculty of Education, a member of the UTS Equity Reference Committee and Co-editor of the Journal Literacy and Numeracy Studies: an international journal in the education and training of adults. Hermine has developed curriculum and professional development courses and materials for organisations and institutions including: NSW State Rail; Kelloggs Australia; TAFE (equivalent) teachers in Mexico; English Language teachers in Argentina; Adult Literacy teachers across Australia; and the NSW Board of Secondary School Education (HSC). She has also worked as a consultant, adviser and trainer for government departments and industry. Her role has been to interview stakeholders.

APPENDIX M: FINAL REPORT REFERENCES

Atsushi, A. (1995). Should physicians tell patients the truth? *The Western Journal of Medicine, 163*(1), 36-39.

Australian Council for Safety and Quality in Health Care. (2003). *Open Disclosure Standard: a national standard for open communication in public and private hospitals following an adverse event in health care*. Canberra: Commonwealth of Australia.

Bate, P., & Robert, G. (2007). *Bringing User Experience to Healthcare Improvement: The concepts, methods and practices of experience-based design*. Oxford/Seattle: Radcliffe Publishing.

Berlinger, N. (2005). *After harm: Medical error and the ethics of forgivenness*. Baltimore: Johns Hopkins Press.

Braithwaite, J. (2002). Setting Standards for Restorative Justice. *The British Journal of Criminology, 42*(2002), 563-577.

COPIC. (2004). COPIC's 3R's Program. *COPIC Newsletter, 1*(1).

Cox, K. (1999). *Doctor and Patient: Exploring Clinical Thinking*. Sydney: University of New South Wales Press.

Cruess, S. R., & Cruess, R. L. (1997). Professionalism must be taught. *British Medical Journal, 315*(7123), 1674-1677.

Davis, P., Lay-Yee, R., Scott, A., Briant, R., & Schug, S. (2003). Acknowledgement of "no fault" medical injury: Review of patients' hospital records in New Zealand. *British Medical Journal, 326*(2003), 79-80.

Davis, R., Jacklin, R., Sevdalis, N., & Vincent, C. (2007). Patient involvement in patient safety: What factors influence patient participation and engagement? *Health Expectations, 10*(2007), 259-267.

Degeling, P. (2000). Reconsidering clinical accountability: An examination of some dilemmas inherent in efforts to bolster clinician accountability. *International Journal of Health Planning and Management, 15*(1), 3-16.

Degeling, P., Sorensen, R., Maxwell, S., Aisbett, C., Zhang, K., & Coyle, B. (2001). *The organisation of hospital care and its effects*. Sydney: Centre for Hospital Management and Information Systems Research, The University of New South Wales.

Dekker, S. W. A. (2005). *Ten questions about human error: A new view of human factors and system safety*. Mahwah, N.J.: Lawrence Erlbaum.

Egan, G. (2006). *The Skilled Helper: A Problem-Management and Opportunity-Development Approach to Helping*. New York: Brooks/Cole.

Gattellaria, M., Butow, P., & Tattersall, M. (2001). Sharing decisions in cancer care. *Social Science & Medicine, 52*, 1865-1878.

Goldsmith, S., & Eggers, W. D. (2004). *Governing by network: The new shape of the public sector*. Washington: Brookings Institution Press.

Goldstein, D., Thewes, B., & Butow, P. (2002). Communicating in a multicultural society II: Greek community attitudes towards cancer in Australia. *Internal Medicine Journal 32*, 289-296.

Harris, M. (2002). Communicating across the divide. *Australian Family Doctor*.

Hollnagel, E. (2006). Resilience: The challenge of the unstable. In E. Hollnagel, D. D. Woods & N. Leveson (Eds.), *Resilience engineering: concepts and precepts* (pp. 9-18). Aldershot: Ashgate Publishing Ltd.

Iedema, R. (2003). *Discourses of Post-Bureaucratic Organization*. Amsterdam/Philadelphia: John Benjamins.

Iedema, R., & Degeling, P. (2001). Quality of care: clinical governance and pathways. *Australian Health Review, 24*(3), 12-15.

Iedema, R., Degeling, P., Braithwaite, J., & Chan, D. (2004). Medical Education and Curriculum Reform: Putting Reform Proposals in Context. *Medical Education Online, 9*(17).

Iedema, R., Jorm, C., Wakefield, J., & Ryan, C. (submitted). A New Structure of Attention? Open Disclosure of Clinical Errors to Patients and Families. *Journal of Language & Social Psychology*.

Iedema, R., Jorm, C. M., Braithwaite, J., Travaglia, J., & Lum, M. (2006). A root cause analysis of clinical errors: Confronting the disjunction between formal rules and situated clinical activity. *Social Science & Medicine, 63*(5), 1201-1212.

Iedema, R., Jorm, C. M., Long, D., Braithwaite, J., Travaglia, J., & Westbrook, M. (2006). Turning the Medical Gaze in upon Itself: Root Cause Analysis and the Investigation of Clinical Error. *Social Science & Medicine, 62*(7), 1605-1615.

Kirby, M. (2000). Medical Malpractice - An International Perspective Of Tort System Reforms, *Opening address to the Royal College of Physicians Annual Conference*. London

Leonard, M., Graham, S., & Bonacum, D. (2004). The human factor: the critical importance of effective teamwork and communication in providing safe care. *Quality and Safety in Health Care, 13*(5), i85-i90.

Lief, H. I., & Fox, R. C. (1963). Training for 'detached concern' in medical students. In H. I. Lief, V. F. Lief & N. R. Lief (Eds.), *The Psychological Basis of Medical Practice* (pp. 12-35). New York: Harper Row.

Lillrank, P., & Liukko, M. (2004). Standard, routine and non-routine processes in health care. *International Journal of Health Care Quality Assurance, 17*(1), 39-46.

Lupton, D. (1998). Medicine and Health Care in Popular Media. In A. Petersen & C. Waddell (Eds.), *Health Matters: A Sociology of Illness, Prevention and Care* (pp. 194-207). Sydney: Allen & Unwin.

Mansell, P., Harris, W., Carthey, J., & Syed, I. (2005). Patient and public involvement in patient safety: the role of the National Patient Safety Agency. London: National Patient Safety Agency.

Mooney, G. (forthcoming). Involving communities in decision making In R. Sorensen & R. Iedema (Eds.), *Managing Clinical Work*. Sydney: Elsevier.

Moore, M. (1995). *Creating Public Value: Strategic management in government*. Cambridge, MA.: Harvard University Press.

New South Wales Health Department. (2004). *The NSW Patient Safety Program: Technical Paper*. Sydney: NSW Health.

NSW Health. (2006). *Policy Directive: Open Disclosure*. Sydney: Department of Health, NSW.

NSW Health. (2007). *Policy Directive: Open Disclosure*. Sydney: Department of Health, NSW.

NSW Ombudsman. (2007). *Unreasonable complainant conduct: A joint project of the Australian Parliamentary Ombudsman*. Sydney: NSW Ombudsman.

Owen, J. M., & Rogers, P. J. (1999). *Program Evaluation: Forms and Approaches*. Sydney: Allen & Unwin.

Parakasuraman, A., Zeithaml, V. A., & Berry, L. L. (1985). A conceptual model of service quality and its implications for future research. *Journal of Marketing*.

Plsek, P. (2001). Redesigning health care with insights from the science of complex adaptive systems. In U. S. Institute of Medicine (Ed.), *Crossing the quality chasm: a new health system for the 21st century* (pp. 309-322). Washington: National Academy Press.

Queensland Health. (2006a). *Clinical Managemernt Implementation Standard*. Brisbane: Queensland Health.

Queensland Health. (2006b). *Queensland Health Incident Management Policy*. Brisbane: Queensland Health.

Reason, J. (2004). Beyond the organizational accident: the need for 'error wisdom' on the frontline. *Journal of Quality and Safety in Health Care, 13*, 28-33.

Runciman, W., Merry, A., & Walton, M. (2007). *Safety and ethics in health care*. Aldershot: Ashgate.

Shotter, J. (1989). Social Accountability and the Social Construction of 'You'. In J. Shotter & K. Gergen (Eds.), *Texts of Identity* (pp. 133-151). Newbury Park: Sage.

Stewart, P., & Martinez-Lucio, M. (1998). Renewal and tradition in the new politics of production. In C. Warhurst & P. Thompson (Eds.), *Workplaces of the future* (pp. 65-83). Basingstoke: Macmillan.

Studdert, D. M., Mello, M. M., Gawande, A. A., Brennan, T. A., & Wang, Y. C. (2007). Disclosure of medial injury to patients: an improbable risk management strategy. *Health Affairs, 26*(1), 215-226.

Timmermans, S., & Berg, M. (2003). *The Gold Standard: The challenge of evidence-based medicine and standardization in health care*. Philadelphia: Temple University Press.

Tuckett, A. G. (2004). Truth-telling in Clinical Practice and the Arguments For and Against: A Review of the Literature. *Nursing Ethics, 11*, 500-513.

Tuckett, A. G. (2005). The care encounter: Pondering caring, honest communication and control. *International Journal of Nursing Practice, 11*(2), 77-84.

Vines, P. (2005). Apologising to avoid liability: Cynical civility or practical morality? *Sydney Law Review, 27*(3), 483-505.

Vines, P. (2007). The power of apology: Mercy, forgivenness or corrective justice in the civil liability arena? *University of New South Wales Faculty of Law Research Series, 2007*(30), 1-29.

Wakefield, J., Jorm, C., & Ryan, C. (2007). Open Disclosure: Details matter - A Response to Studdert et al 2007. *Health Affairs, 26*(3), 903-904.

Wald, H., & Shojania, K. G. (2001). Root Cause Analysis. In K. G. Shojania, B. W. Duncan, K. M. McDonald, R. W. Wachter & A. J. Markowitz (Eds.), *Making Health Care Safer: A Critical Analysis of Patient Safety Practices (Evidence Report/Technology Assessment: Number 43)* (pp. 51-56). Rockville, MD.: Agency for Healthcare Research and Quality.

Wheeler, C. (2007). Apologies - Promoting Integrity And Responsibility In The Public Sector, *Paper presented to the Public Sector Ombudsman Conference: Strategies For An Evolving Profession*. Anchorage, Alaska.

Wojcieszak, D., Banja, J., & Houk, C. (2006). The sorry works! Coalition: making the case for full disclosure. *Journal on Quality and Patient Safety, 32*(6), 344-350.

Woods, M. S. (2007). *Healing words: The power of apology in medicine*. Oakbrook Terrace, Ill.: Joint Commission on Accreditation of Healthcare Organizations.