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## The "100 patient stories" project: Patient and family member views on how clinicians (should) enact Open Disclosure - a qualitative study

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## RESEARCH

# Patients' and family members' views on how clinicians enact and how they should enact incident disclosure: the "100 patient stories" qualitative study

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## Abstract

**Objectives** To investigate patients' and family members' perceptions and experiences of disclosure of healthcare incidents and to derive principles of effective disclosure.

**Design** Retrospective qualitative study based on 100 semi-structured, in depth interviews with patients and family members.

**Setting** Nationwide multisite survey across Australia.

**Participants** 39 patients and 80 family members who were involved in high severity healthcare incidents (leading to death, permanent disability, or long term harm) and incident disclosure. Recruitment was via national newspapers (43%), health services where the incidents occurred (28%), two internet marketing companies (27%), and consumer organisations (2%).

**Main outcome measures** Participants' recurrent experiences and concerns expressed in interviews.

**Results** Most patients and family members felt that the health service incident disclosure rarely met their needs and expectations. They expected better preparation for incident disclosure, more shared dialogue about what went wrong, more follow-up support, input into when the time was ripe for closure, and more information about subsequent improvement in process. This analysis provided the basis for the formulation of a set of principles of effective incident disclosure.

**Conclusions** Despite growing prominence of open disclosure, discussion about healthcare incidents still falls short of patient and family member expectations. Healthcare organisations and providers should strengthen their efforts to meet patients' (and family members') needs and expectations.

## Introduction

Health providers in Western countries are adopting "open disclosure" policies that promote the discussion of healthcare incidents with patients.<sup>1-5</sup> Studies using hypothetical designs have suggested that a gap exists between clinicians' and patients' views of what is appropriate incident disclosure. Clinicians tend to consider unexpected clinical outcomes as less serious and therefore less in need of disclosure than do patients.<sup>6</sup> Clinicians also err on the side of caution, whereas patients expect openness and admission of responsibility.<sup>7</sup> Such breakdowns in the disclosure process exacerbate the distress patients experience from the event itself.

Surveys of clinicians' and patients' perceptions of open disclosure policy and practices also reveal important barriers to open communication with patients after healthcare incidents.<sup>6,8,9</sup> Several studies have highlighted clinicians' concerns about the personal, professional, and legal consequences of disclosure.<sup>10</sup> Clinicians are also concerned about the considerable time and effort often required for incident disclosure,<sup>11</sup> including

managing relationships among practitioners and between practitioners and patients; handling patients' and family members' disappointment, fear, and anger; and justifying to all stakeholders the approach taken and the outcomes produced from disclosure.<sup>9 12</sup> For their part, patients refer to the considerable physical, emotional, and financial burden of incidents causing harm<sup>13</sup>; the unacceptability of inadequate and denied disclosure<sup>14</sup>; and the importance of provider responses that are caring, honest, quick, personal, accessible, and frequent.<sup>15</sup> Some studies suggest that patients may have an interest in extending disclosure discussions to encompass plans for and evidence of practice improvement, with some interviewees indicating interest in contributing to the monitoring of improvement processes over time.<sup>9 14 16</sup>

However, few studies have measured the actual experiences of patients and families with the disclosure process. The dearth of in depth interviews may be due to multiple factors, including health services' reluctance to reveal the details of incidents and disclosures; patients' and families' hesitation to revisit harmful incidents; and the protracted and confidential nature of incident investigations, complaints processes, and litigation proceedings which can limit data gathering. Such interviews are critical, however, if we are to garner robust evidence to support clinicians in communicating well about incidents and avert the possibility of ineffective disclosure prompting more complaints and litigation.<sup>17</sup> The present study was undertaken to produce such evidence.

This Australian study was conducted at a time of progress in the dissemination of disclosure policy and disclosure communication training.<sup>11 12</sup> Ministerial endorsement of open disclosure policy in 2008 led to state level development of such policy<sup>18 19</sup> and requirements for evidence of engagement with disclosure in local health services.<sup>20</sup> We sought to assess whether these developments have translated into tangible benefits for patients. The study had two objectives: to understand patients' and relatives' experiences of healthcare incidents and incident disclosures since 2008, and to enrich open disclosure policy with patients' views of the principles of effective open disclosure.

## Methods

### Study approach

We conducted in depth, semi-structured audio (and video) recorded interviews. This approach had two distinct advantages: it was best able to capture the full range of practical, communicative, and emotional complexities associated with incident disclosure, and it enabled repeated access to recordings for the purpose of checking transcriptions.

### Sample and recruitment

Interview participants were recruited over two phases.

#### *Phase one*

In the initial phase we recruited participants via participating health services. This enabled the inclusion of participants who were reported to have experienced a severe to very severe healthcare incident (involving serious short term or permanent harm or death) and undergone open disclosure between 2008 and 2010. This time frame ensured that interviewees would not overlap with those interviewed for the 2006–8 evaluation of the national open disclosure pilot,<sup>12 16</sup> and that their incidents would be handled under the aegis of the most recent, state issued policies on open disclosure.

Participating health services identified potential interviewees from hospital records who met the inclusion criteria (table 1); they then forwarded an envelope to their address containing a study participation request, information sheet, consent sheet, and reply-paid envelope prepared by the research team. Participants notified the health service of their interest in the study, which then forwarded respondents' contact details to the research team. We conducted 28 interviews with 36 participants recruited in this way for this first phase of the study (table 2).

#### *Phase two*

In the second phase of the study we recruited participants via the national print media and internet research companies (table 1). This strategy ensured that the sample was not restricted to health services vetting cases and participants, and that patients and families had the opportunity to opt into the study directly.

National tabloid and broadsheet newspapers carried a 5×10 cm advertisement asking for people's stories about care gone wrong (see web extra material on bmj.com). We contracted internet research companies to distribute a brief online questionnaire to attract interviewees from their lists of thousands of online respondents. We also asked consumer organisations to gauge interest in the study among members by circulating study flyers on their websites and at public forums.

The newspaper advertisement yielded 43 interviews with 56 participants, the online campaign yielded 27 interviews with 27 interviewees, and the consumer organisation recruitment yielded two interviews with two participants. All incidents that were to be the subject of the interviews were vetted by the project coordinator for time of occurrence and severity. In total, 119 interviewees were invited to participate in 100 interviews (table 2).

### Sample demographics

The healthcare incidents discussed involved patients ranging from 4 days to 94 years old with an average age of 57 (fig 1). Interviewees were from across Australia, but mostly from New South Wales (43%; fig 2). Their incidents had occurred across all clinical specialties, but mostly in medical (28%) and surgical (24%) inpatient settings (fig 3).

### Data collection

All interviewees were contacted by telephone before the interview by the project coordinator to assess eligibility (based on severity and date of occurrence of the incident), clarify project information, obtain consent, and determine whether the interview would be conducted face to face, audio or video recorded, or over the telephone. Half of the interviews were conducted face to face in participants' homes. Interview duration ranged from 20 minutes to three hours. All interviews were audio recorded digitally, and 129 were video recorded. Interviews were conducted by researchers with extensive healthcare and communication experience to deal with the sensitive and often clinical and technical nature of the subject. Counselling supports were available to participants in the event of any additional distress caused as a result of participating in the study. This support was not requested or required at any time during the study. One interviewee responded via email to the interview schedule.

### Data analysis

The interviews were transcribed verbatim, yielding over 3000 A4 pages of single spaced text. Transcripts were discourse

analysed with identification of overarching theme domains, cross thematic relationships, and thematic hierarchies.<sup>21</sup> Three researchers (RI, SA, and KB) analysed all the transcripts. Other investigators analysed selected sets of transcripts for verification of themes. Analyses were compared at regular meetings, and differences in interpretation were negotiated until agreement was reached. Because revisiting the interviews was considered to be burdensome for patients and family members, validation of the transcripts with them was not attempted.

After full verification, thematic domains were imported into and managed in QSR NVivo (Qualitative Solutions and Research, Version 9), a code-and-retrieve software package. NVivo enabled cross linking and ranking of domains, sub-domains, and relevant transcript quotes. The resulting NVivo network of thematic nodes, cross links, and hierarchies enabled identification of the overarching domains of concern. These concerns were then converted into “best practice” principles for effective incident disclosure. This conversion involved, first, using patients’ and family members’ experiences of inadequate incident disclosure as the basis for articulating principles for appropriate disclosure communication. Second, this conversion was complemented with principles formulated from patients’ and family members’ affirmative experiences and suggestions for improvement.

## Ethical approval

Human research ethical approval was obtained from the universities that were part of the project consortium and from the health services involved in the study relevant to the particular method of participant recruitment. The consortium’s lead university’s approval code is UTS HREC 2008/300. Participants had signed and sent in their informed consent sheets before their interview took place.

## Results

### Overarching concerns

All patient and family member interviewees except one expressed concerns about the process of incident disclosure. Overarching concerns were (a) inadequate preparation for open disclosure, (b) inappropriate disclosure of unexpected outcomes, (c) lack of follow-up support, (d) lack of appropriate closure, and (e) insufficient integration of open disclosure with improvement of patient safety. Each of these concerns encompassed ancillary issues. For example, inadequate preparation for open disclosure encompassed institutions not having a complaints mechanism that activates incident disclosure, the disclosure process not being introduced with an appropriate level of formality and explanation, and incidents not being readily acknowledged to the patient and family. The last issue was evidenced by interviewee statements such as: “What they should have done was nip any possible complaint in the bud by knocking on the door, ringing us up, and saying, ‘Come on in, this is what we want to talk about’” (husband, 005).

Boxes 1 to 5 present the ancillary issues of each of the overarching concerns with representative interview quotes illustrating the issues, and the principles of effective disclosure that can be derived from the issues.

### Ancillary issues

See boxes 1–5 for a complete list of ancillary issues. Many interview participants reported having to request or demand incident disclosure from the health service. Having to do so was

viewed as a poor start to disclosure, particularly when an incident was not readily acknowledged by the treating clinician: “We wanted a meeting, and I especially wanted our [specialist doctor] there because I wanted them all to hear what they had done to me” (mother, 039).

A delayed response from the service motivated some patients and relatives to escalate their request for disclosure. Some mobilised their general practitioner for this purpose: “After a week, ten days, the three of us decided that we wanted to see the notes, we ... wanted to see more, we wanted to know if [son] knew what was going to happen to him ... I rang up the GP, his GP, and umm, which I knew and I said, ‘What do I have to do, what is the procedure I have to go through to see the notes? I want to know what happened on Wednesday night. I want to see what the nurse put down.’ So he said, ‘You have to sign for me that you give me the permission, and I’ll do the rest.’ It took him ten days and then he called me” (mother, 009).

Others felt obliged to lodge a complaint, (threaten to) involve the media, or initiate litigation to be granted disclosure. In cases where disclosure was offered, it was often experienced as inadequate. Interviewees felt the disclosure lacked open dialogue, a consistent and trustful attitude on the part of the treating clinicians, a sincere apology, a patient care plan seeking to redress the harm, and clarification of how future incidents would be prevented. The absence of open dialogue was felt to deny patients and family members a say in the questions that should have been asked and of whom, and in deciding whether the explanations that were offered were sufficient and satisfactory: “We want to know what happened that day. Why was she moved from the room? ... That could’ve contributed to her disorientation ... They said, ‘Oh well, we can’t really give you that information’” (daughter, 020).

Interviewees felt disclosure was compromised when clinicians expected them to accept formal investigation findings as evidence that the failure had been addressed. Problems referred to here included the investigation or findings of the “root cause analysis” being framed in systems discourse rather than addressing patients’ and family members’ low level concerns (such as “Why did the nurse move mother from her room?”) and clinical staff expecting to reach closure on the formal investigation before providing the patient or family with answers to their questions, or outlining plans for clinical process improvement (see boxes 1–5): “There has been no follow-up. No one has come to us or written to us. And as far as I’m concerned there has to be a finalisation of everything. And this is not final” (daughter, 004).

### Principles for effective incident disclosure

The breadth of this study justified conversion of the concerns and ancillary issues identified into principles for effective incident disclosure. These principles were formulated as action statements aiming to support and improve existing disclosure procedures. The full list of the principles are in boxes 1–5. In broad outline, they include:

- If clinicians and services are to meet patients’ and relatives’ expectations, they prepare all concerned for the incident disclosure meeting(s)
- They investigate and agree on what went wrong and inform those harmed of the need for a discussion about the unexpected outcome
- Clinicians point out that the disclosure discussion(s) will benefit from a patient support person being present, and from those harmed presenting their own account, views,

**Box 1: Concerns about disclosure of healthcare incidents expressed by affected patients and family members and inferred principles of effective disclosure: preparation for open disclosure**

*Incidents were not readily acknowledged to the patient or family*

"What they should have done was nip any possible complaint in the bud by knocking on the door, ringing us up, and saying, 'Come on in, this is what we want to talk about, are there any more questions?' yes there are, 'Hit us with it. OK, we'll go out and get the answers, we'll go back and talk to you'"—husband, 005

*Best practice principle*—Staff involved in a healthcare incident make sure to acknowledge the incident to the patient within 48 hours, signalling the need for open disclosure

*Institutions did not have an internal complaints mechanism that activated incident disclosure in the interest of the patient*

"I got totally ticked off, and I thought I'm not getting anywhere by letters, so I rang them and said I wanted to have an appointment face to face. Which I did"—patient, 006

*Best practice principle*—In cases where notification of the healthcare incident is absent or does not trigger open disclosure, the patient has access to an internal complaints mechanism that activates open disclosure

*The disclosure process was not introduced with the appropriate level of explanation and formality*

"She called me ... weeks after. I said, 'Excuse me, who are you, where are you coming from?' You don't expect, when you finish everything, that suddenly the hospital will call you and say, 'Hi [name], I'm really sorry, we're going to investigate the matter'"—mother, 009

*Best practice principle*—Staff take care to communicate information relating to an incident with an appropriate level of formality and sensitivity

*Patients and family were not adequately informed about the process of open disclosure*

"We got the open disclosure letter, saying they had an open disclosure policy, and they were quite happy to discuss what had happened ... which was good, because we needed that"—mother, 010

*Best practice principle*—The patient is given information about open disclosure in a language he or she understands, explaining the purpose and processes of open disclosure

*Open disclosure was arranged to take place at times and in locations that were unsuitable for the patient or family*

"It needs to be very clear to people that you have the right to say, 'Not now'"—daughter, 015

"That's what it was like, going to school and going to the headmaster's office, that's what it felt like ... Even if it was at the other hospital, somewhere totally away from the clinic maybe"—mother, 003

*Best practice principle*—The timing and location of the first face to face open disclosure meeting are decided in dialogue with the patient

*Patients were not informed about the possibility of arranging for a personal support person*

"Probably if we had ... some ... 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 ... just somebody to support us through that time"—patient, 013

*Best practice principle*—The patient nominates their open disclosure support person, who represents their interests (a family member, a friend, a representative from an external agency, or, if considered appropriate, a health service professional such as the patient's general practitioner)

*Open disclosure meetings were organised without patients and family members having a say in which staff members would be present*

"I really think the doctor in charge of my mum's care should have been there ... just to know what she was thinking, you know ... just to know what was going through her mind"—daughter, 001

*Best practice principle*—The patient is consulted about which healthcare workers are to be invited to the open disclosure meeting(s)

and questions about what went wrong and what needs to happen

- The disclosure discussion is performed as a two way, exploratory dialogue that produces an explanation that satisfies all stakeholders, bolstered by a sincere apology, a care plan redressing the patient's harm, a strategy for preventing the incident from recurring, and a clear outline of whether, why, and how other agencies (such as a neighbouring health service or hospital, the police, or the coroner) are involved
- Closure becomes feasible when the patient and family members feel they have asked everything they wanted to ask, have received adequate answers to their questions, and are satisfied that their concerns have been taken seriously

- To reassure them that incident disclosure links to practice improvement, they are informed about how the service has addressed the incident and what difference this has made or is making to care outcomes.

## Discussion

This study was conducted against a backdrop of a decade of development of disclosure policy, a nationwide disclosure pilot programme (2006–8), ministerial endorsement of open disclosure policy in 2008, and continued training in disclosure communication within health services. However, our study found that patients and family members only rarely experienced incident disclosure communication as appropriate and effective. Analysis yielded five overarching concerns, each encompassing

ancillary issues, ranging from how disclosure was arranged and communicated to how disclosure incorporated discussion of practice change and improved outcomes. The importance of these findings and strength of the analysis derive from the study's approach and method—recording and closely analysing patients' and family members' in depth accounts shared with independent researchers and in people's own homes, affording frank expression of experiences and views.

## Implications of study results

Taken together, the article's findings, analysis, and principles make three important contributions to the theory and practice of incident management and disclosure. Firstly, despite ethics advocacy<sup>22</sup> and evidence that disclosure need not exacerbate financial and legal risk,<sup>23 24</sup> the push for appropriate and effective disclosure is yet to translate into improved outcomes for patients and family members. Hearing first hand from 39 patients and 80 family members about current incident disclosure practices constitutes the most compelling evidence to date that healthcare institutions and providers should redouble efforts to enhance clinician and support staff disclosure skills.

Secondly, the article's analysis highlights patients' and families' expectation that disclosure should not be a one-way flow of information. Study participants expected incident disclosure to be a patient centred, respectful, and responsive dialogue to promote healing, learning, and safety. In advocating exploratory dialogue when things go wrong, the article highlights the importance to patients and family members of being engaged in a conversation that includes discussion of their questions and views on how to regain acceptable levels of patient safety.<sup>5 25</sup>

Thirdly, patients' and families' accounts yielded practical suggestions that can guide improvement in disclosure because their enactment is identifiable in practice and measurable in principle. Their identification in practice is made possible by being formulated as specific actions, such as "The patient is told the name and role of everyone attending the meeting." In turn, because these action principles are observable, they are measurable: "Patients were informed and given documentation every time about who attended the meeting and what their roles were." These principles enable services and organisations to evaluate and track their own disclosure performance and improvement.

## Limitations of study

This study has some limitations. Firstly, the 100 incidents sample represents a small number of the total number of serious incidents that occurs every year.<sup>26</sup> We sent out a nationwide invitation and do not know why more people did not volunteer for the study. Our lack of epidemiological knowledge about healthcare incidents, however, means that determining an appropriate sample size continues to be difficult.

Secondly, the three pronged recruitment strategy sought to balance incidents selected by the health service with incidents that members of the public volunteered to talk about. We cannot confirm that this strategy indeed compensated for sample bias because we do not know whether those who were aware of the study but not interested in discussing their experience were satisfied because of an effective incident disclosure, still too traumatised by the incident, or still too upset after an unsuccessful disclosure.

## Questions remaining

Health services' local practices and circumstances will constrain how the principles of incident disclosure are enacted.

Clarification is needed about how resources and skills required for doing disclosure well can be best made available and what penetration of training is desirable given a service's geo-demographic catchment.

Another question is how incident disclosure can be made culturally sensitive and relevant. This is critical for two reasons. First, many health services are experiencing the effects of rising patient and clinical staff migration. Second, culturally and linguistically diverse background patients may have lower health literacy and experience more difficulties accessing appropriate care<sup>27</sup> and may therefore also experience more incidents.

A third question relates to how early in their relationship with the health service do patients need to be alerted to what processes are initiated when things go wrong, and in what detail. Earlier and more careful consideration by all stakeholders of the possibility of things going wrong may alleviate tensions when it comes to having difficult conversations.

Finally, practice improvement processes may be able to target, besides organisational and clinical processes, the performance and outcomes of incident disclosure processes. Here too an important question remains about the trade-off between investing in clinical improvement and strengthening service recovery preparedness.

## Conclusion

Health service policy, public advocacy, and research have supported clinicians and services becoming more open about healthcare incidents.<sup>1 2 4 5 25</sup> How patients and their families experience disclosure plays an important role in determining the success of these initiatives. Does incident disclosure meet patients' and family members' expectations? Does it restore their faith in clinical safety and professionalism? If it does not, how do they think incident disclosure needs to be improved? By analysing patients' and family members' views and experiences, we have taken a step towards answering these critical questions. The principles produced from our analysis will enable practitioners and services to alleviate unintended harm with incident disclosure that is appropriate and patient centred.

We thank the patients and family members who contributed to this study. We thank the Open Disclosure Advisory Group for their wisdom and encouragement during the project. We thank the people at the participating health services and human research ethics committees who saw merit in this work and allowed us access to patients who were harmed by a healthcare incident. We also thank those who contributed to the research as colleagues.

Contributors: RI oversaw the research project, analysed data, and synthesised findings. SA managed the day to day components of the project, conducted most of the interviews, assisted in data analysis, and arranged the national stakeholder feedback process. KB assisted in project management; arranging, conducting, and filming the interviews; and carrying out data analysis. DP assisted in conducting the interviews, providing legal advice, and doing data analysis and participated in the national stakeholder process scrutinising and structuring study findings. AB assisted in conducting the interviews, advising project staff on everyday practicalities of incident disclosure, and participated in the national stakeholder process scrutinising and structuring study findings. CG provided research methodological advice and participated in the national stakeholder process scrutinising and structuring study findings. AA assisted in exploring and clarifying the apology dimensions of incident disclosure. LJ assisted in conducting the interviews and participated in the national stakeholder process scrutinising and structuring study findings. AT assisted in conducting interviews. AW assisted in conducting

interviews and participated in the national stakeholder process scrutinising and structuring study findings. EM participated in the national stakeholder process scrutinising and structuring study findings. THG acted as consultant to the project and participated in scrutinising and structuring study findings. All authors, external and internal, had full access to all of the data (including statistical reports and tables) in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis.

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**Competing interests:** All authors have completed the Unified Competing Interest form at [www.icmje.org/coi\\_disclosure.pdf](http://www.icmje.org/coi_disclosure.pdf) and declare they had: funding for this study from the Australian Commission on Safety and Quality in Health Care; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years; no other relationships or activities that could appear to have influenced the submitted work.

**Ethical approval:** Approval was obtained from the universities in the project consortium and the health services involved in the study. The consortium's lead university's approval code is UTS HREC 2008/300.

**Study design:** The study was designed by the Australian Commission on Safety and Quality in Health Care.

**Data sharing:** No additional data available. DVDs produced from the project will be available in 2012.

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## Tables

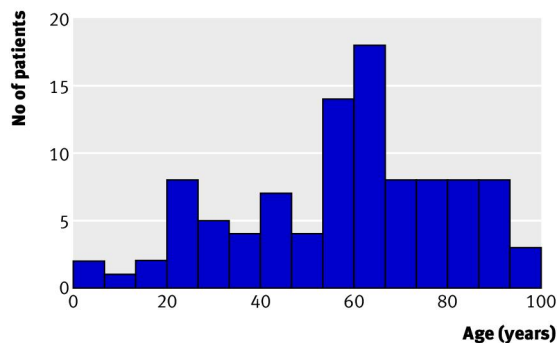
**Table 1 | Recruitment methods and inclusion criteria for patients and family members who were involved in high severity healthcare incidents**

Recruitment method	Inclusion criteria
Health service where the incident occurred	Documentation of patient experience of healthcare incident in Australian hospital in 2008–10 Incident judged to be severe to very severe (involving temporary or permanent harm or death) Patient or family member involved in open disclosure discussions
National print media	Timing of the incident was 2008–10
Market research company (internet)	Seriousness of incident perceived by patient or family to be high to very high
Consumer organisation	Patient or family were granted or demanded a meeting about the incident with health service

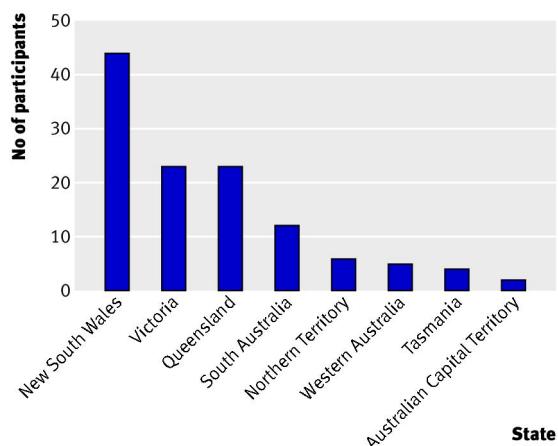
**Table 2| Numbers of participants and interviews conducted by recruitment method among patients and family members who were involved in high severity healthcare incidents**

Recruitment method	No of participants	No of interviews
Health service where the incident occurred	36	28
National print media	56	43
Market research company (internet)	27	27
Consumer organisation	2	2
Total	121	100

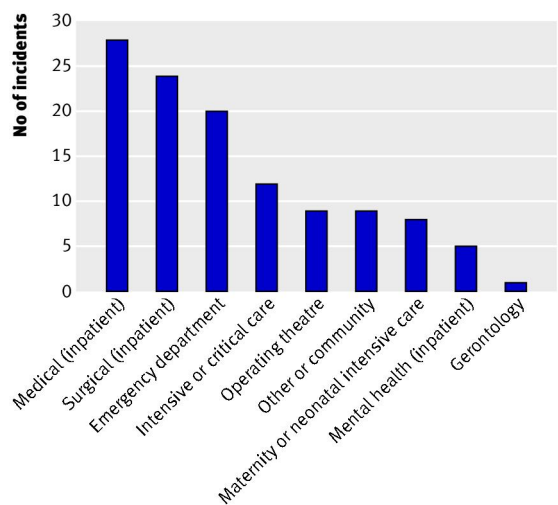
## Figures



**Fig 1** Age ranges of the patients discussed in interviews about high severity healthcare incidents



**Fig 2** Number of interview participants (patients and family members involved in high severity healthcare incidents) by Australian state



**Fig 3** Numbers of high severity healthcare incidents discussed by clinical subject

**Box 3: Concerns about disclosure of healthcare incidents expressed by affected patients and family members and inferred principles of effective disclosure: Providing follow-up support**

*Incident disclosure was reduced to a single meeting*

"The patient representative did make the point that if we wanted another meeting, we could request another meeting ... Sometimes you come away and say, 'Oh, why didn't I ask such and such'"—son, 008

*Best practice principle*—If required or requested by the patient, open disclosure constitutes more than a single meeting, and meetings can be requested at any point in the future

*Patients and family members experienced problems accessing clinical information relevant to their own case*

"I thought, as her next of kin and as the executor, I could just walk up and get her files and show them to my doctor ... because my brothers and sisters were so angry about the whole thing, and I wanted someone to explain it to us in our terms, and they said, 'No no because of the system or whatever we can't do that, we can't release them'"—daughter, 001

*Best practice principle*—Without contravening legal constraints, information requested by the patient is readily provided and with utmost clarity

*Patients and family members were not involved in the investigation or in discussion of investigation findings*

"I actually got to ask, and they answered ... because [health service staff] only look at a medical reason. You only look for medical [things]. You don't look for the actual facts around and what led to it. You only look at what it is when you walked into that room, what you saw, or what you had to treat. You don't look at okay, what happened before you got to that room. ... It's only through them understanding the full story ... [that] you can only bring about change"—wife, 053

*Best practice principle*—The patient and family need to have the opportunity to ask questions of and provide feedback into the incident investigation process

*Staff did not ensure a patient was looked after by the same staff member throughout the whole disclosure process*

"I don't know who to talk to, if they'd be willing to talk to us, so ... yeah I don't know, you'd think that ... after that meeting somebody would have contacted us"—daughter, 004

*Best practice principle*—A stable contact person represents the service, acting as an ongoing point of access, providing information and support, and managing the open disclosure to its completion

**Box 4: Concerns about disclosure of healthcare incidents expressed by affected patients and family members and inferred principles of effective disclosure: Moving forward (towards closure)**

*Patients and family members were not asked whether they were ready for closure*

"We're all starting to move on, the best way we can. We'll always have our memories of them, but, yes. I think within the 12 months. I don't, I wouldn't drag it out any more"—mother, 010

*Best practice principle*—Closure of the open disclosure process occurs by shared agreement between the patient and staff

*At closure of the case, patients and family members were not given a record of what was disclosed, what explanations were offered, what plans were put in place, and what improvements were going to be pursued*

"You need to make sure that people walk away feeling that they've been heard, for closure. Everyone deserves that. ... You must have documentation of that all the way. Because people are emotional, and sometimes they might need to see something in writing and in their own time and space read something"—daughter, 015

*Best practice principle*—At completion of the open disclosure process, all information requested by the patient and available from the investigation is provided to the patient in an appropriately worded and accessible record

*When there was disagreement about an incident after disclosure, patients and family members were not informed about alternative courses of action open to them, such as filing a complaint or litigation*

"If by August, September that review is not on the table then, you know, you have to go further and put a bit more pressure on. ... Maybe a threatening letter from a solicitor might move them on a bit ... then all the paperwork has to come up ... but ... it's just a threat"—patient, 002

*Best practice principle*—In the event that no progress is evident, or no satisfactory conclusion is reached or cannot be negotiated, alternate courses of action (complaint or legal action) are open to the patient

**Box 5: Concerns about disclosure of healthcare incidents expressed by affected patients and family members and inferred principles of effective disclosure: Integrating incident disclosure with practice improvement**

*Incidents were not recorded and investigated as expected by patients and family members*

"What I said to them was that the entire investigation has totally missed the point of my concerns and, instead of addressing them, they tried to cover the hospital's position from a legal viewpoint, and that was basically the last thing I had on my mind"—patient, 006

*Best practice principle*—Staff ensure the incident is reported, recorded, and investigated in line with health service policy

*The medical record was not up to date, slowing down the investigation and disclosure and leading to disagreements about what happened and what was done*

"For example ... there is a note [in the medical record] that says, '3am patient feels worse Endo Registrar contacted and Cortisone given.' And it makes it sound like it was an immediate thing, and it wasn't; there is no mention of the other five times she was called into my room. ... There is nothing there. ... So it covers them legally as well, 'No we didn't do anything wrong'"—patient, 006

*Best practice principle*—The medical record is up to date before the first meeting, including a comprehensive account of the adverse event as it is understood. In the case of death due to the incident, a copy of the medical record is accessible to all those who will be involved in the open disclosure process

*Open disclosure was not regarded as being able to inform learning or bring about improvement*

"I think it's more important to have an atmosphere of openness and frankness and that, hopefully, at the end of the day, the participants on both sides, the doctors as well, they're forced to closely review what's happened and their own conduct, etc, and that they go away learning something as well. If that happens, that's about the best you can expect I think"—son, 008

*Best practice principle*—Open disclosure acts as a feedback process that promotes learning and practice improvement in the context of just culture. This rules out blame unless the incident resulted from blatant misconduct

*Patients were not involved in practice improvement even when they had crucial information about an incident*

"I could have had counselling until the cows come home, but it would not have had the same effect as talking to those people about improving the way they transport babies"—mother, 042

*Best practice principle*—The health service and hospital explore ways of involving the patient in practice improvement initiatives

*Staff were not well supported by colleagues within their own organisation, limiting their acceptance of and the effectiveness of incident disclosure.*

"I got this letter from the [professional] board that said that they were going to have a disciplinary hearing for the [junior clinician]. I rang up the board and asked why, and what they were going to do. They basically said that the junior [clinician], her mistakes rose to the level of where it was quite possible that she'd lose her practising licence. ... I didn't really think that was fair. She [the junior clinician] told me that it was the first week on the ward, and yet she'd done a silly thing [causing harm] ... but she wasn't being supervised, that was clear. ... The way she talked to me, she was unsure about things. I just didn't believe that somebody placed in that situation should deserve to lose their entire career, regardless of the fact that she basically stuffed up my life for a while, and [I] asked the [professional] board to be able to come and give evidence. I went to the board and explained to them the events as I was aware of it"—patient, 050

*Best practice principle*—The patient engages in open disclosure with clinicians who themselves are supported by their colleagues, managers, and organisation, both personally (emotionally) and professionally (appropriate training, preparation, and debrief)

*Organisations did not evaluate their incident disclosure processes for the purpose of improving disclosure communication*

"At the end of the day, you know, when an unfortunate accident happens like that, that [inappropriate disclosure communication] could be avoided in the future. ... It would be good to know that my dad's death, you know, sort of prompted some changes in that area, you know, and I'm sure that if he was around, he would like to know that as well—daughter, 007

*Best practice principle*—At the conclusion of open disclosure, the patient and staff are surveyed to ascertain their satisfaction with the process as part of an open disclosure improvement process

**What is already known on this topic**

Patients and family members expect open and early admission that a serious incident has occurred, an apology, an explanation of its causes and its consequences for them, and a plan to avoid similar incidents in the future

Patients' expectations are often not met, and patients tend to regard incidents as more serious and in need of more open communication than do clinicians

**What this study adds**

The prominence of open disclosure policy and training in incident disclosure have not yet significantly improved incident disclosure outcomes for patients and family members: communication about serious incidents rarely met the expectations of 39 patients and 80 family members, compounding their distress

Analytical findings converted into a comprehensive set of principles for effective incident disclosure derived from the findings could guide healthcare organisations in improving incident disclosure