The partnership between patients and families and healthcare providers is one of the most important parts of our care. When we need care we often feel very vulnerable. We may also be frightened, upset and uncomfortable. Healthcare settings are generally not that familiar to us. The conversations that we have with our healthcare providers about our health and care plan, including possible risks and outcomes, both before and after care or treatment, help reassure us and allay some of the fears that we may have. The open sharing of information helps strengthen our trust in our care team and improves the safety and experience of our care.

Safety and Patient and Family-Centred Care First

When we need the healthcare system, we expect that our care will be safe and that it will be sensitive to our needs and wishes – the principles of patient and family-centred care. To us this means:

- The care we receive is safe.
- We are treated with respect.
- We are given information that we need to help us understand and make reasonable decisions about our health and our care.
- We can communicate openly and honestly with our healthcare providers and they will communicate openly and honestly with us.
- As we are able, we are involved with our healthcare team as partners in our care.

Immediate Response - Unexpected Situations

When things don’t go as expected – when conditions change or when harm occurs, the principles of safety and patient/family-centred care are even more important to us. Whether this is believed at the time to be a complication, an error, an oversight, a safety incident or a case of “we just don’t know right now”, patients and families need the healthcare system to support them and commit to finding out what happened and to making improvements. For us disclosure, learning and making improvements for the safety of the next patient are the most important parts of this process.4,17

When unexpected situations occur, we need the healthcare system and our providers to:

1. Explain what unexpected event or change happened;
2. Apologize that it happened;
3. Help us understand how and why it happened;
4. Explain what will happen next and commit to us in these next steps; and
5. Include us in the fact gathering process, enabling us to contribute what we know from our perspective.

**The Analysis – What, How and Why it Happened**

In helping us understand what happened, we need our healthcare providers to speak to us as soon as possible, using language we understand. We need our healthcare providers to be even more compassionate in these situations by showing us that they really care about us and what has happened. An acknowledgement that ‘something unexpected has happened’ is so important. We could be the first to see, feel or sense something isn’t right. Not responding or delaying openness creates more fear and erodes trust.

We understand that ‘how and why it happened’ may not be fully known at the time of initial disclosure and that more information and time may be needed to gather all the facts. Please explain this part of the process to us so that we understand what will happen next. This includes talking to us about our care plan and how our situation will be reviewed.

When analyses are needed, please include us in the fact gathering process. Invite us to meet with the analysis team so that we may provide our perspective and information that we may know about the situation. In some cases the analysis process can be very simple and straightforward. In other situations it might be more complicated and involve many different people. Where possible, please include us from the start. A review of the facts, particularly when serious harm is involved, is not complete until all of the perspectives and information from everyone involved, including the patient/family, have been gathered.

Involving us in the fact gathering stage also validates respect for our point of view as the expert in the patient experience. This emphasizes that the patient, not the system, is at the centre of concern. The goal is to make the system safer for patients through understanding, learning and improvement.

While timely analysis is critical, there may be different circumstances depending on what has happened – such as the shock of the event, significant changes in our health and implications for our family and loved ones – which may prevent us from participating in this process right away. Be understanding of our limitations and help find reasonable ways we can participate where this is our wish. The respect, empathy and understanding of what we could be going through at the time, helps rebuild our trust in providers and the healthcare organization.

Many of us will want to keep in contact with the organization during the analysis process. Please make this easy for us. Give us contact information at the time of the acknowledgement. It may help if this person is someone with whom we already feel comfortable.

Often there is information that we too would like to review as part of our ongoing care. It could be our medical record or charts, reports or results of tests that were done. When you meet with us, please make it easy for us to access these important records about our health. It is easier to communicate, understand and re-establish trust when we all have the same information.
In some situations where patients have been seriously harmed or where there may be significant system failures, it may be difficult for patients or families (and sometimes even the general public) to re-establish trust with the healthcare organization or system. Doubts may arise that analysis teams, when recruited from within the organization, will be as thorough or unbiased as outside experts. In these situations, please consider our request for an external analysis team, or for including external reviewers and experts as members of the analysis team. Having a member of the public and someone who is familiar with the perspective of the patient and family on the analysis team may also be important so that we can be assured that our interests and perspectives will be included.\textsuperscript{18}

In more complicated situations, it may take additional time to complete all aspects of the analysis. Please make sure that we are aware of the timelines and keep us informed of any delays or changes.

**Following the Analysis**

After the analysis has been completed, ask to meet with us in person when this is our wish, at a time and place that is agreeable to us. If a date for follow-up was previously agreed upon, please try and keep this commitment. If a delay is expected, please inform us and give us the reason for the change. Send us the information or reports that will be discussed in advance of these meetings so that we can also review them and come to meetings prepared with our questions.

These meetings can be very emotional for us. Please do everything possible to make this time easier for us. Ask us about our perspective, and include our suggestions for learning and improvements. The patient and family view is a valuable resource for finding effective solutions. Who better to suggest improvements than those who have experienced failures in care and the system? Talk with us about next steps and how we can continue to be informed or involved in developing or promoting these improvements. To us, this shows continuing commitment to our safety and the safety of other patients.

**Partners in Building Trusting Relationships**

Review and incorporate all current best practices and related national guidelines in your care sites and operations, and share your learning with others.

As new ways of incorporating safety and quality into healthcare are being considered, start to involve patients and families in the process. Work with patients and families to ensure that these advisory experiences are beneficial for all parties – and especially the patient and family.\textsuperscript{6,19}

Patients and families have important insights, information and experiences to share. There are many different ways that we can help.\textsuperscript{20} We are patients and families. We are committed partners in the safety and quality of our care. See the checklist (Appendix F) for highlights of these important patient/family considerations in incident management.