

Sharing of Patient Stories at In Sixty Steering Committee and Large Group In Sixty Events

The Patient Participation Advisory Group (PPAG) believes that the sharing of patient stories:

- is key to understanding the patient experience of care
- connects health care providers and administrators back to the patients they serve
- informs health care providers and administrators of patient expectations and needs
- involves patients as partners in their care
- influences individual spirit and passion for improvement
- informs systemic opportunities for improvement thru reflection on individual patient experiences.

As such, the PPAG recommends that:

- All steering committee meetings begin with a 10 minute patient story.
- All large group (more than 20 people) IN SIXTY events begin with a 10 minute patient story.
- Immediately following the sharing of a patient story, the patient/family member who shared the story depart and meeting participants spend 5 minutes reflecting on the systemic implications and opportunities which surfaced through the patient's story (reflection questions attached).
- 5 minutes of discussion on 1 or 2 systemic reflections occur.

The PPAG also acknowledges that sharing one's story can be emotionally difficult and stressful. Cancer patients have often reflected concern that the sharing of their story will be perceived as negatively speaking about the providers whom they feel have, in many cases, saved their lives. In other cases, cancer patients have reflected concern that their experience may be dismissed, or explained away, by health care providers and or administrators as being exceptional or as having occurred due to the patient's actions or inaction. The sharing of a patient's experience is not a value judgement or an effort to place blame. Patients and families who share their stories are not seeking a resolution to their specific situation. They are sharing their stories in hopes that the people who experience care after them have an improved experience.

In respect of the individual's experience and their sharing, the PPAG recommends that:

- Questions or discussions with the person sharing their story **not** occur.
- Audience members consider the systemic implications or opportunities versus the individual's specific situation.
- If audience members require enhanced understanding of an individual's specific situation to help determine what systemic opportunities could be undertaken, questions be written down and provided to the patient story coordinator for follow up action.
- A brief overview of the goals and guidelines for audience members be circulated prior to the sharing of patient stories (attached).

Patient Story Reflection Questions

1: In reflection on this individual's story and experience, what systemic opportunities for improvement were identified?

2: What improvements could occur in my work environment/area of responsibility which would address the systemic issue identified through this individual's experience?

3: How will I share what I learned from this individual's experience with my working group / colleagues / staff?

4. From this individual's story, what do I need to understand more in order to enable me to undertake systemic improvements for future patients?

Patient Story Goals and Guidelines for Audience Members

Thank you for taking the time to listen to and reflect on this patient/family's lived experiences with the health care system.

Through sharing patient stories, we hope you will better understand the patient/family's experience of care, become better informed about patient needs and expectations, and that patient/family's experiences, needs and expectations will inform and inspire systemic opportunities for improvement.

Sharing one's story can be emotionally difficult and stressful. The sharing of a patient/family's experience is not a value judgement or an effort to place blame. The sharing of a patient/family's experience is also not to seek solutions to the issues identified within a specific story or to have those listening to the story offer solutions or follow up actions from the patient's story.

In respect of the individual's experience and presentation, we ask that you:

- Be physically and mentally present by turning off your phone, blackberry and or computer
- Provide the presenter with eye contact
- Reflect on what systemic opportunities are identified through this individual's experiences
- Do not try to "make sense" of this individual's experience or look for explanations of why they experienced what they experienced. Focus on how the experience impacted the individual.
- Do not ask questions
- Do not clap following the patient / family's story
- Consider systemic improvements and actions which will ensure future patients improved experience
- If you have questions to help inform your understanding to undertake future systemic improvements, please write them down and provide them to the patient story coordinator who will follow up with the patient / family on your behalf.

We ask that you use the 5 minutes of reflection time following this patient/family's story and departure to reflect on the following questions:

1: In reflection on this individual's story and experience, what systemic opportunities for improvement were identified?

2: What improvements could occur in my work environment/area of responsibility which would address the systemic issue identified through this individual's experience?

3: How will I share what I learned from this individual's experience with my working group / colleagues / staff?

4. From this individual's story, what do I need to understand more in order to enable me to undertake systemic improvements for future patients?