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How to successfully engage patients and families in building quality-improvement initiatives

10 LESSONS LEARNED FROM PATIENT AND FAMILY ADVISORS

The Canadian Foundation for Healthcare Improvement (CFHI) works shoulder-to-shoulder with organizations to build their capacity to partner with patients and families to improve quality across the continuum of care. We support patient-centred healthcare improvements that engage patients and families in their design, delivery and evaluation. Co-designing these solutions with patients and families can provide project teams with more diverse perspectives, greater insights, and better results than those experienced if they were working on their own.

Through the work of CFHI collaboratives in quality improvement, Patient and Family Advisors have provided insights into what works best for them to partner in meaningful ways.

HOW TO SUCCESSFULLY ENGAGE PATIENTS AND FAMILIES IN BUILDING QUALITY-IMPROVEMENT INITIATIVES

LESSONS LEARNED FROM PATIENT AND FAMILY ADVISORS

1. Clarify my role.

Clearly communicate why Patient and Family Advisors have been invited, what the purpose of the engagement is, and what is expected of them. Patient and Family Advisors are more likely to actively and meaningfully contribute to the improvement conversation when they feel prepared and are confident in their role.

2. Educate others on my role and the value I bring.

Team members should understand the unique role Patient and Family Advisors have on the improvement team. Ensure all team members understand why Patient and Family Advisors have been engaged, how to respect their expertise and experience, how to solicit and appreciate their input, and how to incorporate their perspective.

3. Equip me with the information I need to be successful.

When inviting advisors to participate, share information that is accessible, relevant, and easy to follow, such as background resources providing context on the issue. Advisors require a clear understanding of the project and its purpose before agreeing to participate.

4. Involve me from the beginning.

Patient and Family Advisors want to be involved from the beginning of an initiative to provide insights and input into what the priorities are and how the initiative evolves. Involvement from the beginning allows for a co-design approach rather than a top-down approach.

5. Including one patient advisor is good; including more is better.

If possible, include more than one Patient and Family Advisor on any initiative to gain more diverse perspectives and to alleviate any pressure one person may have to provide 'the patient voice'. Multiple Patient and Family Advisors can also support and mentor each other.

6. Sustain my involvement throughout the process.

Regular team meetings foster the ongoing involvement of Patient and Family Advisors and allow for the development of relationships and commitment from all team members throughout the process.

7. Make engagement activities accessible and provide options for how I can get involved.

Covering expenses, such as parking and childcare expenses, creates an accessible environment and eliminates barriers to participation. Include advisors as meetings are being scheduled to ensure meeting times and other options to be involved (e.g. via Skype or phone) work best for all.

8. Promote networking opportunities.

Opportunities for advisors to network and converse with team members, including leaders, can promote further buy-in and understanding of the importance of the patient experience and how advisors can be embedded in other aspects of organizational work and strategic priorities. Networking among patient advisors provides further opportunities to share resources and learning.

9. Continue working with us after the project has finished.

Engagement is not a one-time occurrence. You can continue to sustain engagement with Patient and Family Advisors after the project is complete. Conduct a project review and evaluation, and consider other quality improvement committees advisors may want to be a part of. Always close the loop and let Patient and Family Advisors know the outcome of their involvement on the initiative.

10. We can do much more than just tell our stories.

The power of patient experiences, stories and feedback is significant; however, engagement and partnership extend beyond telling stories. Patient and Family Advisors can provide their perspectives and insights throughout all phases of an initiative.