

Patient and Care Partner Reflections

WHITE PAPER

Patient Advocacy Data: Discovering the hidden gems in patient feedback

Every individual sees the world through their own lens. In healthcare, the perspectives of patients and families are often different from those who deliver care. Anywhere you see the “eyeglass” icon, enjoy a companion resource written through the lens of patients and families.



INTENTION

The intention of reflecting on this white paper through the lens of patients and families is to support patients, families and PFAs by providing a more relatable entry point for The Beryl Institute’s resources. This accessibility through a peer voice enables patients, families and PFAs to be more effective and engaged members of the PX Community.

Each of these reflections fits within the Experience Framework. This reflection falls under the following Strategic Lens(s):

PATIENT, FAMILY AND COMMUNITY ENGAGEMENT

The “Why”

Central to any experience effort are the voices of, contributions from and partnerships with those receiving care and the community served.

The “Impact”

When the experience of patients and families are included in all of the organizations’ processes and executive leadership strategies, patients and families feel respected and valued as both integral part of their care experience.

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I often tell people that I am the epitome of the Sandwich Generation, having many years of experience as a caregiver to my grandmother and my parents before having children of my own and becoming a caregiver to them. As an active member of my community, I have become an unofficial advocate and guide to others as they navigate the healthcare system. I “officially” became a Patient and Family Advisor in 2016 when I joined the Patient and Family Advisory Council at Cambridge Memorial Hospital in Cambridge, Ontario, Canada, now serving as the Chairperson. Through my work at Cambridge Memorial Hospital, I was introduced to The Beryl Institute and I have found my passion! Receiving The Beryl Institute’s Innovative Patient Family Advisor Award in 2020 was a proud moment for me and inspired me to join the Global Patient and Family Advisory Board, where I have collaborated with other Patient and Family Advisors to present at Patient Experience and Quality Conferences. I recently obtained my CPXP designation and continue to advocate for kind, accessible and appropriate care in my community.

AUTHOR'S PERSPECTIVE

As a patient, family member and caregiver, I have had many unique and diverse experiences related to healthcare or the healthcare of a loved one. It is easy to share a positive experience, but so much harder to share when it is the opposite. Whether the care itself was competent is not enough, but how the entire experience makes the patient and family member feel is of the utmost importance. Too often patients and family members are afraid to speak up and ask even the most general questions about their care, let alone let the practitioner know that they are not satisfied.

Through my work with the Patient and Family Advisory Council at Cambridge Memorial Hospital, I often bring feedback from patients and family to the attention of Patient Relations. The value in this feedback is the opportunity for healthcare providers to use this to improve not just the specific patient’s experience, but to bring about positive change for others in the future.

GENERAL SUMMARY

“While low numbers of complaints may be viewed as positive under the assumption that patients are satisfied with their care, this may also be reflective of under-reporting, which may be associated with cultural issues and fear of sharing complaints.” (P 11).

Quite often, as a patient or family member, we are fearful of repercussions if we are to speak up or challenge the care provided, myself included. Recently, my daughter had an appointment with a physician over the phone that lasted all of six minutes. The provider was abrupt, inattentive and dismissive. Despite knowing full well that this interaction was not productive, I considered whether or not to actually say something about it. By doing so, I risked being disliked by the provider and being labeled as a complainer. As a parent, caregiver and advocate, I know it is not appropriate, and as such, I reached out to share my experience with Patient Relations with the hope of an improvement in our future interactions.

I want more than an apology; I want to know that my feedback is valued and will be used to improve the experience for others, including patients, family and providers. When I hear of multiple patients and family members sharing the same complaint or concern, it frustrates and concerns me as they are giving the organization an opportunity to learn from and improve. It is not easy for a patient or family member to speak up, especially when they are feeling most vulnerable. Feedback that is not used to make experience better for others is wasted.

Key Points to Consider as a Patient or Family Caregiver

“In some healthcare organizations, the patient advocacy role may be seen by staff as exclusively focusing on and supporting patients and not necessarily (on) staff” (P 18).

I often say that patient experience is not a “the customer is always right” mentality, but rather if the patient and family member is satisfied and views their experience as positive, then it makes for a much more pleasant provider experience. **Patients and families have the opportunity to help shift the perception about caring being limited to the patient.** By embracing the “human experience,” we can build a truly collaborative approach to healthcare.

CONCEPTS, IDEAS OR PRACTICES WORTH SHARING WITH YOUR ORGANIZATION

There is no question that the past two years have been beyond difficult for patients and providers alike. Our healthcare system has been stretched beyond its capacity and has been both physically and emotionally exhausting for everyone.

Some organizations are using a collaborative approach with their Employee Wellness or Engagement Teams to design ways to support staff. These programs may help the workforce reconnect to aspects of their roles that bring them the most joy, translating that into the care they provide to their patients. **Patient and Family Advisory Councils and Patient and Family Advisors could further support this collaborative approach through storytelling.**

Organizations must demonstrate a “commitment which fosters a culture of valuing patient feedback. Patients and families need to feel that the organization cares about their experience.” (P 16) As Patient and Family Advisors, we must **challenge our organizations to take this feedback seriously, investigate and respond appropriately in a timely manner.** In many cases, a PFA shares their experience in an effort to make improvements for the next person.

FINAL THOUGHTS

The feedback provided by patient and family members is of the utmost importance for many reasons. As stated in the title of this white paper, it is a hidden gem and offers much more to the healthcare provider and organization than criticism. It is an opportunity to improve upon the experience of care for the patient, family members and the provider, and in doing so can improve the processes at the organizational level to bring about meaningful change for all so that we **elevate and improve the human experience in healthcare.**