

## Patient Partnerships: Three Levels of Change

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I suffer from multiple chronic diseases. For the past 45 years, as a severe hemophiliac who became infected with HIV and hepatitis C after receiving tainted blood in the 1980s, my journey has taken me through several of Canada's healthcare systems. When I was first diagnosed with hemophilia in the 1970s, I was fortunate to experience cutting-edge care environments. Sadly, they are still widely considered state-of-the-art to this day. Those environments were “cutting edge” because patients and families were put at the centre of the clinical process, recognized as partners who were able to draw on their experiential knowledge and to develop their own care skills. My family and I were regarded as full-fledged members of the clinical team whose objective was not only to heal me, but also to increase our collective self-reliance.

I was fortunate to have been surrounded by an interdisciplinary team, which included a physician, a nurse, a physiotherapist and a psychologist. I was involved in the development of my care plan and I played an active part in the decision-making process regarding my treatment options. I was also trained to recognize events that could

potentially be harmful to my health, how to react to them and how to self-manage if necessary. At the age of 6, I knew how to self-infuse and I had acquired sufficient skills to be marginally autonomous. My parents and my grandparents were also trained to monitor and look after me. In short, we were true partners of care, and I was convinced that all care settings worked that well. How wrong I was.

When I became HIV positive in the 1980s, I realized that, in fact, only a small fraction of care settings shared this philosophy. Very few of them were truly centred on the needs of their patients and worked in partnership with them. Even today, much remains to be done, because a massive cultural shift must occur to get to this end state, both in terms of managing healthcare services and transforming collaborative practices between healthcare professionals and patients.

The 10 case studies gathered here describe patient-centred experiences of care as well as care that is provided in partnership with patients. The accounts remind me of my own past experiences, and it is for this reason they affect me deeply. The merit of this type of care seems intuitively obvious, but it still primarily occurs in forward-thinking care settings and it remains difficult to scale up such care. Yet, the outcomes presented in these case studies clearly show the need to do things differently in order to meet the tremendous challenges posed by the integration of chronic disease management and the growing desire of patients to be recognized as partners in their own care.

These case studies also help us understand the key success factors for implementing such approaches. Indeed, they underscore how important it is to implement these changes on several levels simultaneously to ensure their success. The first level pertains to governance and the need to have strong, resolute leadership to manage the change, starting with the Canadian Foundation for Healthcare Improvement (CFHI) at the national level. The second level relates to the settings that are affected by change and the need to fully and systematically integrate patients and families in projects in order to draw on their wealth of experiential knowledge and to acknowledge that they are vital partners of change. The third level focuses on supporting individuals and the need to train and systematically support managers, health professionals, patients and families.

### **First Level: Governance and Leadership**

Strong leadership to support the implementation of an initiative is a common feature presented in all the case studies. Leadership that is generally exercised at all decision-making levels, including operations, seems to be an absolute prerequisite to successfully implement such a cultural shift. One of the most remarkable examples of such strong leadership can be found at Kingston General Hospital, where the role of the chief executive officer and her management team is essential to the overall deployment and sustainability of patient involvement across the organization. It should also be pointed

out that when management demonstrates strong leadership, it allows real patient leadership to grow, which, in turn, ensures that patients' voices are heard at all levels and genuinely make a difference. In the case studies, it is also apparent that shared leadership must sometimes embrace a community focus (e.g., Northumberland Community Partnership), a clinical focus (e.g., Whittington Health), a hospital focus (e.g., Cincinnati Children's Hospital Medical Center) or even a government focus (e.g., Saskatchewan Health Quality Council and Saskatoon Health Region). In short, the 10 case studies show that a variety of paths can be taken, but success largely depends on enlightened managers who work in close partnership with influential patients.

### **Second Level: Systematic Patient Engagement**

Quite incredibly, the quality movement in healthcare has often ignored the voices of patients and families. In fact, it has been difficult for healthcare institutions to recognize the extraordinary added value provided by the experiential knowledge derived from living with a disease and its relevance when considering the evolution of our healthcare system. In this regard, another strength of these case studies lies in their ability to reveal to what extent this type of knowledge is crucial to the implementation of a relevant and innovative project. Whether it's to improve patient safety and experience (e.g., Kingston General Hospital), to transition toward patient-centred approaches and partnerships in care (e.g., Patients as Partners), to design health services (e.g., McGill University Health Centre) or to teach health sciences students (e.g., Augusta University Health System), these case studies illustrate the immense wealth of knowledge patients and families can contribute to opening up new potential solutions, fostering greater humanity in care interactions and enhancing the healthcare system's effectiveness. In addition, patients and families provide a systemic perspective of the care experience that extends well beyond the walls of a hospital and includes local community services (e.g., Northumberland Community Partnership) and the daily management of their own environment.

### **Third Level: Support and Training for Partners**

In order to ensure the success of these projects and to engage patients in their implementation, nothing should be left to chance. Rather, the case studies reveal just how important it is to design partnership approaches by working rigorously and in accordance with the best available models. It is also apparent that support (if not training) and follow-up are necessary for all partners. Co-building, co-designing, co-managing and other collaborative activities are not necessarily natural concepts, and they demand a certain level of change management for all participants, whether they are patients, families, leaders or healthcare professionals. For instance, the Cincinnati Children's Hospital Medical Center has built customized training programs to support its initiatives; the Northumbria Healthcare Trust created an official director of patient experience position to manage the whole process; and the Patients as Partners program developed infrastructure to support optimal expertise and knowledge sharing among all partners.

As a patient myself, reading these case studies has given me encouragement through their varied portrayal of the development of shared leadership between patients, health-care professionals and leaders. I believe that patients and families will increasingly have the opportunity to be at the centre of their care experience, guided and supported as I was in hemophilia clinics, and that this will gradually become the norm rather than the exception. Drawing lessons also from what the Université de Montréal has done since 2010 in deploying the *Direction collaboration et partenariat patient* program across all sectors of care, research and teaching, I also believe that the cultural change will need to be supported by all levels of government to ensure its sustainability and success on a larger scale. In fact, CFHI's leadership in this matter has been exemplary, and I hope it will pull along other institutional leaders in its wake who will, in turn, also contribute to accelerating change.