Supporting Client and Family Engagement in Care Through the Planning and Implementation of an Online Consumer Health Portal

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Abstract

Web-based portals and electronic health records are making it easier for clients and families to access health information. This improved transparency and access to information has the potential to promote activation and improve outcomes, but to realize these benefits, the information needs to be valuable, meaningful, and understandable. Engagement of the end users in the planning and implementation will ensure that the product meets the needs of the consumers. The purpose of this case study is to describe the client and family engagement strategies that were employed to support the process of planning and implementing an online consumer health portal at a pediatric rehabilitation hospital to support the successful launch of this new information-sharing technology platform.

Keywords

patient activation, client and family engagement, consumer health portal, electronic health record

The existence of Web-based portals and electronic health records is making it much easier for clients and families to access health information in a timely and convenient manner, and this access has the potential to promote the activation. Activated healthcare consumers are those who have the skills, knowledge, and motivation to participate as active members of the team and to manage their care (1,2).

However, it is not solely access to the indiscriminate elements of health information that creates activated healthcare consumers. The information needs to be valuable, meaningful, and understandable to have the desired effect (3).

The purpose of this case study is to describe the client and family engagement strategies that were employed to support the process of planning and implementing an online consumer health portal called connect2care. Patient engagement and patient activation are often used interchangeably in the healthcare literature. For the purpose of this article, engagement refers to the actions and efforts of the project team to involve clients and caregivers as active participants in the planning, development, refinement, and evaluation of our connect2care portal. This definition is aligned with The Canadian Foundation for Healthcare Improvement's (4) notion of patient engagement. Patient engagement describes how patients and families are involved to shape healthcare services more broadly, whereas patient activation is more individual and

speaks to the beliefs and behaviors of the healthcare consumer with respect to his or her own healthcare.

Facilitating access to health information and appointment schedules and connecting consumers with their clinicians online promote overall transparency in healthcare delivery and can support the activation of consumers as active partners in care.

A large children's rehabilitation hospital in Toronto, Canada, successfully received federal funding to implement a consumer e-health solution as a result of the planned integration of the client and family voice from concept development through to full implementation.

This engagement was facilitated by the existence of a well-established, robust structure in the hospital called the Family

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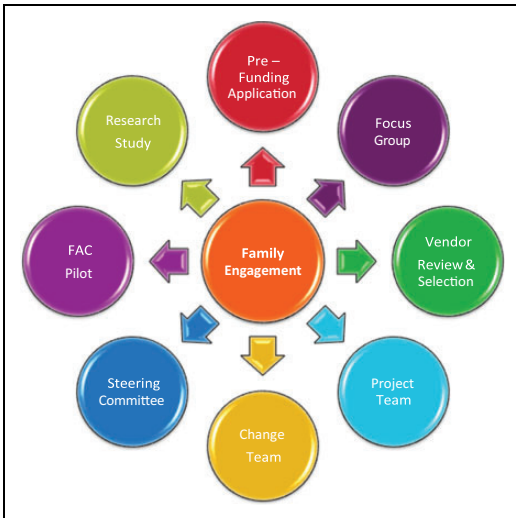Email: jmaxwell@hollandbloorview.ca

Figure 1. Client and family engagement.

Leadership Program. The program, which was formed in 2011, boasts 140 volunteer family and youth leaders who are committed to contributing their expertise, time, and lived experiences to help inform decision-making across the organization.

Representatives from the Family Leadership Program were recruited and engaged in a number of formal and informal ways throughout the process (see Figure 1).

Concept Development Phase

The early portal project team, including family leaders, partnered to define how to optimize the benefits of a portal. It became clear that for the portal to be successful, it would need to be shaped by the needs and wants of our clients and families to ensure the portal was valuable and supported activation in care. The proposal emphasized the organization's commitment to client and family-centered care and detailed the planned engagement strategies that would be employed throughout planning and implementation.

Stakeholder Focus Group

Following confirmation of funding, a focus group of families, clients, and clinicians was held to prioritize the functions and features required to maximize the benefits of the portal, to explore potential challenges, and to consider future enhancements.

Features that were considered of high value included:

- secure 2-way messaging with care providers,
- clinical documentation to support self-management,
- access to appointment schedules and appointment information,
- e-mail reminders of new information and upcoming appointments,
- assurance of privacy of information,
- an easy-to-find medical history that could be shared with other providers,

- a list of providers, their roles, and contact information, and
- a list of current medications.

Ideas for future enhancements included:

- ability to reschedule or request appointments through the portal,
- ability to contribute to the record or import reports from other providers,
- link to records and appointment schedules from other hospitals,
- ability to share picture or video files via the 2-way messaging,
- previsit screening tools, and
- education materials and resources specifically related to their care needs.

Vendor Review and Selection Committee Involvement

Requirements gathering and vendor selection were conducted with full participation of family leaders. Once the vendor selection was formalized, a committee structure, including a steering committee, project team, and change team, was initiated to support the range of activities required to integrate this new tool into practice. Client and family leaders were recruited as members on all committees, partnering with frontline clinicians, managers, and project leaders. The committee structure is attached (see Table 1), with the accountabilities of each committee outlined.

The family voice at the portal change team was particularly valuable. This committee, which is comprised largely of frontline clinicians, was the forum for many discussions around practice changes related to the implementation of the connect2care portal. With respect to documentation, the ease of accessibility to clinical notes afforded by the portal created challenges for some clinical staff. The voice of the family leaders helps to increase the awareness and understanding of the importance of sharing of clinical documentation and allowed for dialogue around how to shape documentation to best support involvement in care and activation. There is much more to be done to improve documentation to support activation, but family leaders have been instrumental in helping articulate why this is so essential.

Additionally, the change team members also grappled with the new work flow and process changes related to the implementation of the 2-way messaging. Although challenges remain, the voice of families was critical to changing perceptions and emphasizing the opportunities of secure messaging, and there are now over 100 clinicians available via messaging throughout the hospital.

Family Advisory Committee Pilot

Toward the end of 2014, an initial version of the portal was ready for live implementation. In advance of a broad launch

Table 1. Family Leader Involvement in Key Committees.

Committee	Mandate/Accountability	Reports to	Membership
Steering committee	Guidance and strategic leadership Key decisions	Chief executive officer (CEO) and senior management team	Executive sponsors Senior leaders External funding partner Project leaders 3 Family leaders
Project team	Day-to-day implementation and management of the project	Steering committee	Project manager Project leads and key staff 2 Family leaders/enrollment leaders
Change team	Support change across the organization Inform implementation and education plans	Steering committee	Internal stakeholders and champions Clinical staff Operations leads 4 Client and family leaders 1 youth leader
Requirements gathering and vendor selection	Define parameters for Request for Proposals (RFP), review RFP responses, and make recommendation to steering	Steering committee	Project team leadership 2 Family leaders

planned for January 2015, the hospital's family advisory committee (FAC) members were engaged to provide testing and feedback around the enrollment and registration process as well as reviewing the portal content. Their survey feedback informed refinements to the process and tools prior to the live launch in early 2015. For example, the FAC provided feedback on how to improve the enrollment forms and they asked a number of questions that helped shape a frequently asked questions document. In addition, the FAC pilot identified that few youths were able to provide 2 pieces of picture identification, so the enrollment process was modified to accommodate this reality. Finally, the FAC pilot also provided learnings related to technical challenges such as the need to upgrade the battery on the mobile computer trolley and the need to clear the cache every night on the iPads that were being used for enrollment.

Research

A formal research study looking at the impact of the portal on client/family activation and communication with providers is underway with a family leader included as a co-investigator. In addition to the formal research, evaluation includes monthly reporting of the number of enrolled users and the number of unique log-ons (uses). The number of 2-way messages sent and received is also monitored monthly, as is the number of cancellations and requests for appointments that are made via connect2care.

Enrollment Leaders

A final example of the central role of families in the portal implementation is the decision to hire 2 family leaders to lead the enrollment efforts. These family leaders were actively involved in the development of all enrollment materials (forms, education materials, communication materials, instructional videos). As enrollment leaders, these

individuals spent time with each client and family explaining the value of the portal from their own personal experience as well as being able to share the stories of other families that had enrolled. The enrollment leaders answered questions, allayed concerns, and provided resources to optimize use. They utilized their access to a network of family leaders to encourage new enrollment and actively sought out opportunities for enrollment in waiting areas, in clinic rooms, at evening and weekend programs, and in the hospital community settings. Their active involvement in enrollment facilitated ease of communication with portal users and provided a unique perspective on all aspects of the process. Early enrollment numbers were well in excess of targets. By midyear, 608 clients and families had enrolled, representing 84% of the full-year target of 721. Uses (log-ins) was also well in excess of targets at midyear with over 2400, surpassing our first-year target a full 6 months ahead of schedule.

The engagement of family leaders as enrollment leaders was instrumental in this early success. To clients and families, the family leaders are credible champions of the portal as they can speak to the value of connect2care based on their own personal experiences. The sustainability of this model is unclear, however, it is clear that ongoing enrollment will require specific resources and defined accountabilities to ensure continued success.

Discussion and Conclusion

As evidenced in the literature (5,6), clients and families are seeking more information and greater transparency. The accessibility of information afforded by a portal has the potential to address these information needs and change the dynamic of control over the health information in very significant ways (7,8).

The research suggests that access to clinical notes could improve understanding of health, foster productive communication, stimulate shared decision-making, and ultimately

lead to better outcomes, improved patient engagement, and quality of care (9,10).

What is often missed in the implementation of healthcare technologies is that the degree to which such incredible benefits can be reaped is necessarily linked to the degree to which the technology meets the needs of the users (11,12). If the features are not the right ones, or they are not presented in the right way, uptake will be poor. The mediocre success of early portals might be attributed in part to the fact that they typically provided access to test results and medications but rarely the notes of clinicians (3,13). More than test results, they are seeking information that helps them in actively managing their health and understanding the care that is being provided. In other words, they want to be activated healthcare consumers.

This case report highlights that consumer engagement is an instrumental success factor for all stages of development and implementation. A model that engages clients and families in the identification and selection of the solution, the prioritization of features, the development of processes, and the implementation of the tool is, by design, more likely to ensure that the solution meets the needs of the consumers.

Declaration of Conflicting Interests

Funding

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Author Biographies

Joanne Maxwell is Project Manager, Clinical Adoption and Transitions Strategy Lead at Holland Bloorview Kids Rehabilitation Hospital in Toronto. Joanne has held a number of operations and project management leadership positions in healthcare over her 20 year career. In her current role, Joanne leads the activities related to improvement and enhancement of the Electronic Health Record with a focus on change management, interprofessional collaboration and client and family engagement. Joanne has a clinical background in Occupational Therapy and is a certified Project Management Professional.

Laura Williams is the Director of Client and Family Integrated Care at Holland Bloorview Kids Rehabilitation Hospital. Laura has worked extensively in the field of healthcare in adult and pediatric settings in both frontline and leadership roles. She has successfully implemented new programming in several healthcare settings, with a specialty in family supports and family-centred care integration. Laura has been Co-Chair of the Canadian Family Advisory Network and co-ordinates the annual symposium on family-centred care in pediatric health systems.

Keith Adamson is the Senior Director for Collaborative Practice at Holland Bloorview. Keith brings more than 20 years of professional experience in clinical, management and professional practice leadership roles with a focus on the development and implementation of best practices in inter-professional collaboration. Keith's primary area of research has been inter-professional collaboration and its impact on patient care.

Amir Karmali joined Holland Bloorview as a parent advisor after his son went there for rehab after a sporting accident. He now oversees the Family Leadership Program at Holland Bloorview and is the staff lead for the Family Advisory Committee and the Bloorview Research Institute Family Engagement Committee. Amir is also a certified healthcare simulationist and teaches client and family centred care principles to all new clinical staff, existing staff and students through the use of simulations.

Becky Quinlan is a family-centred care specialist at Holland Bloorview Kids Rehabilitation Hospital. As an educator, Becky's professional career has spanned management of adult education programs to teaching very young children with disabilities in specialty settings. Becky is committed to advancing client and family-centred care and patient activation in care. She is currently an enrollment lead for the connect2care project at Holland Bloorview, an online tool providing access to the medical record and scheduling functions. Becky also shares her insights of the health system due to her experiences with her son, Jack, who has been treated in both and acute and rehabilitation settings.