The Role of Information Governance in the Implementation of Patient Portals

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A robust information governance program helped the National Institutes of Health Clinical Center (NIHCC) in a successful patient portal implementation and guided the organization through its project transition. The NIHCC, which is often referred to as America's Research Hospital, maintains an electronic health record (EHR) called the Clinical Research Information System (CRIS), which supports approximately 3,200 users and interfaces to all of the typical clinical information systems.

As was the case at NIHCC, health information management (HIM) professionals are positioned in their organizations to guide and lead efforts like the patient portal implementation. As patient information navigators, HIM is responsible for ensuring patients and their care providers have the information necessary to provide safe and timely healthcare. HIM professionals are also experts in recommending and establishing policy around patient confidentiality and health information release.

Overwhelmingly, the patient portal at NIHCC has positioned patients to be well informed in a timely manner about their clinical information and test results. They are able to review the information and come prepared to visits with questions as necessary, both about results and research studies in which they are participating.

History of the Portal Project

In 2012, NIHCC first approached the idea of implementing a patient portal in order to provide patients with an easily accessible electronic view of their medical record. NIHCC's Patient Advisory Group heavily supported the organization moving forward with implementation along with the Medical Executive Committee (MEC).

NIHCC went live with its initial stand-alone patient portal in July 2013. The portal was very simplistic and met the needs of the organization at the time. Care providers and the patients they served were both able to easily adapt to the implementation.

While patients were generally pleased with the patient portal, it was clear that there were opportunities for improvement. Discussions began in 2015 regarding the transition of the patient portal to a personal health record (PHR). Initial concerns regarding this transition centered on the fact that existing patient accounts would not transfer to the new system as well as the inability to customize the new patient-facing website for organizational-specific information. Realizing the greater potential of such an upgrade, the organization moved forward and implemented the PHR in January 2017. The PHR would ultimately include such capabilities as appointment viewing, secure messaging, and a mobile application.

A PHR goes beyond the patient portal by giving the patient control of the health record and allowing the inclusion of data from multiple organizations as well as by the patient.[1] While still EHR-tethered so that results and documents may be released to the PHR, patients who seek care through other organizations using the same EHR system will have only one account where all of their records reside.

One of the many positive aspects of the new system included a mechanism to send automated email invitations to join the PHR to patients as well as the permanent transfer of information from the EHR to patients' accounts, no longer requiring that they have a separate account for the stand-alone patient portal. Ultimately, NIHCC transitioned to a vendor product.

Information Technology Governance

Information technology (IT) governance involves processes to guide the review, selection, implementation, management, monitoring, and setting of the IT roadmap representing the organization's business owners, stakeholders, and IT staff.[2] For

NIHCC, all information technology system requests must be routed through an IT governance process beginning with a request to the Information Technology Advisory Governance (ITAG) committee.

As a new concept to the NIH community and organization, the request to implement a patient portal required significant education for stakeholders. The first step for the request was to define a patient portal and the desired outcomes of the system. The Office of the National Coordinator for Health Information Technology (ONC) defines a patient portal as a secure website for patients that provides access to data stored in one organization's EHR, including lab results, medication lists, and clinical documentation; gives patients the capability to request medication refills, schedule appointments, and review billing; and enables secure messaging with the care team. Using this definition, the chief of NIHCC's HIM department submitted the request to implement the portal.

Upon receipt of any IT project request, the ITAG facilitator works with the requester to develop a business plan, project scope, and project charter. The project is then submitted to ITAG for review and scoring based on strategic alignment, areas of benefit, operational efficiencies, quality of care, patient satisfaction, patient safety, number of patients impacted, and number of research protocols impacted. Based on the scoring, projects are recommended to the chief executive officer for final consideration and approval. The portal project was highly endorsed, approved, and submitted to the Department of Clinical Research Informatics (DCRI) for scheduling.

DCRI convened a project management team to support the effort. Based on the patient engagement component, the data policy aspects, and the complex technical components, the project management team leadership included representatives from NIHCC's business, clinical, and technical teams. The business side included the chief of HIM, while the clinical side included a representative of the patient safety and clinical quality team. The technical side included a lead project manager from DCRI as well as a clinical informatics lead.

Information and Data Governance

NIHCC leveraged its information governance (IG) structure to ensure a project of this magnitude was successful. A strong IG program highlights the organization's commitment to managing information and recognizing that it is a valuable asset.[3] For the patient portal implementation effort, the IG structure ensured organizational policies were in place to support the implementation.

Within IG, data governance is another key consideration in the implementation of a patient portal. Data governance involves defining, managing, and monitoring data, data use, and data policies and practices to maintain the integrity, privacy, and security for all data assets within the organization. In a healthcare organization, examples of procedures and practices managed and monitored under data governance include the monitoring and resolution of duplicate medical records and the practice of "cut and paste" in clinical information systems.[4] Data governance aspects of a patient portal and a personal health record include data transparency, system access, authorization, and data integrity.[5]

To work in conjunction with the project management team, NIHCC assembled a workgroup to review the data and information governance impacts presented by the patient portal project. Specifically, these components included the types of data that would be provided, time frame in which the data would be provided, functionality of the system, and how the data would be stored and managed. This workgroup was comprised of clinicians, researchers, clinical department representatives, nursing staff, and hospital communications staff. The project management leadership team met weekly to discuss project status and ensured it remained on schedule. The entire patient portal workgroup met along with the project management team on a biweekly basis to review the IG and organizational requirements of the patient portal.

In parallel, the technical team also met along with the project management team to review each of the items recommended by the workgroup. They identified all configurable options available within the system. Project management leadership presented these options to the entire workgroup and they reviewed all options for each setting. Project leadership then presented recommendations from the workgroup to the MEC for final approval. Once approved by MEC, the workgroup wrote policies to support the final decisions.

Technical and Policy Decisions

The implementation of the organization's patient portal required many complex technical discussions and decisions. The project management team and executive sponsors very deliberately kept the highly technical discussions separate from the portal's workgroup, which included clinicians. The project management team did not want clinicians and others to feel overwhelmed or disinterested in the project by having to sit through many of these discussions. The workgroup made recommendations that were forwarded to the technical team to discuss and consider potential technical solutions to meet those needs. The workgroup was also responsible for recommending organizational policies ultimately reviewed and approved by the MEC.

During the implementation phases of both the initial patient portal and the PHR, discussions revolved around which results and documents to release and the timing of those releases. Ultimately, the workgroup categorized each result into one of three groups: results that would never be released, results that could be manually released by an NIH provider, and results that would automatically be released within a specified time frame of posting as final in the EHR. The document types approved to be made available included discharge instructions, discharge summaries, and initial outpatient encounter reports.

The workgroup also spent significant time discussing the result release timing parameters. The greatest concern among team members was that patients may view results prior to their NIH care team discussing them. The workgroup decided that the best approach was to start with a lengthier release time frame to give the organization time to become accustomed to the use of a portal and then adjust it as necessary. Initially, lab results and other non-imaging results were sent to the portal after seven days, imaging results were sent after 14 days, and more sensitive results required manual release by providers (pathology, HIV, pregnancy).

With the implementation of the vendor product, the organization had an opportunity to reconsider what results and documents were made available to patients and the timing of the availability. The patient portal workgroup conducted benchmarking with other facilities and ultimately recommended including additional document types such as consultation, history and physical, examination, and procedure reports. All documents are made available immediately once finalized in the EHR. Additionally, the result release policy was modified so that all results—other than imaging results—were immediately released to the portal once they were finalized. Imaging results were sent 72 hours following finalization and other sensitive results continued to be only manually released by clinicians.

Project's Next Steps

The organization plans on sending another round of surveys to continue to gather information to improve the patient experience. Plans for expanding functions include the ability for patients to complete forms that can be accessed by the clinicians in the EHR and tele-visits for remote follow-up. NIHCC also is working toward the ability for patients to pre-register online and submit consents electronically.

Notes

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