

Development and Preliminary Evaluation of a Patient Portal Messaging for Research Recruitment Service

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Abstract

The electronic medical record patient portal offers great potential to engage patients in research. This paper describes the development of an institution-wide service to support patient portal messaging for recruitment of research participants and pilot results. The service assists investigators in identifying eligible potential study participants through the electronic medical record and delivering study invitations through patient portal messaging. The effectiveness of patient portal messaging in comparison to traditional recruitment methods is described.

Introduction

With the proliferation of electronic medical record and accompanying tools including patient portals, researchers conducting studies on human subjects are increasingly leveraging electronic methods of cohort identification, recruitment, and data collection. Failure to efficiently recruit sufficient numbers of participants is commonplace, with substantial consequences, including increased trial costs and delays in generating and translating research findings.(1–3) Electronic methods of recruiting and administering surveys have the potential to save time and cost compared to traditional methods.(4) The patient portal serves as a technology platform for healthcare systems, including healthcare providers, to securely connect with patients and coordinate care, and has great potential to engage patients in research.

The mandated meaningful use criteria of the Centers for Medicare and Medicaid Services Electronic Health Record Incentive Program includes providing secure messaging between the patient and provider and ability to send patient reminders for preventative services.(5) Patient portal messaging has been shown effective as a patient engagement strategy. For example, the use of patient portal secure messaging as a one-way communication tool for preventative care and appointment reminders found that it successfully decreased missed appointments and encouraged higher usage rates of preventative services.(6) Sending messages to patients through the patient portal allows their contact and health information to remain within the secure environment of the electronic medical record. The patient portal can engage patients in research through notification of research opportunities, recruitment, consent, survey administration, and participant retention efforts such as disseminating study newsletters and results.

The limited available evidence suggests that patient portal messaging may be more effective than email, while also being cost and time efficient compared to traditional recruitment methods. A surgical research study found that there was a 14% enrollment rate using patient portal messaging recruitment, and there were similar demographics between participants recruited from both patient portal and traditional methods.(7) Findings indicate that secure message reminders are most effective when they are tailored to population and context.(6) However, the majority of research exploring the effectiveness of patient portal as a recruitment tool was done in situations where the providers recruiting the participants had an ongoing relationship with their provider.(8–10) An institution-wide patient portal messaging recruitment service differs by allowing investigators to send patient portal messages to patients within the health system for whom the investigator is not a provider. Rigorous evaluations and comparisons of recruitment strategies are sparse.(11–13) Examining whether patient portal messaging is an effective, cost-efficient, and well-received recruitment strategy is essential to determining whether it is worth devoting resources to employ an institution-wide patient portal messaging recruitment service.

The purpose of this paper is to describe the creation of an institution-wide patient portal messaging recruitment service, and to report patient satisfaction with the service and the effectiveness of the service in comparison to traditional methods.

Methods

A team of data analysts, experts in research participant recruitment methods, and experienced clinical researchers collaborated to create the patient portal messaging recruitment service. By creating an institutional service, we are promoting an efficient process for studies seeking to use this recruitment method and proactively addressing concerns regarding satisfaction and privacy among patients within the health system. We have engaged key stakeholder groups including the Johns Hopkins Hospital Patient and Family Advisory Council, health system clinicians, the Johns Hopkins Medicine Institutional Review Board, and the Center for Clinical Data Analytics in establishing the service. Initial policies developed as a result of stakeholder input include: 1) one-time messaging per study, 2) limited frequency of messages to any given patient, and 3) simple opt out process for patients who prefer to not receive recruitment messages.

We worked with two study teams led by experienced principal investigators to pilot the service. The multi-stage process is detailed in Figure 1 and includes: 1) Institutional Review Board approval, 2) Clinical data analysts creating a computable phenotype using the study team inclusion and exclusion criteria and applying this computable phenotype to query designated electronic medical records, 3) Electronic Medical Record Research Team creating a workbench report based on the computable phenotype that updates weekly and is accessible to the human subjects research trained recruitment service team member, 4) Recruitment team member sending bulk messages to the potential participants identified, and 5) Patient responding to study team to learn more about the study or opting out of patient portal recruitment messages. Prior to roll-out of the service, the Vice Dean for Clinical Investigation sent an email introducing the patient portal recruitment strategy to clinicians so they would be prepared to answer questions that they might receive from patients.

Through an iterative process, the recruitment service is working closely with the institutional review board to develop required elements for inclusion in patient portal messages. Any patient portal message sent for research recruitment must contain 1) directions on how to opt out of receiving research recruitment messages, 2) directions on who to contact for more details regarding the use of patient portal for research, and 3) a link to a “Frequently Asked Questions” webpage specific to the use of patient portal messaging for research. In addition, the patient portal “Terms and Conditions” were updated to include a statement notifying patients that the portal may be used to send research messages and directions on how to opt out of receiving these messages.

Once the studies receive institutional review board approval, they meet with the clinical data analytics team to identify eligible participants through electronic medical records. The study team works closely with the clinical data analytics team to determine how to apply their inclusion and exclusion criteria to the available electronic medical record data to discern eligible study participants. The result is a computable phenotype, a Structured Language Query (SQL) code identifying the desired study population. The Electronic Medical Record Research Team applies the computable phenotype to the electronic medical record, and the application of the computable phenotype results in a workbench report of patients that meet the study’s criteria. An iterative process is required to refine the phenotype and optimize sensitivity and specificity. Messages were tested in a “practice” environment to reduce risk of errors in mass messaging. A recruitment staff member trained in human subjects research is given access to the report in the electronic medical record and is responsible for sending bulk patient portal messages to the identified patients. During the pilot phase of the service, we are administering a brief, 3-item survey to assess patient perceptions of patient portal use for research recruitment messaging.

The patient portal messaging committee oversees the patient portal messaging service. The committee meets monthly and includes experts from the Institutional Review Board, clinical data analysts, and Electronic Medical Record Research Committee. The committee collaborates with patient advocates and clinicians to ensure they are maximizing the effectiveness of patient portal messaging recruitment and minimizing any burden for patients and clinicians. This committee is responsible for overall governance of research endeavors using the patient portal, and creates and refines guidelines and policies related to the use of electronic medical records for recruitment.

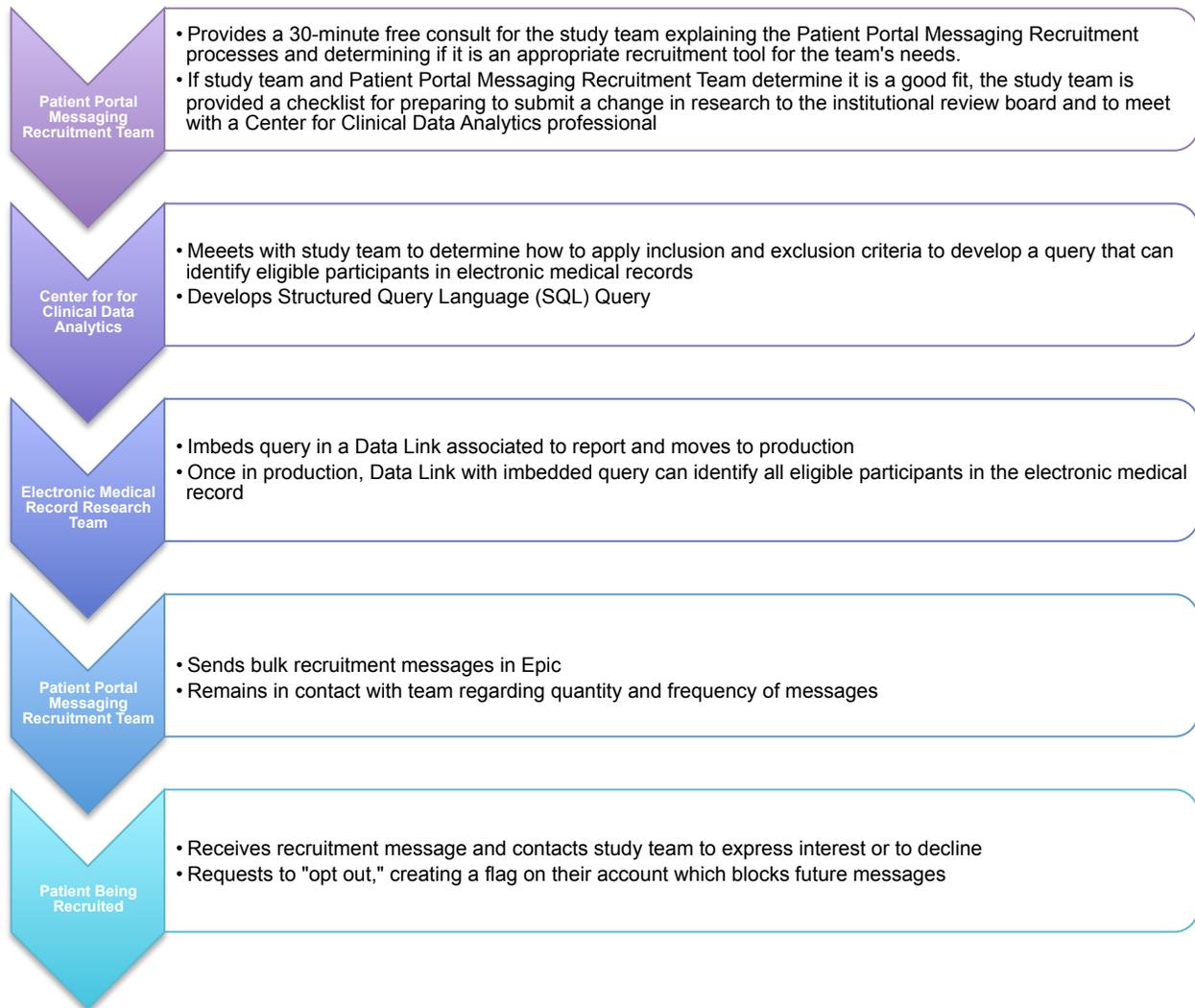


Figure 1. Process for Patient Portal Messaging Recruitment

Results of Pilot Efforts

Patient portal messaging for recruitment, consent, and survey administration was piloted with a longitudinal cohort study investigating patient-reported outcomes in atrial fibrillation patients. Potential participants were identified through electronic medical records using a computable phenotype with the inclusion and exclusion criteria. The query to identify patients in electronic medical records included: atrial fibrillation ICD9 and 10 codes, at least 3 non-emergency department visits within the last four years, age ≥ 18 . The query excluded participants if they received the diagnosis of AF one month after cardiac or abdominal surgery, one month before or after a thyroid-related issue, and 12 months before or after prescription for methimazole or propylthioracil. The effectiveness of and patient-reported satisfaction with patient portal messaging in comparison to other recruitment methods and patient reported satisfaction with patient portal messaging was examined. Multiple strategies including email, patient portal messaging, post mail, in-clinic, and telephone calls were used to recruit participants. Identified potential participants were contacted with study invitations through in-person, email, phone, patient portal messaging and post mail techniques to ensure a representative sample. Potential participants were approached in clinic or called only after receiving a post mail or email indicating their interest in learning more about the study. Ultimately, 6,666 participants were contacted, 5,363 through post mail, email, telephone, and in-clinic, and 1,303 through patient portal messages. 5% (n=318) participants were enrolled.

Of the 5,363 potential participants contacted through post mail, email, telephone, and in-clinic, 3.5% of participants (n=191) enrolled (figure 2). Patient portal messages were sent to 1,303 potential participants and 9.7% of those participants (n=127) enrolled in the study. In preliminary analyses, the patient portal recruitment rate (9.7%) was significantly higher than the recruitment rates of email and post mail. The majority of the participants recruited were white (91%), male (67%), and were on average 70 years old (± 10).

The vast majority (91%) of patients reported that research recruitment messaging was a good use of the patient portal, and only 1% reported that it was not a good use. One patient contacted the recruitment team with concerns that her privacy was violated and staff clarified that her information had not been distributed. The majority of patients (59%) reported that receiving the recruitment message through the patient portal did not change their satisfaction with being a patient at the medical institution. Forty percent of patients reported increased satisfaction with being a patient at Johns Hopkins because of the recruitment message.

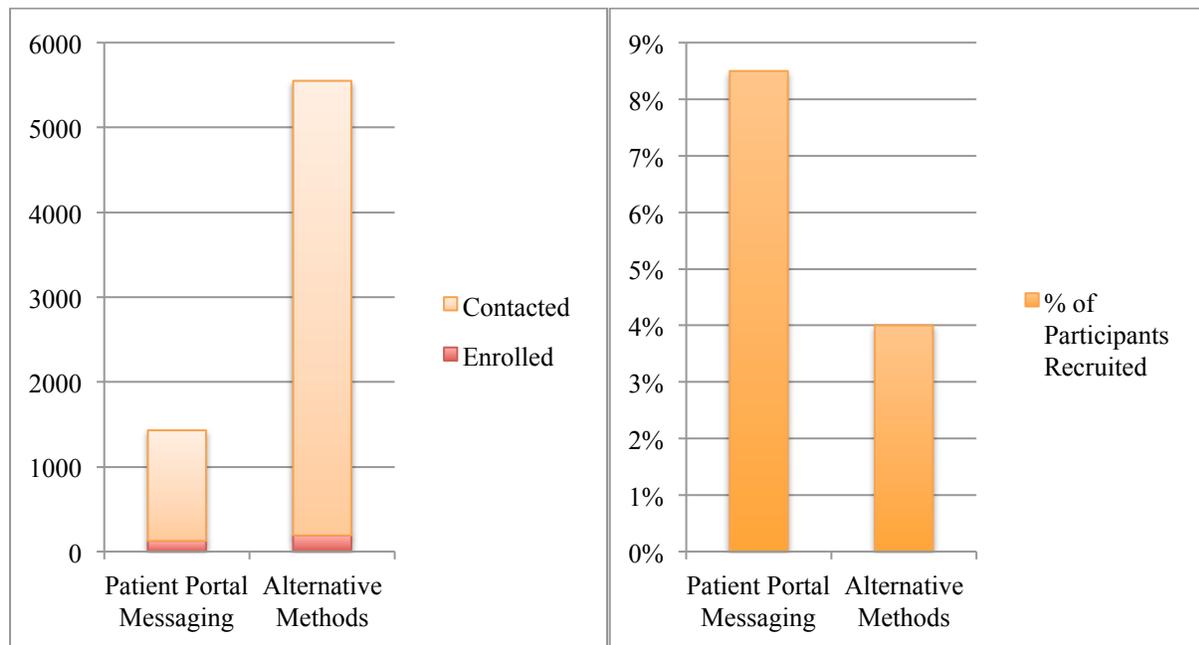


Figure 2. Number of Participants Recruited and Enrolled through Patient Portal Messaging Versus Alternate Methods

Discussion

In our early experience, patient portal messaging was found to be more effective than traditional methods in recruiting and enrolling study participants. However, there are important considerations in using patient portal messaging for recruitment. The generalizability of the sample may be impacted by using an internet tool that requires prior engagement with the healthcare system. The sample recruited in the atrial fibrillation study was largely white and male. A systematic review of online survey methods in older adults described limitations across studies since individuals of higher socioeconomic status were more likely to be recruited.⁽¹⁴⁾ Racial and ethnic barriers to patient portal use have been reported across multiple studies.⁽¹⁵⁾ Non-whites, older adults, and men are less likely to use the patient portal.⁽¹⁶⁾ Multiple studies examined disease patterns and complexity to determine the effect on patient portal usage; those with complex illnesses requiring multiple visits with providers were more likely to use the patient portal.⁽¹⁶⁾

Patients have reported barriers to communicating via patient portal. The primary issue identified across multiple studies was that patients lack awareness the patient portal existed.⁽¹⁶⁾ A need for greater education and training was reported among patients who knew about the patient portal.⁽¹⁶⁾ Patients reported concerns related to security and privacy.⁽¹⁶⁾ Addressing barriers to patient portal use will be essential for it to be used as an effective recruitment tool.

Efforts at increasing patient portal use have reported promising results. A recent pilot project aimed at increasing patient portal usage in patients attending an ambulatory cardiac clinic identified lack of knowledge of the health portal, patient motivation, portal usability, and portal functionality as themes that support patient portal utilization.(17) Previous studies have addressed the challenge of older adults' inability to use the internet by including an in-person educational intervention to teach older adults how to access and use the internet.(14) Patients who are made aware of the benefits the portal can offer, as well as the convenience factor, viewed the portal more favorably.(17) The opportunity for hands-on learning with the patient portal increased patients' satisfaction with the portal.(17) By helping patients access the patient portal, there would be increased likelihood that researchers could reach a larger and more generalizable population for their studies.

Required resources for the patient portal messaging recruitment service and for the study teams wishing to use patient portal messaging for recruitment must be considered. For our service, we found that we needed active engaged representatives from the center for clinical data analytics, the institutional review board, the electronic medical record research team, and clinical investigators. The billing structure for this service includes time spent by the data analysts, the electronic medical research team, and the staff member interacting with study teams and delivering the patient portal messages. The principal investigators and other study team members also spent considerable time working with the service to develop the optimal phenotype, receive institutional review board approval, and track responses and complaints to the patient portal messages. Further, we require that study teams track enrollment rates. Developing the service continues to be an iterative process as we perfect the service's workflow and patient and investigator experience with the workflow.

In conclusion, use of the patient portal for research was both effective as a research recruitment strategy and met with high patient satisfaction in pilot efforts. Developing a service for patient portal messaging required a knowledgeable, engaged team from diverse departments of the healthcare system. Resources and a high level of engagement are needed both for the service, and for the studies using the service. The patient portal offers an exciting opportunity to increase patient engagement in research.

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