

**Patient Generated Data Hearing**  
**HIT Policy and Standards Committee**  
**Panel 2: Emerging Practices**

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**Background**

Partners HealthCare, an organization that includes Massachusetts General Hospital (MGH) and Brigham and Women's Hospital (BWH), launched its effort to institute Patient Reported Outcome Measures (PROMs) in 2011. With the ultimate goal of having patients report outcomes across clinical conditions and sites of care, Partners launched the first phase of the initiative in patients with diabetes and patients undergoing coronary artery bypass graft (CABG) surgery at select clinics at BWH and MGH. We have partnered with Quality Data Management (QDM) to help administer and report PROMs. In 2013, we are expanding clinical conditions (e.g. stroke, total knee replacement, and others) and sites (non-academic medical centers).

**Collecting Patient Reported Outcome Measures**

The process of collecting PROMs is as follows (some of the steps below are in the midst of implementation):

1. Patients with the given clinical condition are identified by the participating clinic.
2. This list of patients is automatically cross-referenced with the clinical scheduling system to find which patients have appointments on any given day.
3. A tablet (iPad) in the control of the clinic administrative staff is populated using this system with the list of patients eligible for PROMs (currently patients with diabetes or CABG).
4. When the patient checks in for her appointment, the staff clicks on the name of the patient on the tablet and hands the tablet to the patient.
5. A brief video explains PROMs to the patient and provides instructions for use.
6. The patient taps through 16-20 questions on the iPad.
  - a. All patients receive the *general* questions: PROMIS global health-10 and a health utility question.
  - b. Patients also receive *condition-specific* questions (e.g. questions related to chest pain and shortness of breath for patients undergoing CABG).
  - c. The patient chooses a method for subsequent PROMs reporting. Current choices include email using Patient Gateway, Partners' electronic patient portal, or phone using interactive voice response (IVR). A smart phone app for iPhone and Android may be available as an option soon.

7. The patient returns the iPad to the staff.
8. A report is generated by QDM in real time.
  - a. The *general* questions are used to compute a Physical Health score and a Mental Health score generated from the PROMIS-10. The health utility score is also reported.
  - b. The *condition-specific* questions are reported in various ways (e.g. an aggregate symptom score).
  - c. Both the patient's most recent scores and her trend for each over time are reported. A range is provided based on population data as a reference for each score and time point.
9. The report is available to the patient on Patient Gateway immediately.
10. The physician must click on "Accept Patient Generated Data" in the electronic medical record. She can then view the report in the electronic health record (EHR).
  - a. A PDF version of the report is visible in the "Notes" section of the EHR.
  - b. The *general* numerical scores (e.g. Physical Health score) are incorporated into "Flowsheets" (where other vital signs are entered into the EHR). Clicking on these values will show the trend over time.
11. At the designated time interval (e.g. every 6 months), QDM uses the method designated by the patient to contact the patient either through Patient Gateway or by phone in order to collect PROMs.

### **Implementation: Challenges and Lessons**

As with all healthcare delivery implementation, project design must consider each stakeholder group as each has the power to obstruct successful implementation. In particular, patients, physicians, and the clinic staff whose workflow is impacted are important considerations. Population and quality managers must be consulted with regard to PROM tool design, but are generally enthusiastic about PROMs and are not critical roadblocks to implementation. Other administrators have been willing to accommodate requests as long as patients, physicians, and staff are amenable.

### ***The Patient Perspective***

#### **Data Collection**

PROMs data collection in five pilot clinics started in March 2012. In contrast to our expectations, patients have been consistently and overwhelmingly positive about the implementation of PROMs. In the lead up to launching PROMs, we heavily sought the patient perspective. We anticipated the following problems, none of which materialized:

1. Difficulty with the platform - except for the rare patient who was illiterate or suffering from advanced dementia or severe lack of coordination, the tablet interface was very user friendly and intuitive to patients. Moreover, most report *enjoying* using the tablet.
2. Concerns about privacy – though patients in focus groups expressed concern over symptom-related questions being too personal, in practice this has not been an issue. This may be because, in response to these concerns, the opening of the tablet sequence emphasizes that the information that the patient is about to enter is between her and her care team and will not be seen by anyone

else. In fact, this is a design choice that is pervasive across the implementation of PROMs. From the patient perspective, all communication appears to come from the patient's own clinic and not from Partners corporate or even the hospital.

3. A lack of investment in the questions – an ongoing concern is that patients will feel that the questions we are asking about functional status and symptoms are superfluous or irrelevant. On the contrary, so far patients have responded with comments such as, “These are the questions I should have been asked all along.” They seem to intuitively understand the value of these questions and, in many cases, are pleased to be reporting them.

### Data Reporting

We are still in the process of designing and delivering reports for patients. The following are some of our current considerations:

1. We are attempting to strike a balance between having reports that are rich with information yet simple enough to understand even with lower education levels. The current prototype reports highlight the most important scores over time on the primary report. We plan to provide electronic access to patients to their reports through the patient portal where they can drill down further into the minutia of the report.
2. Current plans are to include a reference value or range for each score (e.g. “Your Physical Health Score is 63. Most people have a score between 40 and 60.”) We have not yet determined whether reference values should be based on the US population average or whether the appropriate comparison is age-matched, gender-matched, or perhaps most importantly, condition-matched.
3. Regardless of which reference value or range is chosen, we do not yet know how patients will react to being below their reference range. We anticipate that this might lead to anxiety in some patients, though some argue that a patient with a poor functional status is likely aware of this and that such a report will not be a surprise.
4. The timing of initial reporting is discussed further in *Workflow* below.

### Multi-Modal Technology for Follow-up

While the initial on-site PROM collection has been highly successful, we anticipate that there will be significant attrition by the second follow-up PROM collection via email/web-based patient portal or phone/IVR. We determined early on that a multi-modal approach was critical to achieving a high response rate. The on-site tablet was determined to be the best way to initially engage patients. We may decide to do subsequent PROM collection using the tablet at subsequent clinic visits, but our current plan is to use tablets only for the initial PROM collection.

The two current modes of PROM collection outside of the clinic are by email via Patient Gateway, the Partners online patient portal, and by phone, using IVR. Our preferred mode of communication and collection is Patient Gateway. We are trying to consolidate all patient communication, results reporting and data collection into this single system. When patients fill out the initial on-site PROM and are prompted to choose phone or email, they will be prompted to sign up for Patient Gateway if they select email. We hope that this will spur patient adoption of the web-based patient portal.

Despite our desire to have all patient use Patient Gateway, we chose the multi-modal approach because most of our population is not currently registered for Patient Gateway, and we are concerned about the computer literacy of many of our elderly or less educated patients. IVR was selected over human operators because it is less expensive to scale up, has less reporting bias, and is well-suited to the types of questions we are asking. Our elderly patients were very comfortable with IVR and though we anticipated that patients would have a negative reaction to an automated voice, the fact that the phone message was coming from the patient's own clinic is thought to make them more invested in continuing with the phone call.

QDM will aggressively pursue 100% reporting by keeping track of individuals who have failed to complete PROMs on time and reaching out to them via alternative methods such as a human operator by phone. Depending on attrition rates, this may not be financially sustainable.

Finally, we are in the process of creating multiple applications for smart phones. On the most basic level, it would be simple to send the PROM tool to an iPhone or Android phone where it could be completed either in a web-browser or in a dedicated application. We are also currently collaborating on a research project with a company that uses passive data collection from smart phones with respect to phone use, motion, and other features that they have shown correlate well with health states. There are privacy concerns, but this may be appropriate in the future for some patients. Ultimately, increasingly ubiquitous smart phones will likely be critical in regular PROM collection.

## *The Physician Perspective*

### Primary Concerns

1. Workflow – this was perhaps the biggest concern of physicians until rollout began. Once rollout began it was clear that there was very little detriment to workflow given our design.
2. Information overload – this has now replaced workflow as the biggest concern. This concern stems from an accurate feeling that there are increasing demands placed on the physician to promptly handle more data streams and no additional time or support to accomplish this. Furthermore these physicians are concerned that they will be forced to confront new issues that they don't have the resources or wherewithal to address, in particular mental health resources. We believe that this data could be used as an argument for more resources, though there will admittedly be a lag between a recognition of the shortfall and the provision of additional resources.
3. Liability – given that patients may be submitting PROMs at any time from home, it is unclear what the responsibility of the physician is to check these results in a timely manner and respond to them. We are in the process of setting alert thresholds for some PROMs and connecting these with the Critical Result Notification system.

### Variable Appreciation of the Benefits of PROMs

Because there are few large-scale examples of PROM implementation, only a fraction of physicians comprehend the potential benefits. Even those who are well-versed in the proposed

benefits have yet to experience them first-hand. The following are two significant issues that we believe physicians will appreciate once PROMs are successfully implemented:

1. More systematic monitoring of individual patients – PROMs may capture things such as a slow, steady decline in the patient’s functional status that may not be readily apparent by history alone but may be revealed by a graphic trend of functional status, for example. However, clinicians trust greatly in their own skills of history-taking and are skeptical that PROMs will add value to their care of an individual patient. Assertions that clinicians are missing things in their current practice are ill advised and possibly untrue. PROMs may be pitched as a screening tool to help as we move toward team-based care to trigger some actions by the care team that do not require the careful attention and history-taking of a physician or that can occur remotely without a visit even occurring.
2. The value of population-based data – one great hope for the aggregate data from PROM is that we can use it to show the absolute and relative effectiveness of different treatments and procedures. A physician could review with a patient, for example, the previous 1,000 patients that have had a total knee replacement and the average functional status and pain score of these patients over time. We believe that this would represent optimal patient engagement helping patients to make better health decisions and have more accurate expectations. Because physicians currently get by without this information, it is often difficult for many to see the value of it.

We have also had some success enticing physicians with the use of tablets as a platform for other patient generated health data. Tablets may be used for medication reconciliation, allergy confirmation, family and social history, a nested review of symptoms, and many others. Parallel projects are underway to generate these applications.

## ***Workflow***

### Choosing the Tablet as the Initial Tool

Initially, we believed that rapid implementation necessitated the use of paper questionnaires to collect PROMs. Paper forms would be delivered to patients in waiting rooms who would fill them out in addition to the rest of their pre-visit paperwork. These individual forms would have to be manually entered electronically by part of the care team in order to compute scores such as the PROMIS-10 Physical Health score. Alternatively, the raw data could be scanned in to the medical record, though this would not allow any scoring or the ability to trend results.

It quickly became clear that paper forms were a non-starter. In order to provide real-time scores, trend scores over time, and aggregate data on a population, electronically coded data is essential. The additional time and effort required of staff to enter data was not acceptable to practice managers.

It was also felt that “enrolling” patients in the clinic for electronic follow-up by phone or email would lead to too much attrition if the patient had not had the experience of completing the PROM tool for the first time at the point of care.

Finally, we considered establishing a designated desktop terminal for PROMs in the waiting room. One concern with this idea was that since only select patients in the clinic were selected for PROMs, they might feel embarrassed to be singled out to have to use the terminal. Furthermore, it was felt that the use of a mouse and a standard computer interface would be *more* challenging than the tablet interface for a population that is significantly skewed toward the elderly.

Tablets turned out to be an ideal choice for our PROM tool. Initially in focus groups, and later in the clinics, patients were thrilled to be using the tablet and indeed found the user interface very intuitive and required very little guidance from staff. Once connected to the existing IT system, tablets allowed for instant and reliable electronic data that was easy to incorporate into the EHR (*see step 10 above*). Clinics also appreciated the tablets. They appreciated patients' reactions to them, and staff felt that clinics were moving toward the future of healthcare. Several clinics are working on developing other tablet-based applications to help with clinical care such as post-discharge follow-up and medication reconciliation smart phone applications.

#### Tablet-Specific Challenges

1. Device cost – purchasing three iPads per clinic is a non-trivial expense. The conviction of senior leadership at Partners in the importance of PROMs led to the provision of funds to purchase iPads.
2. Concern for theft – each clinic has developed its own method to manage the iPads. Most keep them locked in the medication room. They are retrieved by medical assistants, given to patients already in clinic rooms who are waiting for their physician, and collected once again by medical assistants. They are being fitted with anti-theft tracking devices. To date, no iPad has gone missing.
3. Connections to IT systems – most of these hurdles were small and surmountable, but required consideration and effort. They include connecting to the wireless network, allowing QDM to run a server for the data behind our firewall, to send out e-mails to patients with Partners' signature, to connect to the EHR and scheduling system.

#### Anticipated workflow challenges that did *not* materialize

1. Medical Assistants did not mind administering the tablets – surprisingly, they found incorporating the tablets into their workflow was not much of a challenge. It seems that at least to some degree, their enthusiasm for the project stems from *patients'* positive reactions to the tablet and the questions. On the rare occasions that they needed to help the patient to fill it out because of severe disability, it did impact their workflow.

#### Reporting-related Workflow Challenges

One important piece of PROMs is real-time feedback to the patient. Immediately seeing the results of their efforts in a visually pleasing report is more likely to lead patients to fill out the PROM tool on subsequent iterations. As such, we would like to display the PROM report immediately on the tablet screen.

One concern, however, is that the patient will be entering their encounter with their physician with asymmetric information. Especially with time-constrained visits, physicians are wary to have their entire visit derailed by a patient anxious about a low Mental Health score. If the visit

will be taken up by such a concern, most physicians have expressed a desire to at least have the information before entering the room so they have the opportunity to formulate a plan.

One potential solution to this is to have the report automatically print and be left for the physician to bring into the room with her if desired. This has the added benefit that the act of a physician reviewing the results of the PROMs with the patient will strongly reinforce the importance of the patient filling out PROMs on a subsequent occasion.

### **Summary**

Partners HealthCare is in the process of implementing PROMs across clinical conditions and sites. Patients will initially submit PROMs using tablets and subsequently by email and phone. PROMs include general and condition-specific results. These results are incorporated into the EHR as both a report and as trendable numerical data. Results are also reported to patients in as close to real time as possible.

To date, implementation has gone better than expected. In particular, patients are very positive about all aspects of PROMs. In addition, the current implementation design has not adversely affected workflow. We still have challenges in convincing physicians of the merits of PROMs and alleviating their concerns, which largely revolve around a lack of resources to respond to additional information. We anticipate that as we ramp up reporting, the merits of PROMs will become more evident.

We also have yet to tackle the issue of attrition as we attempt subsequent PROM collection in patients outside the clinic setting. To ensure a successful and meaningful implementation of PROMs, we have set a goal of having at least 60-70% of patients report throughout the multiple data entry time points.

We have high hopes for this initiative and its implications for clinical care.