

# QUESTION 7:

## How, where, and with what frequency will PROs be administered?

**Irene Katzan MD,**  
Cleveland Clinic

**Judy Baumhauer, MD, MPH**  
University of Rochester Medical Center

# 6 Questions

1. Should the EHR coordinate the administration of questionnaires for multiple purposes (research, operations, and clinical care) and across different stakeholders?
2. Should the PRO-EHR system build in quality/error checks?
3. Should data from multiple modes be combined by the EHR for presentation to providers?
4. Should the PRO-EHR system collect meta-data on how the PRO was completed and by whom?
5. How can the PRO-EHR system monitor compliance/alert to missing questionnaires?
6. When and with what frequency should PROs be obtained?

# (1) Should the EHR Coordinate the Administration of Questionnaires for Multiple Purposes (Research, Operations, and Clinical Care) and Across Different Stakeholders?

- Synchronization of questionnaire deployment is an increasingly important consideration as PRO measure collection expands
- Effectiveness of synchronization of deployment is dependent on the degree that the content of PRO collection is standardized

Synchronization: questionnaire administration is coordinated across clinical areas.

- *Example: If a depression screen was collected in Clinic A, patients with an office visit in Clinic B the following day will not be asked to complete the depression screen again.*

Standardization: the same questionnaires/scales are used to measure the same construct across clinical areas.

- *Example: Patient Health Questionnaire 9 is used as the depression screen across clinics*

# Should the EHR Coordinate the Administration of Questionnaires for Multiple Purposes and Across Different Stakeholders?

## **Option 1: Synchronization of all questionnaires across clinical areas**

*Questionnaire administration is coordinated across clinical areas. Patients are not asked to complete a questionnaire if it was previously completed within a specified time interval at another clinic.*

### **Advantages:**

- Reduces patient burden
- Reduces duplication of effort related to PRO deployment
- Allows providers to review data not collected at the visit
- Reduces workflow disruption by decreasing the number of questions patients are asked to complete at a given visit

### **Disadvantages:**

- Dependency on technological capabilities of the PRO-EHR systems to track deployment and display results across contexts
- To minimize patient burden, it is necessary for different stakeholders to agree on using the same questionnaires that cover the same constructs.

# Should the EHR Coordinate the Administration of Questionnaires for Multiple Purposes and Across Different Stakeholders?

## **Option 2: Deployment of questionnaires are not synchronized**

*Questionnaires are administered independently within each clinical area without consideration of whether it was previously completed at another clinic.*

### **Advantages:**

- Less technically resource intensive
- No dependency on technical capabilities of PRO-EHR system

### **Disadvantages:**

- Increased burden for patients seen in more than one clinic, which may increase patient frustration, and reduce patient completion rates and satisfaction
- If different instruments are used to measure the same construct, limits the ability to compare different populations
- Increased workflow disruption

## (2) Should the PRO-EHR System Build in Quality/Error Checks?

- Quality of patient data is critical when using aggregate data for research or operational analyses or using patient-level responses for clinical care.  
*Nonsensical data*: example, 1-10 pain level response = “100”  
*Missing data* - example, non-answered questions preventing calculation of scale score
- Quality/error checks can be considered a requisite for patient-entered data collection.

# Should the PRO-EHR System Build in Quality/Error Checks?

## Option 1: Range and format checks built into the patient-entered data collection system

*Range and format checks do not allow entry of nonsensical data elements.*

### **Advantages:**

- Reduces amount of unusable data
- Increases the proportion of completed responses that can be used in analyses or clinical care
- Reduces interpretation errors

### **Disadvantages:**

- Requires programming effort

# Should the PRO-EHR System Build in Quality/Error Checks?

## Option 2: Some patient questions are “required” to move to next question

*Patients see a notation that a response is required before moving on to the next question.*

### **Advantages:**

- Reduces missing data
- Increases number of fully completed scales

### **Disadvantages:**

- Does not allow patient preferences to opt-out of completing questions, which reduces patient autonomy and may cause patient frustration
- May reduce questionnaire completions
- Analysis of non-completed questions can provide information that can be used to improve PRO content
- May not be allowed by some institutions



### **(3) Should Data from Multiple Modes Be Combined by the EHR for Presentation to Providers?**

- Availability of multiple modes of questionnaire administration such as office visit, patient portal, interactive voice response system, mobile apps, will improve with advances in technology
- Ability for providers to view all questionnaire responses from different administration modes would improve provider workflow and allow providers to view trends in data over time.

# Should Data from Multiple Modes Be Combined by the EHR for Presentation to Providers?

## **Option 1: Integrated reporting of questionnaire responses collected using different modes of administration**

*A provider can view scores and/or responses from patient questionnaires collected using different methods of collection. This requires that data elements are stored in the same place with the additional attribute of modality of collection.*

### **Advantages:**

- Allows providers to more efficiently track all patient responses over time and obtain a broader picture of the patient's health status
- Allows flexibility in data collection, which may result in better completion rates

### **Disadvantages:**

- Dependent on the technological capabilities of the EHR
- Data quality in different modes of collection may vary
- Responses collected using different modes of administration may not be comparable

# Should Data from Multiple Modes Be Combined by the EHR for Presentation to Providers?

## **Option 2: Reporting of questionnaire responses collected using different modes of administration is not integrated**

*A provider cannot view scores and/or responses from patient questionnaires collected using different methods of collection on one data display.*

### **Advantages:**

- May be faster to deploy if not concerned with making sure multiple modalities all file to common data structures

### **Disadvantages:**

- Less efficient for providers
- More difficult for providers to identify trends in questionnaire responses over time due to lack of integration

## (4) Should the PRO-EHR System Collect Meta-data on How the PRO was Completed and by Whom?

- The inability of patients to complete patient-reported questionnaires due to physical or cognitive limitations or language barriers is a known limitation of patient-reported outcomes.
- Proxy responses, typically obtained from family caregivers, can be used in these instances.
  - “Proxy-patient” perspective - the proxy assesses a patient as the proxy thinks the patient would rate his or herself.
  - “Proxy-proxy” perspective - the proxy projects themselves as how s/he would respond if s/he was the patient.
- In addition, health care providers may complete questionnaires by patient interview in cases where patients did not complete the electronic questionnaire or where patients started but did not finish all questions.

# Should the PRO-EHR System Collect Meta-data on How the PRO was Completed and by Whom?

## **Option 1: PRO-EHR system collects whether questionnaire data was collected by interviewer**

*Meta-data on source of questionnaire completion is stored in the EHR and are available to the provider when viewing previously completed questionnaires and for use in reporting and data analysis.*

### **Advantages:**

- Allows analysis of clinical workflow and improved understanding of operational aspects of questionnaire collection
- Assists in interpretation of questionnaire responses
- Potentially allows for adjustment of scores for biases based on interviewer administration

### **Disadvantages:**

- Dependent on the technological capabilities of the PRO-EHR system

# Should the PRO-EHR System Collect Meta-data on How the PRO was Completed and by Whom?

## **Option 2: PRO-EHR system collects whether questionnaire completed by caregiver proxy**

*Questionnaire set includes a question on who completed the questionnaire (patient, caregiver, or health care provider). An additional question may ask the relation of the person completing the questionnaire to the patient.*

### **Advantages:**

- Allows provider to interpret questionnaire responses more accurately
- May be necessary for some applications in research
- Potentially allows for adjustment of scores based on proxy response

### **Disadvantages:**

- Requires building and integrating an additional question within the questionnaire set
- Definition of role of the caregiver proxy would require additional questions (i.e., “What is your relationship to patient?”, “How long have you known the patient?”)

# Should the PRO-EHR System Collect Meta-data on How the PRO was Completed and by Whom?

## **Option 3: Information on who completed questionnaire is not collected and stored**

*No information is collected on who completed the questionnaire.*

### **Advantages:**

- Does not require additional resources

### **Disadvantages:**

- Lack of this information may hinder utilization of data, especially in research
- Clinicians not provided with information that will help them interpret responses

## **(5) How Can the PRO-EHR System Monitor Compliance/Alert to Missing Questionnaires?**

- Low completion rates limit the effectiveness of collecting patient-reported data for clinical care and impact the ability to use data for aggregate analysis, such as quality reporting or research.
- Questionnaire completion may be impacted by patient-level factors such as cognitive or physical impairments, literacy, computer literacy, or language barriers, or operational factors such as clinical workflow, questionnaire content, or patient burden.
- Measuring completion rates is a necessary step to understanding reasons for suboptimal completion rates and developing interventions to improve performance.



# How Can the PRO-EHR System Monitor Compliance/Alert to Missing Questionnaires?

## **Option 1: the PRO-EHR system generates reports of completion rates**

*This may entail regular group-level reports that can be used by providers and administrators, or it may consist of an individual-level tally of the proportion of questionnaires completed by a single patient, similar to a 'no-show' rate of a patient.*

### **Advantages:**

- Can be used for operational analyses and quality improvement activities
- Metric of success of questionnaire collection process

### **Disadvantages:**

- Dependent on the technological capabilities of the PRO-EHR system

# How Can the PRO-EHR System Monitor Compliance/Alert to Missing Questionnaires?

**Option 2: The PRO-EHR system sends automated notifications to the health care team when patients do not complete questionnaires**

*May be in the form of a “best practice alert” or other notifications within the patient record or an email-like message to a recipient who can follow up with the patient.*

## **Advantages:**

- Allows attempts to capture missing questionnaires in real-time

## **Disadvantages:**

- Dependent on the technological capabilities of the PRO-EHR system
- Requires additional effort from health care team, can increase alert fatigue
- Utility of notifications is dependent on follow-through of collection attempt by health care team
- Feasibility of this approach unknown

## (6) When and With What Frequency Should PROs Be Obtained?

- Clinical workflows for questionnaire administration will vary widely depending on the goal of data collection and specific questionnaires.
- Health risk assessments or health-related quality of life questionnaires may be deployed at specific intervals or tethered to specific visit types
- Questionnaires assessing symptoms may be deployed in specific clinical situations, such as patients undergoing certain interventions.
- In instances when questionnaires are not completed at each visit, logistical issues arise in identifying which patients should be approached to complete questionnaires and what questions should be asked.

# When and With What Frequency Should PROs Be Obtained?

## Option 1: Questionnaires are administered to all patients at each visit

*Specific questionnaires, identified by specific time interval since last completion and/or by diagnosis, procedure, or clinical situation are administered at a visit. If no questionnaires need to be completed, a message is displayed to the patient that there are no questions to complete*

*Alternatively, a “base” questionnaire can be administered to all patients so patients always complete some questions at their visit.*

### **Advantage:**

- There is a consistent questionnaire collection workflow for front desk/check-in staff and consistent setting for completion by the patient

### **Disadvantages:**

- Potentially unnecessary questionnaire administration, increasing patient burden
- Patient satisfaction may decrease

# When and With What Frequency Should PROs Be Obtained?

## **Option 2: Questionnaires are deployed at the time of a visit only to patients who have been identified as requiring questionnaire completion**

*Specific questionnaires, identified by specific time interval since last completion and/or by diagnosis, procedure, or clinical situation are administered at a visit. Patients are given tablets at the visit only if there are questionnaires to complete.*

### **Advantages:**

- Minimizes patient burden
- May reduce workflow disruption/delays in through-put at clinic visit

### **Disadvantages:**

- Method to determine which patients require questionnaire completion must be identified
- Requires additional decision-making by front desk staff or clinical providers
- May reduce completion rates if identification of patients requiring questionnaire completion is not consistently implemented
- Dependent on the technological capabilities of PRO-EHR system

# When and With What Frequency Should PROs Be Obtained?

## Option 3: Questionnaires only deployed remotely

*Questionnaires are deployed remotely via patient portal or email invitation, only if the patient has a questionnaire that should be completed based on time interval since last completion, diagnosis, or other methods.*

### **Advantages:**

- No workflow disruption at office visit
- Minimizes patient burden

### **Disadvantages:**

- Requires technological ability to deploy questionnaires remotely
- Lower completion rates possible; requires patient willingness to provide data outside of a clinic visit in the requested mode of data collection
- Will not capture questionnaire data on patients who do not have their own device (computer/tablet/smart phone)
- If questionnaires are deployed through a patient portal, requires that patients be active on patient portal
- May require system to monitor questionnaire responses if they are clinically actionable

# KEY INFORMATION GAPS AND RESEARCH QUESTIONS

- What is the validity of proxy responses when collected in routine clinical care?
- In what situations is remote deployment of questionnaires appropriate and/or adequate?
- Are there differences in responses to questions according to mode of administration?
- Is real-time notification of incomplete questionnaires feasible and does it lead to improvement in completion rates?
- How do you apply PRO data to improve patient care across different clinical scenarios?