QUESTION 7:
How, where, and with what frequency will PROs be administered?

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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?
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.
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
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 questionnaires 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
**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?