

# User's Guide to Integrating Patient-Reported Outcomes in Electronic Health Records

## **Question 1: What Strategy will be Used for Integrating PROs in EHRs?**

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# Chapter 1 Organization

- Each integration option is presented individually with advantages and disadvantages
- Perspectives of the patient, provider, researcher, and administrator are provided
- Future research and useful references are summarized at the end.

**NOTE:** Some advantages and disadvantages may overlap integration options.

# So You Want To Use Patient Reported Outcomes?

- Strategy Covers a Wide Range of Options
- Collection:
  - Paper
  - Electronic
- EHR Integration Strategies
  - Manual Upload
  - System Linkage
  - Native

# PRO / EHR Integration Options

1. Minimal Integration (LOW)
2. Separate PRO Collection System (MED)
3. Full PRO-EHR/Native Integration (HIGH)

# Minimal System Integration (LOW)

- Definition: Any mention or use in an EHR. Often paper and assessed in clinic.
- Collection Methods: Any
- Common Data Capture and Storage Options:
  - Scanned Paper Form
  - Manual Data Entry
  - Manual PRO Documentation in the Clinician Note

# Minimal System Integration (LOW)

- Data Linkage
  - PROs pushed uni-directionally to EHR
  - No Bi-directional communication
- Data Reporting
  - Manual Scoring Common
  - Only Manual Feedback to Patients or Providers

# Minimal System Integration (LOW): Patient Perspective

## Advantages

- Paper-based collection may be easier for those less comfortable using technology
- Similar to current paper survey administration methods across research and practice

## Disadvantages

- Paper-based collection has no option for screen reader or text size adjustment
- Possible redundancy in data captured between different clinics.
- May limit distribution of PRO findings across clinical care team

# Minimal System Integration (LOW): Provider Perspective

## Advantages

- Very low-cost up-front assessment

## Disadvantages

- Manual scanning or data entry could delay in-visit use
- Without discrete data filing, PROs cannot be used for automated decision support
- PRO administration relies heavily on staff (manual process and workflows)



# Minimal System Integration (LOW): Research Perspective

## Advantages

- Ability to establish PRO surveillance independent from the clinical care system
  - Telephone (IVR)
  - Mailed surveys
  - Stand-alone electronic PRO collection

## Disadvantages

- PRO information may not be structured
  - Limits data reuse for research
  - Limits associated meta-data

# Minimal System Integration (LOW): Administrative Perspective

## Advantages

- Less specialized technical support needed for:
  - Implementation
  - Integration
  - Maintenance

## Disadvantages

- Manual identification of patient eligibility for PROs necessary
- Relies on staff to track PRO administration across multiple patient visits
- Lack of continuity across clinical visits and settings

# Separate PRO Collection System (Medium)

- Definition: Electronic Assessments are conducted using a specialized system. Collected PROs linked to the EHR.
- Collection Method: Electronic Only
- The broadest category of PRO collection.
- Data Capture and Storage:
  - Stand-alone system
  - 3<sup>rd</sup> party vendor
  - Developed internally

# Separate PRO Collection System (Medium)

- Data Linkage
  - EHR data may be pulled asynchronously to inform the PRO assessment
  - Data pushed to the EHR in real-time
  - Data can be linked to discrete EHR data fields
  - Specific interface required for communication between PRO collection system and EHR
  - Data mapping required for PRO data to flow discretely into EHR

# Separate PRO Collection System (Medium)

- Data Reporting (Outside System)
  - Automatic Scoring Likely
  - Feedback and Score Interpretation Options Likely

# Separate PRO Collection System :

## Patient Perspective

### Advantages

- User interface is designed and used solely for PRO administration
- May provide patient-facing PRO reporting options and features
- Minimize redundant information collection by drawing on prior information

### Disadvantages

- Different interface may distance PRO collection from clinical care
- Alerts or email reminders are not integrated within care workflows
- Remote home access requires a unique user name and password

# Separate PRO Collection System :

## Provider Perspective

### Advantages

- Wide range of PRO content for specific clinic needs.
- Customized, real-time integration for clinical decision-making
- PRO collection both outside and during the clinical encounter
- Many standard and customized report formats may be available
- Time saving for staff over manual entry

### Disadvantages

- Workflow integration may require more staff oversight and specific training
- Missing PRO assessments (prior to visit) may not be easy to identify within the clinic workflow
- Additional steps by the provider to access a PRO system may be necessary

# Separate PRO Collection System : Research Perspective

## Advantages

- Assessment Meta-data is available
- Can be extracted alongside other EHR data
  - Laboratory tests
  - Procedures
  - Events

## Disadvantages

- Complete data may require extracting data from 2 systems
- Linking multiple data sets can be complex



# Separate PRO Collection System :

## Administrative Perspective

### Advantages

- System may have dedicated technical support
- Configuration is not dependent on EHR IT teams (or a specific EHR system)
- New technology-based options (e.g., mobile) may be more quickly implemented

### Disadvantages

- Data integration requires additional IT resources & expertise
- Cost to maintain an independent PRO system may be higher than an integrated system
- Updates or enhancements to PRO system may require changes to EHR system or integration tools to maintain compatibility
- Additional security concerns
- Additional vendor agreements are necessary

# Full PRO Integration within the EHR

- Definition: PRO assessment is collected as an integral part of the EHR
- Collection Method: Electronic Only
- PRO information is pulled from and pushed to the EHR in real-time to:
  1. Inform or tailor PRO assessment
  2. Make integrated PROs available for broad use within the EHR including:
    - a. Decision support
    - b. Longitudinal tracking in conjunction with symptoms and treatments
    - c. Seamless feedback to patients
- PRO scoring can be automated

# Full PRO-EHR Integration: Patient Perspective

## Advantages

- PRO data are collected in a singular patient portal
- Flexibility of assessment locations based on EHR vendor support
- Real-time reporting of PROs to patients may be possible
- Minimizes redundant information by drawing information from prior PROs or patient information

## Disadvantages

- Limited ability to change administration format
- Remote home access requires a patient portal account with user name and password
  - As distinct from paper collection, where this is not required

# Full PRO-EHR Integration: Provider Perspective

## Advantages

- One place for all PRO assessment actions
- Results presented alongside other clinical data
- Real-time scoring and reporting
  - Automated workflows for actions and follow-ups
  - Alerts for actionable scores
- Standardized report formats include longitudinal scores
- Integration for EHR data for reports
- Can initiate long-term follow-up based on trigger event
- PRO completion can be done within the same workflow as other patient-facing data collection
- Real-time integration of content for clinical decision-making
- Time-saving for provider and staff over paper collection

## Disadvantages

- Customized PRO assessment beyond current available content and features requires local EHR IT team
- Presentation of PROs to patient and provider is limited by the capabilities of the EHR
  - Customization may require involvement of local EHR IT team or additional external product

# Full PRO-EHR Integration: Research Perspective

## Advantages

- PROs can be extracted alongside other EHR data
- Possible to have extensive assessment-specific meta-data

## Disadvantages

- Implementation of PROs may be focused on clinical utility
- May not be designed for staff to identify and monitor missing PRO data

# Full PRO-EHR Integration: Administrative Perspective

## Advantages

- Part of EHR system—may be no additional contracts or costs
- Standardized list of validated PROs to select and use
- Easier aggregation of PROs alongside other standard performance measures
- Automated reminders to complete PROs can be added to standard in-clinic workflow and within patient portals

## Disadvantages

- May be difficult to customize PRO assessments across clinical settings
- May have restrictions on launching additional, non-standard PROs
- System may not easily allow for monitoring of missing PRO data

# Information Gaps & Research Questions

- What drives patient perception of benefit from PRO collection?
- Does greater system integration matter more than a targeted, customized PRO collection system?
- Do PROs collected within or outside of a clinical encounter facilitate patient care
- Do providers prefer EHR-integrated PRO reporting or PRO-specific systems?

# Information Gaps & Research Questions

- What system features facilitate and sustain PRO use by patients and providers?
- Which system design is more feasible and sustainable...
  - In community-based settings?
  - For multi-morbid patients?
  - By care setting?
- What features in PRO collection and reporting are preferred by...
  - Patients?
  - Providers?
  - Researchers?
- Do feature preferences differ by sociodemographic characteristics of patients?



# Useful References/Resources

- Acquadro C, Berzon R, Dubois D, Leidy NK, Marquis P, Revicki D, Rothman M. Incorporating the patient's perspective into drug development and communication: an ad hoc task force report of the patient-reported outcomes (PRO) harmonization group meeting at the Food and Drug Administration, February 16, 2001. *Value Health*. 2003;6(5): 522-531.
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