



# PRO Core Update

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The Collaboratory



# Purpose of the PRO Core

- The PRO Core was established to help researchers to identify opportunities for collection and assessment of patient reported outcomes (PRO) within Collaboratory projects.
- To give guidance to researchers on PRO data collection, with regards to the 4 major issues in PRO data collection:
  - Addressing IT infrastructure software/hardware issues
  - Choosing appropriate instruments for PRO data collection
  - Defining how to integrate their research and collection in the care process in a meaningful appropriate way.
  - Preparing for real-time reporting/analytic feed, as well as statistical analysis of PRO data



# Demonstration Projects

- We currently have 3 of 6 projects collecting PRO data
- Instruments being used include:
  - Brief Pain Inventory (BPI)
  - Patient Health Questionnaire-9 (PHQ-9)
  - Short Form-36 (SF-36)
- Range of PRO data collection methods and processes being utilized
  - Paper-pencil
  - Electronic via Patient Portal
  - Telephone using Interactive Voice Recognition System (IVRS)
- Potential issues for investigators collecting PRO data
  - Compliance
  - Missing data
  - Data standardization



# Addressing the Issues

## 1. Landscape Summary of successful PRO implementation

- Months reviewing recent literature regarding the use and implementation of PROs for clinical care. Recently added PRO intervention literature to this list

## 2. On-site Investigations

- This is an “on the ground” review of how PRO data collection activities are being implemented in various settings with the purpose of bring this information back to the Collaboratory
- Focused on healthcare systems/institutions that have successfully established processes for routine collection of PRO data.
- Currently developing interview questions and strategy
- First on-site visit scheduled for mid-March

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# Addressing the Issues

## 3. PRO/PROMIS Workshop

- Planning 1.5 day meeting workshop (~30 participants)
- The intention of the workshop is to address issues of PRO use in clinic settings. Focus will be on PROMIS.
- We are inviting PROMIS investigators to present cases studies that do the following:
  - Show impact of PRO data/implementation on clinical outcomes.
  - Address areas where PROMIS/ current PRO instruments work well/do not work at all/effect can not be ascertained and explain why.
  - Highlight best methods for using PROs in clinical care/research.
  - Demonstrate superior data/analytics use of PROs/PROMIS.

# Addressing the Issues

## 4. Generalizable knowledge about PROs and useful resource links distributed via the HCS Collaboratory Living Textbook

