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 bringing 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
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