

Center for Healthcare Transparency

Subgroup 4: Patient-Reported Data

Patient-reported data includes patient experience, patient-reported functional outcomes, shared decision making, patient reported quality of life; patient-reported compliance

- For each intended use
 - What elements are needed?
 - What elements are needed to validate the data?
- Best sources of desired data elements
- Best practices in working with entities and/or individuals that supply and receive patient-reported data
 - Providing context to providers for patient-reported data
- Standards for data feed (fields, values, periodicity, etc.)
 - E.g., exact question that was asked
 - E.g., responses that were offered
- Standards and processes for assessing accuracy and completeness of data
 - Can and should patient reported data be cross-validated with other available data?
 - Including documenting and communicating condition of data clearly so users know what the data will and will not support
- Helping stakeholders interpret and use data
- Potential impact of emerging technologies
 - Modalities for collecting patient-reported data
 - Personal health records
 - Applications with patient-reported feedback to providers