

# Center for Healthcare Transparency

## Subgroup Meeting Highlights

(phone meetings in September and October)

### Patient Reported Data Subgroup

Group members are very intrigued with the possibilities offered by different types of patient generated data but also identified current barriers to using such data to its full potential including:

#### *Patient Generated Health Data - General*

- Integrating use of Patient Generated data into provider workflow
  - How do providers get notified about changes in data?
  - Who pays for the time it takes to do the integration?
  - What happens when remote patient generated data comes in “after hours”?
- Education of providers on how to use this data
- Provider concern over quality of patient data generated outside of a clinical setting
- Provider concerns about liability once data is received
- Difficulty of validation when there is no second source
- Lack of standards for how data gets incorporated into EMRs, how provenance is tagged
- Lack of standards for untethered Personal Health Records, not covered under HIPAA
- Multiple steps for information moving to/from untethered Personal Health Records
- Proliferation of apps and sources of data
- Accessibility issues for patients to use portals, etc. for contributing, validating data
- Incompatibility of many in-home medical devices with options for uploading information

#### Patient Reported Outcomes

- Challenge of getting sufficient responses from paper tools
- High cost of some attractive measurement tools like PROMIS

#### Patient Experience

- Costs of running surveys
- Limits on questionnaire length and how much can ask
- More efficiently getting information input
- Figuring out how information gathered can be used for meaningful improvement
- Setting expectations for what will change and when as a result of patient input

#### ***Topics for Further Discussion***

- Greater detail in patient experience reporting
- Liabilities associated with receiving patient reported data
- Challenges differentiating between shared decision-making and shared consent (one member is researching and will report back)