

Patient Generated Data Hearing

Summary of Presentations, Discussions, and Blog
Responses

RTI White Paper

- Broad definition
- Distinguishes between data capture, data transfer and data review
- Barriers
 - Limited processing power
 - Not all PGHD is of equal value to everyone
 - Health literacy

Major Themes:

- PGHD is cross-cutting and has applications in each MU Policy Priority
- Specifying a plan for collection and use of PGHD, along with clear objectives and goals is a key component of successful efforts
- Information must be meaningful and useful for BOTH patients and providers
- Modularity and mobility are critical

Major Themes (Continued)

- Attribution of source is critical; but this is true for ALL INFORMATION as we move toward integrating data from multiple data sources
- Standards are important, but sharing of information is paramount
- Much PGHD is accommodated by current stds
- PGHD should follow the same standards as all other information

Quality, Safety, Efficiency, Disparities

- PGHD can be triggering function for CDS; this is critical for PROMs
- Can be pivotal in addressing disparities
- PROMIS work should be leveraged

Patient Engagement

- Critical for SDM, on both individual and population levels
- Build upon patient portal
- Use of assessment scales (such as PAM) can be useful for individualized care AND resource allocation

Care Coordination

- Think of the patient as an HIE of one
- Creating a supportive environment between encounters requires ongoing, 2-way communication loop
- Collection of caregiver status
- Use and availability of community resources

Public Health

- Adverse event and safety implications
- Post-market surveillance
- Use of info for setting of expectations and decision-making

Privacy and Security

- Need requirements for data integrity, sourcing, metadata, etc.
- Patient authentication is essential for trust
- Mobile platform

Potential Steps for HITPC

- Design criteria to require collection and use of PGHD (specify the HOW), but leave lots of room for individual variation (less prescriptive on WHAT).
- Logical and achievable starting places
 - Pre-visit communications
 - Questionnaires and responses