

CENTER FOR HEALTHCARE TRANSPARENCY
Meeting Summary
Regional Data Center Collaborative
SubGroup 4: Patient Reported Data
September 18, 2014

Attendees: Megan Hardin, CHPI, Beth Newsom, CIVHC, Bradd Lehmann, HealthBridge, Deepthi Rajeev, HealthInsight,

Staff: Kristin Majeska, Harriett Wall, Mary-Isabel Aromando

Introductions were made and participants shared successes using patient reported data.

- Using consumer mediated data such as home glucometers for diabetes
- Patients having information to make specialist appointments for pcps with the increase patient engagement (continuity of care)
- Outcomes of additional medication management
- Patient provider assessments which are factored in to P4P reimbursements
- Joint registry patient reported outcomes

Participants also shared challenges including:

- Helping physicians understand how to input and/or use patient generated information
- Reimbursement for extra steps to integrate patient data
- How to tag data based on its provenance
- Very minimal data standards for Patient Health Records
- Being tied to paper responses for patient assessments
- Patient response rates too low to be publically reported
- High cost of electronic and attractive alternatives (like Promis) when hospitals don't have to pay
- Accuracy of patient reported information (like medications currently taking)
- How to validate information such as family/social information or family history
- How to factor in qualitative measures/patient perceptions

Project Background

The overarching goal of the project is getting data into the hands of stakeholders who can use the information to increase transparency. There will be a detailed implementation plan that is viable by 2020. There is urgency around this because data is taking on a larger role in the debate about healthcare policy. What type of resources will it take to get past the barriers to producing and disseminating the information to consumers, purchasers and providers? The effort needs to be market driven. It is not a mandate, there must be value to the product.

Subgroup Deliverables

Group members will be sharing their materials and experience with patient reported data and will generate consensus recommendations for best practices. We will identify opportunities to leapfrog. The group will try to be as specific as possible with examples, templates and documents.

There will be online repository for the group. CHT staff will create folders for each organization and for documents available to all Collaborative members.

Initial topics include:

- What elements are required for the intended uses for patient reported data
- What are the best sources for accessing the data?
- What are the standards for data feeds?
- What is needed to validate the data?
- What is the potential impact of emerging technologies (personal health records for example)?

Will be helpful for the group to look at specific use cases.

Assessing the completeness and accuracy of patient reported data may be difficult based on group members' experience. Patient reported data is inherently subjective. Patient reported data can be collected in various forms. Where are the validation points across two sources of data?

How do we help physicians understand how and when to use or integrate patient reported data into their work?

It is important when examining emerging technologies to consider cost to providers/practices. We can also bring this consideration back to other subgroups that may be able to weigh in on the practical implications of cost. Providers may not be prepared to include patient reported data into their workflow. How are they going to be reimbursed for their time spent interacting with patients via patient portals, for example? It is also important to identify the source of information being given to providers

Next Steps

Members are asked to provide the following to hwall@nrhi.org by October 10th

Two examples of patient-reported data you report or plan to report (publically or privately) that you believe consumers or purchasers particularly value, with brief description of data sources, data elements, and primary use cases

Our next meeting is October 16th. Prewrite may be circulated.