

CAH/DSD Workgroup
Regional Meeting 04.15.10

Participating: Linda DiMeglio, IN; Kupper Wintergerst, KY; Ming Chen, MI; Kristi Bentler (guest, presenting IBEM-IS), Amy Gaviglio, Ann Jurek, Kiki Sarafoglou (workgroup lead), Joe Sockalosky, Nancy Vanderburg, MN; Susan Rose, OH; Gary Hoffman, WI.

I. Demonstration of IBEM-IS (K. Bentler)

- Described uniform data elements
- Walked through sample data entry for enrollment and interval visits
- Demonstrated access to data
- Reimbursement for data entry is currently \$50 for each completed enrollment survey
- Refusal to participate rate is very low
- Exploring interoperability with state department systems
- DocSite platform is very basic
 - Issues identified
 - Having to enter your own unique identifier – currently system does not generate
 - Doesn't do index searching – have to run reports which is time consuming
 - Only runs on internet explorer
 - Can seem overwhelming – you scroll and scroll – tabs for specific areas would make more user-friendly
 - When the answer is “no” it should not ask for more n/a information.
- Only see your own data
- If the registry goes national, what vendor will be used? – unknown at this time, though DocSite is positioning itself for consideration
- If people use the test site and the user guide, could training be skipped? Probably

II. How does group want to proceed?

- If clinicians will not use DocSite, do we wait for the national movement & platform? Consensus = “no”
 - Explore further development of the DocSite platform; e.g., skip patterns and other improvements.
 - Don't wait on national movement – we want to continue to lead
 - Good to start with DocSite to learn and test data integrity

III. NBSTRN LTFU meeting

- There was no discussion of platform for registry and no timeline was given
- Next meeting is early June

IV. Next steps

- Each clinic obtain IRB approval
- MPHI has R4 staff assigned to assist with IRB application development
- Focus on entering new and currently being since kids – no need to go retrospective at this point
- Enter all kids being seen – not just those identified by NBS. We want to include all kids, even those missed by NBS in the registry

V. Next meeting

- Proposed changing monthly meeting date from third Tuesday to Second Thursday.

Notes by Vanderburg