



Priority 2 Workgroup Telemeeting
Agenda ~ Friday, July 16, 2010 @ 2 pm ET/1 pm CT
1/866/489-0573 at the prompt, enter *4545164*

Handouts:

- #1. Intake/Interval Surveys in IBEM-IS Report
- #2. CDC PRAMS
- #2. Pregnancy Survey
- #4. IVA elements
 - Items in yellow, unique to this survey
 - Items in red, to be added to all surveys that contain this question
- #5. SBCAD elements
 - Unique elements in yellow
 - Red highlighted will apply to all surveys with that question
 - The other two differences between this and IVA enrollment are
 - question on this one as to whether mother and father were tested for this IBEM
 - question on whether FAO probe was done with this condition
 - Didn't build in enzyme question for either IVA or SBCAD since I don't see anywhere in US where it is clinically available
- #6. Specific Aims (will not be posted to website at this time)

- I. Welcome & Roll Call - by State, Region, HRSA Berry/Members
 - Please announce: **your name**, your state, and, if applicable, the **clinic you are representing** and provide a **brief update** of where your center is in the IBEM-IS engagement process (waiting for **approval, finalizing IRB application, consenting, entering patient info, etc.**)*

- II. IBEM-IS
 - A. New training format – update Ostrander
 - B. IBEM-IS intake/interval surveys completed update report (Handout 1) Berry
 - C. Pregnancy Survey
 - a. CDC PRAMS (Handout 2) Bentler/Members
 - b. Pregnancy Survey Elements (Handout 3)
 - D. C5 enrollments
 - a. IVA (Handout 4) Bentler/Members
 - b. SBCAD (Handout 5)

- III. Natural History RO1 Cameron/Berry
 - A. Overview Cameron
 - B. Budget Cameron
 - C. Specific Aims (Handout 6) Berry

- IV. Other Business/Announcements Members

- V. Adjourn Berry

Notes from June Meeting were distributed via email following the June meeting and posted to the R4 website, for your reference.