

Data Operations Advisory Group Meeting August 18, 2009 12:00 PM EDT – 1:30 PM EDT

Meeting Summary

I. Overview/Introductions – Roll call was taken. Please see the attached list of participants.

- Ernestine Briggs-King described that since the previous Data Operations meeting, she has been scheduling and meeting with the collaborative groups about data specific to each population or consumer of interest. Ernestine inquired if there were other questions regarding the survey or the areas that need further committee involvement (i.e., grief, substance use and resiliency). Leslie Ross shared that her center (Center 3005-00, Children's Institute International, Los Angeles, CA) has a lot of experience in the area of grief and bereavement, including the use of the Family Relationships Index. Ernestine Briggs-King shared that the Data Operations team would prefer to find and implement an assessment instrument that was free or low cost to aid with sustainability. Ernestine stated that she is scheduled to meet with the Family workgroup on 01 September to discuss potential assessment measures. **Leslie will have Patrick provide the adapted version of the assessment used at CII which focuses on the change in family behavior.**
- Action Item: Leslie Ross will provide Ernestine with the entire domestic violence battery used at CII. CII has data of domestic violence from a variety of projects that have occurred over the last 7 or 8 years.
- Mark Rains is interested in adding some questions to the Core Data Set (CDS) that assess resiliency, although this aspect was not explored directly in the recent CDS enhancements survey it has been a part of previous conversations about CDS enhancement. This topic should be discussed on a later call.

II. Publication Guidelines Update

- Ernestine Briggs-King described the recent history of the Publication Guidelines document. Upon receiving comments and requested changes from SAMHSA on the latest version, Ernestine considered and integrated the changes requested, and forwarded the document to the Executive and Steering committees (EC and SC) for review. In the meantime, a summary of the activities prescribed by the Publication Guidelines was submitted informally to the Duke University Hospital System (DUHS) IRB for feedback and discussion of formal submission strategy. SAMHSA has requested that a Data Use Agreement (DUA) be executed to fulfill each request for data under the Publication Guidelines. The DUKE legal offices are preparing a draft of this DUA, which will then need to be shared with SAMHSA and other stakeholders (EC and SC, etc., as necessary), before this document template can be finalized. The revised Publication Guidelines document will be sent to SAMHSA in the meantime for a final review.
- Bart Evans added that the DUHS IRB has indicated that because the datasets that will be made available via the Publication Guidelines process will be anonymized (all identifiable variables will be removed/masked), analyses of these datasets will not be considered "human subjects research," and will therefore be considered "exempt" by the DUHS IRB. It is still important for each and every collaborator involved in these or any analyses to submit a protocol/application to their IRB of record for a review of the planned analyses and use of the data per local policies.
- Ernestine Briggs-King shared that the goals of the Publication Guidelines are to:
 - i. Foster collaboration
 - ii. Reduce redundant analyses and publications
 - iii. Inform the field based on analyses of the aggregate datasets

- Ernestine confirmed that throughout the various iterations and versions of the Publication Guidelines these goals have not changed. But, over time there have been some sections added and then removed (e.g. sections regarding Freedom of Information Act and 508 compliance, etc.).
- Types of analyses, publications, and presentations expected under the Publications Guidelines include submissions for journal review, conference presentations, or any papers based on analyses of data from the Core Data Set.
- The Publication Guidelines describe in detail:
 - i. The types of documents subject to the Guidelines
 - ii. The Publications Review Committee
 - iii. Authorship issues
 - iv. IRB and HIPAA concerns
 - v. Tracking of the proposals
 - vi. Timelines
 - vii. Other information regarding SAMHSA
 - viii. Appendices including the Review Form for submitting a proposal, and the flow chart of the review process.

III. Publication Review Committee Membership

- Ernestine Briggs-King asked the Data Operations Advisory Group members in attendance to consider volunteering for membership on the Publications Review Committee (PRC). Ernestine mentioned that past members and other NCTSN members and affiliates have already expressed interest. Individuals from SAMHSA, MACRO, the EC and SC, Data Operations, and other NCTSN Centers (CAT I, II, III, and affiliates) will make up the PRC. Membership will be on a rolling basis, so if someone is interested, but unable to commit to joining now, the opportunity will be available later. In addition, if a special topic is proposed for an analysis or publication, the PRC will bring in “experts” on a case by case basis to help inform the approval of such proposals.
- Ernestine described the web-based tracking system that will be used to submit, review, comment, provide feedback, and approve the proposals for analysis of the aggregate NCTSN datasets. The system is currently available on the NCTSN intranet. The system follows a workflow very similar to that of other peer reviewed publication websites. The system will enable the PRC to track the status of proposals, and also the status of the publications or presentations based on the analyses conducted upon PRC approval of a proposal.
- **If you or someone you know is interested in joining the PRC, please contact Ernestine Briggs-King at brigg014@mc.duke.edu or email the NCTSN Data and Evaluation team at nctsn@dcri.duke.edu.**

IV. Publication Datasets

- Ernestine Briggs-King stated that there are currently, approximately 11K clients have baseline visit records entered into the Core Data Set. For each of these clients, there are approximately 6K variables if each set of forms (Baseline, Trauma, and Follow-up) is completed once. While there is some missing data, the number of variables possible for each case has created several challenges to the design of the aggregate analysis datasets.
 - i. First, for each client the incredible number of variables possible for each client can be overwhelming to anyone trying to string data together for a single case. The team has tried to reduce the number of variables by combining some variables, and is considering removing others that may not be useful in the majority of analyses. Any data that is removed could be made available from a raw dataset, if necessary.
 - ii. Second, because there is no limit to the number of follow-up visits, or episodes of care, a few patients have an impressive number (7 or more) of follow-up visits completed over time, further complicating how this data is formatted in the dataset. Many SAS users will prefer “stacked data” while, other statistical software users will prefer “strings of data” on each case or client.
 - iii. Some other characteristics of the aggregate datasets are that approximately 50% of cases have an end-of-treatment visit identified, with a sizable number of cases still in treatment.
 - iv. The team is trying to design and format the analysis datasets to maximize the amount of data available, optimize the flexibility of the data for analyses to answer as many questions as possible, and minimize the difficulty in handling the data during the programming of analyses.

- Some NCTSN centers have capacity to perform fairly complex statistical analyses, while others do not. This highlights and opportunity for collaboration within the NCTSN.
- The Datasets will consist of 3 datasets based on the visit forms; Baseline, Trauma, and End of Treatment.
- Mark Rains suggested that types of analyses might be grouped into 4 basic categories:
 - i. NCCTS Data and Evaluation Program – investigate overarching themes and metrics about the NCTSN, clients served, services, etc.
 - ii. Individual Centers – performing analysis for evaluation, administrative reporting, or publications and presentations of data from their own clinics
 - iii. Collaborations – centers within the NCTSN propose analyses via the Publication Guidelines and receive the datasets for analysis
 - iv. **PROPOSED:** Data Operations Advisory Group – develop some basic analysis questions and establish some priority areas for analyses that would promote further investigation by NCTSN centers and affiliates and advance knowledge in the field. **Ernestine Briggs-King will propose this category, and investigate the availability of supplemental funding via NCTSI or some other mechanism to support these analyses.**
- Leslie Ross suggested that the Data Operations Advisory Group consider supporting and assisting some analyses and modeling of program evaluation tools. There is an increasing awareness within the NCTS of how data can be used to inform and contribute to program evaluation. Yet, many centers have little to no experience designing the approach to data informed program evaluation. Ernestine Briggs-King noted that the NCCTS Data and Evaluation Program staff has been assisting NCTSN centers with the establishment of program evaluation and metrics on a case by case basis, as centers have required technical assistance. After further discussion, **Leslie Ross suggested contacting Lori Ebert about reviving the Evaluation Sub-committee of the Data Operations Advisory Group.**

V. Next Steps

- Look for an announcement about the meeting soon. In the meantime, please visit the Data and Evaluation intranet page often for updates on current activities, minutes from this meeting, new resources and tools, and to submit discussion topics to our discussion thread.

<http://intranet.nctsn.org/sites/data/default.aspx>

For additional information, or if you have any questions, please email us at nctsn@dcri.duke.edu.

**NCTSN Data Operations
Advisory Group
Meeting Participants**

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If you would like to become a member of the Data Operations Advisory Group, please contact E. Briggs-King or B. Evans or send an email to nctsn@dcri.duke.edu.