

The National Children's Study Metadata Repository Workshop

January 23, 2012

11:00 AM – 5:30 PM

Natcher Conference Center (Room E1/E2), NIH Campus, Bethesda, MD

Overview:

The goal of this meeting is to exchange knowledge and experiences in the use of metadata in the data lifecycle of studies, inform the development and population of the Metadata Repository (MDR) for the National Children's Study (NCS), and promote connections and collaborations between metadata curators and users.

Objectives:

- Provide an introduction to the NCS Metadata Repository as a semantically-aware system that supports interoperability and collaboration within the Study
- Learn how various organizations are using metadata to support their data lifecycle and data needs
- Establish connections to use metadata and data standards in research

Agenda:

Note that in each session the speakers will present brief talks on the subjects given below and will then participate in an interactive panel discussion on the topic

Agenda Item	Description	Speaker(s)
1. Welcome and Introduction	Welcome, Agenda, Workshop Goals Introduction to the NCS, its goals and direction, data lifecycle, and metadata approach; NCS Concept of Operations	Dr. Steven Hirschfeld, Associate Director for Clinical Research, Eunice Kennedy Shriver National Institute of Child Health and Human Development (NIH/NICHHD), Acting Director, National Children's Study
2. Morning Sessions	How the Data Documentation Initiative (DDI) Version 3 Standard Represents Reusable Data Elements in Longitudinal Studies	Ms. Wendy Thomas, Chair, DDI Technical Implementation Committee
	CONCEPT: Measuring Wellness in the NCS – A Case Study (NCS Health Measurements Network and NCS Terminology)	Dr. Christopher Forrest, Professor of Pediatrics, Children's Hospital of Philadelphia Dr. Michael Padula, Medical Director of Informatics, Division of Neonatology, Children's Hospital of Philadelphia Dr. Mark Adams, Biotechnology Executive, Booz Allen Hamilton
	Introduction to the NCS Master Data Elements Specification (MDES) and the Metadata Repository (MDR)	Dr. Brian Haugen, Senior Scientist, NCS Program Office
	From Word Document to Workbench: History and Uses of the MDES in the NCS	Mr. Andrew Westdorp, NCS Project Director, Social and Scientific Systems

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Break – Lunch		
3. Afternoon Sessions	Introduction to the MDR as a Reusable Metadata Repository that Chronicles Data Collection, Data Processing, Data Dissemination, Data Analysis and Study Changes in a Longitudinal Study	Dr. Jay Greenfield, Scientist, Booz Allen Hamilton
	Use of Standards in Metadata	Mr. Wayne Kubick, Chief Technical Officer, Clinical Data Interchange Standards Consortium (CDISC)
	COMPUTATION: Metadata-Driven Survey and Study Development	Dr. Warren Kibbe, Associate Director, Northwestern University Biomedical Informatics Center Dr. Umit Topaloglu, Director of Information Technology Research, University of Arkansas for Medical Sciences
	ANALYSIS: Using Metadata in Data Archiving, Data Analysis and Study Evaluation	Dr. William Block, Director, Cornell Institute for Social and Economic Research (CISER) Dr. Timothy Mulcahy, Project Director, National Opinion Research Center (NORC) Data Enclave Mr. Pascal Heus, Executive Manager, Open Data Foundation
4. General Discussion and Wrap-Up	Summary of Key Workshop Outcomes	Dr. Steven Hirschfeld