Phenotype, Data Standards, and Data Quality Core

Update, Steering Committee Meeting, August 19-20, 2014
Bethesda, MD

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Rethinking Clinical Trials
Phenotype, Data Standards, Data Quality Core Participants

- **Monique Anderson**, Duke
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- **Denise Cifelli**, U. Penn
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- **John Dickerson**, Kaiser Permanente Northwest
- **Bev Green**, Group Health Cooperative
- **W. Ed Hammond**, Duke
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- **Rosemary Madigan**, U. Penn
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- **Renee Pridgen**, Duke
- **Jon Puro**, OCHIN
- **Tammy Reece**, Duke
- **Rachel Richesson**, Duke
- **Shelley Rusincovitch**, Duke
- **Jerry Sheehan**, National Library of Medicine (NIH)
- **Greg Simon**, Group Health
- **Michelle Smerek**, Duke
- **Kari Stephens**, U. Washington
Charter

- Promote multi-disciplinary discussion and collaboration.
- Participants will share their experiences using EHR to support research in various disease domains and for various purposes.
- Identify generalizable approaches, methods, and best practices to support the widespread use of consistent, practical, and useful methods to use widely available clinical data to advance health and healthcare research.
- Suggest where tools are needed.
- Explore and advocate for cultural and policy changes related to the use of EHRs for identifying populations for research, including measures of quality and sufficiency.
Projects

- Phenotype Use Cases in Collaboratory (ongoing)
- Environmental Scan (will be posted this week)
- Literature search guidelines (posted on Collaboratory KR)
- Registry of phenotypes (ongoing)
- Standard phenotype template (ongoing, collaborative w/EMERGE)
- Phenotype validation guidelines (just starting)
- Table 1 project (plan: data element standards + Phenotypes)
- Data quality guidelines (version 1.0 now posted on Collab. KR)
- Knowledge dissemination (ongoing)
Electronic Health Records-Based Phenotyping

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See Acknowledgments for full list of contributors

• Introduction and Definitions
• Finding Existing Phenotype Definitions
• Evaluating Phenotype Definitions
• Data Quality
• Identification and Development of Phenotype Definitions
• Implementation of Phenotype Definitions
• Recommended Phenotype Definitions
• Phenotypes, the Collaboratory, and PCORnet
• Bibliography
Break-out Sessions for New UH2’s

A lot to discuss:

• Assignment of a participant for the Core
• Contact person for your phenotype definitions
• Phenotype definitions and other characterizing info.
• Planned data sources
• Planned Data Quality Assessment activities
• Assistance needed in Phenotype definition or validation, data standards implementation, or DQA
Dissemination

• **Collaboratory Knowledge Repository:** Suggestions for Identifying Phenotype Definitions Used in Published Research


• **Living Textbook Chapter** – Richeson RL, Smerek MM, Electronic Health Records-Based Phenotyping

• **Collaboratory Knowledge Repository:** Sex Data Standard

• **Collaboratory Knowledge Repository:** Race/Ethnicity Data Standard

• **Collaboratory Knowledge Repository:** Type 2 Diabetes Mellitus Phenotype Definitions


• **Collaboratory Knowledge Repository:** Zozus, MN; Hammond WE, Green BB, Kahn MG, Richesson RL, Rusincovitch SA; Simon GE, Smerek MM, Assessing Data Quality for Healthcare Systems Data Used in Clinical Research (Version 1.0).
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