Phenotype, Data Standards, and Data Quality Core

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

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Rethinking Clinical Trials
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- **Jerry Sheehan**, National Library of Medicine (NIH)
- **Greg Simon**, Group Health
- **Michelle Smerek**, Duke
- **Kari Stephens**, U. Washington

Rethinking Clinical Trials
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 Acknowledgements for full list of contributors
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


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