NIH Collaboratory

Health Care Systems Research Collaboratory

Phenotype, Data Standards, and Data Quality Core

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

Bethesda, MD

Rachel Richesson, PhD
Assoc. Professor, Informatics
Duke University School of Nursing

William Ed Hammond, PhD
Dir., Duke Center for Health Informatics
Dir., Applied Informatics Research, DHTS
Professor of Community and Family Medicine

Meredith Nahm Zozus, PhD
Assoc. Director, Clinical Research Informatics
Duke Translational Medicine Institute

Rethinking Clinical Trials

Phenotype, Data Standards, Data Quality Core Participants

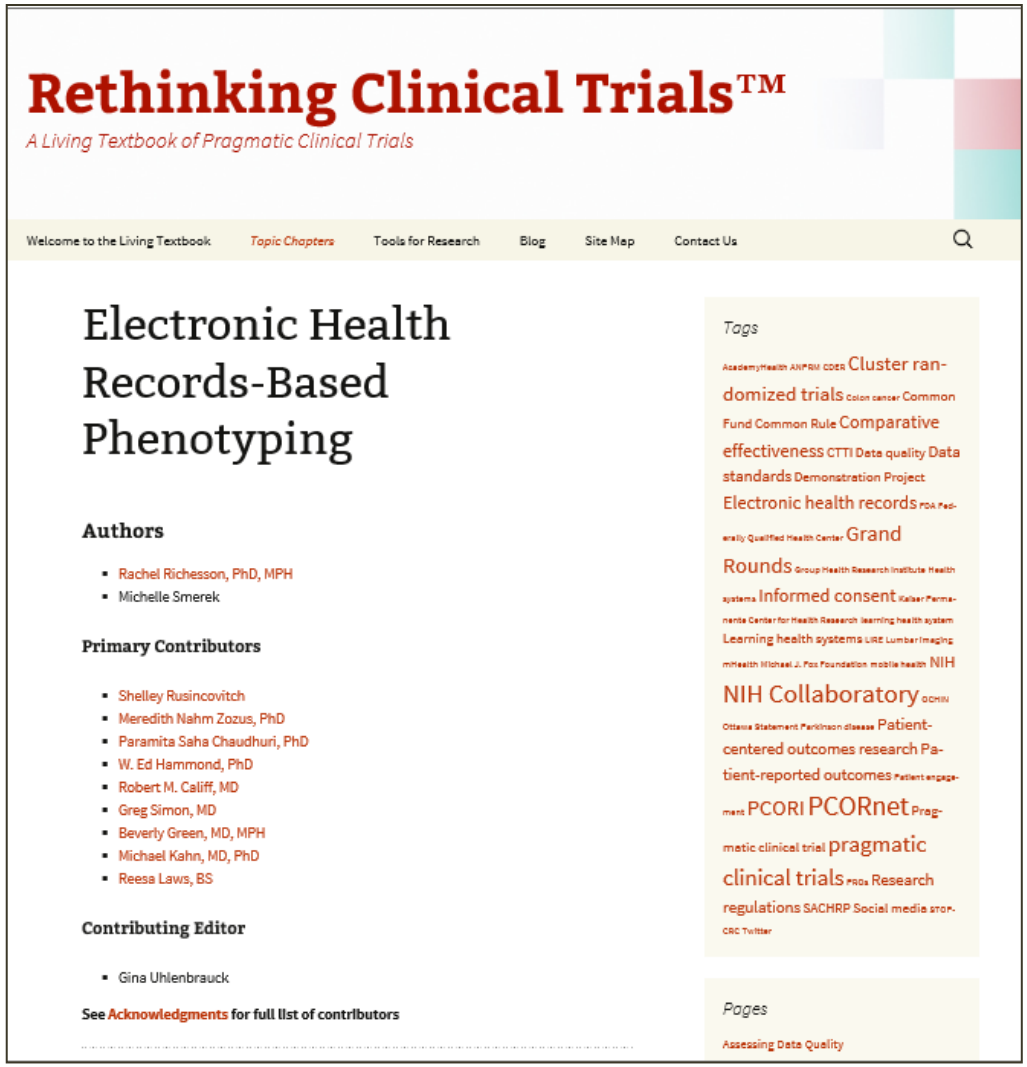
- **Monique Anderson,** Duke
- **Alan Bauck**, Kaiser Permanente
- **Denise Cifelli**, U. Penn
- **Lesley Curtis,** Duke
- **John Dickerson**, Kaiser Permanente Northwest
- **Bev Green,** Group Health Cooperative
- **W. Ed Hammond**, Duke
- **Chris Helker**, U. Penn
- **Michael Kahn,** Children's Hospital of Colorado
- **Cindy Kluchar,** Duke
- **Reesa Laws,** Kaiser Permanente
- **Melissa Leventhal,** Univeristy of Colorado Denver
- **Rosemary Madigan,** U. Penn
- **Meredith Nahm Zozus,** Duke
- **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)



Rethinking Clinical Trials™

A Living Textbook of Pragmatic Clinical Trials

Welcome to the Living Textbook | *Topic Chapters* | Tools for Research | Blog | Site Map | Contact Us

Electronic Health Records-Based Phenotyping

Authors

- Rachel Richesson, PhD, MPH
- Michelle Smerek

Primary Contributors

- Shelley Rusincovitch
- Meredith Nahm Zozus, PhD
- Paramita Saha Chaudhuri, PhD
- W. Ed Hammond, PhD
- Robert M. Califf, MD
- Greg Simon, MD
- Beverly Green, MD, MPH
- Michael Kahn, MD, PhD
- Reesa Laws, BS

Contributing Editor

- Gina Uhlenbrauck

See Acknowledgments for full list of contributors

Tags

AcademyHealth ANPRM CDER Cluster randomized trials Colon cancer Common Fund Common Rule Comparative effectiveness CTTI Data quality Data standards Demonstration Project Electronic health records FDA Federally Qualified Health Center Grand Rounds Group Health Research Institute Health systems Informed consent Kaiser Permanente Center for Health Research learning health system Learning health systems LIRE Lumbar Imaging mHealth Michael J. Fox Foundation mobile health NIH NIH Collaboratory OCHIN Ottawa Statement Parkinson disease Patient-centered outcomes research Patient-reported outcomes Patient engagement PCORI PCORnet Pragmatic clinical trial pragmatic clinical trials PROs Research regulations SACHRP Social media STOP-CRC Twitter

Pages

Assessing Data Quality

- 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
- Richesson RL, Hammond WE, Nahm M, Wixted D, Simon GE, Robinson JG, Bauck AE, Cifelli D, Smerek MM, Dickerson J, Laws RL, Madigan RA, Rusincovitch SA, Kluchar C, Califf RM. Electronic health records based phenotyping in next-generation clinical trials: a perspective from the NIH Health Care Systems Collaboratory. **J Am Med Inform Assoc**. 2013 Dec; 20(e2):e226-31. PMID: 23956018
- **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
- Richesson RL, Rusincovitch SA, Smerek M, Pathak J. Standardized Representation for Electronic Health Record-Driven Phenotypes. **AMIA Clinical Research Informatics Summit**, San Francisco, April 7-11, 2014.
- **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).

Acknowledgements

The work presented here was funded by the Health Care Systems Research Collaboratory Coordinating Center grant number 1U54AT007748-01 through the National Center for Complementary & Alternative Medicine, a center of the National Institutes of Health.