U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

National Institutes of Health

Network Rave Data Standards (NRDS) Policy and Governance WG

Judi Manola and Mike Montello June 15th, 2015

Agenda

- Review Guiding Principles
- Governance Discussion
- Next Steps

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Draft Policy Guiding Principles (from 6/15/2015)

- Minimal Necessary
 - Rationale: There should be a core set of elements that we think are universally important, only standardize elements when the benefits outweigh the risks.
- Keep it simple
 - Rationale: Makes sense
- Start small
 - Rationale: We can test the impact of the most important changes before expanding.
- Change codes for existing data elements ONLY when a need exists
- Change codes for existing data elements ONLY when the benefits outweighs the risks
 - Rationale: Depending on the application, the codes can be mapped downstream. There will be no universally
 acceptable set of codes that will avoid the need for re-mapping, so harmonizing codes may not be the highest priority.
- When creating new codes, keep it as short text strings with 10 characters or less
 - Rationale: There is a high chance of error with the use of numeric codes when it comes to mapping
- When considering a new standard data element, try to use a short text string as the code where possible.
 - For example: instead of "1=CR" use "CR"
 - Rationale: Will prevent interference with groups' existing coding systems
- Change data elements ONLY when necessary
- Rationale: Changes will have impact (and associated cost) on existing systems if there are changes that do not justify the associated cost

Governance Discussion

- How do we want to handle audits?
 - "Health inspector" approach:
 - Random unannounced requests for a study's architect loader spreadsheet, and then examine the setup for that study.
 - Require the use of global libraries at each site and examine the library contents.
 - Other ideas for ongoing compliance?
 - Do we want to identify a set of metrics to report with the audit process to analyze success and failure rates?

Next Steps

- Determine if we want to change our meeting to a monthly meeting
- Continue identifying Policy guidelines and Governance
 components as the Content WG moves forward

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Reference Information / Questions

- NCTN Co-Lead
 - Judith Manola, M.S., Biostatistician, Department of Biostatistics and Computational Biology, Dana-Farber Cancer Institute
 - jmanola@jimmy.harvard.edu
- NCI Co-Lead
 - Mike Montello, PharmD, MBA Associate Branch Chief for Clinical Trials Technology
 - montellom@mail.nih.gov
- Project Management Support
 - Neesha Desai, PMP, Project Manager, NCI CBIIT
 - Neesha.Desai@nih.gov

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