U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

National Institutes of Health

#### Network Rave Data Standards (NRDS) Committee

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### Agenda

- Project Status
- Policy/Governance WG Update
- Training/Communication WG Update
- Content WG Update
- Rave Integrations Presentation

# POLICY/GOVERNANCE WORKING GROUP UPDATE

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### Policy and Governance Working Group

- Recurring meeting: 1<sup>st</sup> and 3<sup>rd</sup> Monday of each month at 2:00pm EST
- Representation from
  - Alliance, COG, ECOG-ACRIN, NRG, SWOG
- Co-leads
  - Judi Manola (ECOG-ACRIN)
  - Mike Montello

## Policy and Governance Working Group Update

- Alliance provided an overview of their global library and the governance, curation and the QA Checklist Report of the standards.
- Group agreed to potentially move forward with the use of a Global Library.
  - Subset of the bigger library with a small scope/focus to ensure the standards are useful
- Next Steps
  - Identifying a list of subject areas that the group will need to create policies around

# TRAINING AND COMMUNICATION WORKING GROUP UPDATE

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## Training and Communication Working Group

- Recurring meeting: 2<sup>nd</sup> and 4<sup>th</sup> Tuesday at 11:00am EST
- Representation from
  - COG, ECOG-ACRIN, NRG, SWOG, Theradex, Westat
- Co-leads
  - Ginger Riley (Westat)
  - Holly Massett

### Training/Communication Working Group Update

- The group finalized their goals and objectives
- The group agreed that an FAQ document is a critical component of the training.
- The group emphasized the need of building a compressive stakeholder list as a first step.
- Discussed how others have managed EDC training at their organization
  - Theradex: Informal with a user guide and screen shots
  - NRG: Nothing formally implemented
  - SWOG: Roadmap that contains template forms for minor adjustments
- Identified a list of key stakeholders
- Next Steps
  - Begin filling out the communication matrix
  - Key stakeholder, role, message

### NRDS Project Stakeholders

- National Cancer Institute NCTN (NCI)
  - DCTD
    - CTEP
  - DCP
  - DCCPS
  - CCCT
  - CBIIT
  - CTSU
- **ETCTN** ٠
  - Theradex
  - Investigators and associates

- - NCTN Network Groups
    - Alliance
    - COG
    - ECOG-ACRIN
    - NCIC
    - NRG
    - SWOG
  - NCTN Research Sites
    - Investigators and associates

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# CONTENT WORKING GROUP UPDATE

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### **Content Working Group**

- Recurring weekly meeting: Every Tuesday at 4:00pm EST
- Representation from
  - Alliance, COG, ECOG-ACRIN, NRG, NCIC, SWOG, Theradex
- Co-leads
  - Tina Taylor (ECOG-ACRIN)
  - Dianne Reeves

### **Content Working Group Next Steps**

- Formal consensus to start with the OPEN Demography Content
  - Initials Name
  - Patient's Date of Birth
  - Ethnicity
  - Gender of a Person
  - Country of Residence
  - Zip Code
  - Method of Payment
  - Race

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#### **Content Working Group Next Steps**

- Groups are reviewing the content for any modifications needed to meet their organizational and scientific needs
  - Utilize the CDUS coded values or other codes for the PVs?
  - Use the existing PVs with modifications (shorten terms)?
  - Use the human readable value meanings for reporting?
- The group identified the risk of confusion/error in outputs when mapping to codes instead of text (ex: Male or '2')
- The group will review how Rave integrations are collecting OPEN Demography content so that they can identify a consistent approach.
- The group will continue to review OPEN Demography content and make recommendations for revisions.

# RAVE INTEGRATIONS PRESENTATION

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