CTSA Steering Committee Meeting Summary
Zoom Conference
July 24, 2023; 2:30-3:30 PM ET

Steering Committee Attendees:

Michael Kurilla, Co-Chair	Jessica Kahn
Duane Mitchell, Co-Chair	David McPherson
Stephan Bour	Ruth O'Hara
Daniel Ford	Doris Rubio
Melissa Haendel	Larry Sinoway
Laura James	Randy Urban
Tesheia Johnson	Rosalind Wright
Karen Johnston	Ted Wun

SC Regrets:

Arleen Brown, Don McClain

NCATS Attendees:

Audie Atienza	Stacia Fleisher	Clare Schmitt
Jane Atkinson	Ken Gersing	Stephen Seidel
Heather Baker	Brittany Gibbons	Yolanda Vallejo
Penny Burgoon	Chris Hartshorn	Salina Waddy
Jennie Conroy	Rebecca Katz	Robin Wagner
Jamie Doyle	Andrew Louden	Ken Wiley
Stephanie Ezequiel	Erica Rosemond	
Josh Fessel	Joni Rutter	

Support Center:

CCOS: Lauren Fitzharris, Beck Lazelle, Cindy Mark

Welcome and Update on Working Group Proposals (Slides 2-3)

Speakers: Michael Kurilla and Duane Mitchell

M. Kurilla and D. Mitchell welcomed the members of the Steering Committee and facilitated the Steering Committee call.

The Advancing Equity-focused Dissemination & Implementation Sciences in Clinical Research, Clinical Practice, and Communities working group proposal was approved by a vote of 91% in favor. CCOS will follow-up with the group.

POD Feedback (Slides 4-9)

Speakers: Erica Rosemond and POD Leads

Presentation Summary:

J. Kahn (University of Cincinnati) provided a summary report for the Pod including members from Purdue, Minnesota, Madison, Florida, and Iowa.

1. The N3C team recently provided a PowerPoint presentation followed by discussion. A summary of questions and responses is below.
    a. How does the N3C team support resource-intensive data cleaning at sites?
        1) The N3C team uses existing Hub data models, where available, to minimize workload. Data cleaning to correct data quality issues sometimes leads to quality improvements to the models.
        2) N3C-Clinical returns data in OMOP if sites do not already have OMOP.
        3) Sites should provide consensus recommendations for informatics funding needed.
        4) N3C has found that sites using common data model research networks do not incur substantial additional costs.
    b. Who is responsible for ensuring interpretation of data collected in hospital settings is completed without bias? How are we addressing these challenges?
        1) Each site has its own distinct population, but N3C seeks to mitigate inclusion of intrinsic bias in estimations wherever possible.
        2) Datasets include non-hospital data to improve generalizability.
        3) In lieu of a national centralized healthcare model in the United States, N3C provides much-needed centralized healthcare data.
        4) The N3C team's publications committee sometimes realizes there was bias in data analysis and advises the team to adjust accordingly.
        5) The team regularly examines disparities in outcomes.
        6) A governance meeting open to anyone occurs weekly.
    c. What have been the experiences of the informatics teams working with N3C?
        1) N3C assembled informatics teams and encouraged open communication, which provided a community-building experience.
        2) Acknowledging that informatics resources vary greatly across the CTSA, N3C did not impose strict deadlines for addressing quality control issues, thus allowing sites with fewer resources additional time to clean data before loading to the enclave.

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3) N3C made clear to institutions that participation in CTSA is voluntary and data is stored in a secure data enclave that does not allow for data downloads.
4) Some hospitals feed data directly into N3C.

2. At the ACTS Spring meeting, there was discussion about presenter Joni Rutter's vision for data science.
   a. Though resources may not currently align with FOA, as the vision is articulated resources needed should become clear.
   b. Sites may need to de-prioritize other work to devote attention to this area.

Questions and Discussion:

- M. Kurilla asked whether hospitals are actively addressing data quality issues.
  - J. Kahn stated it varies by Hub but data quality is a major priority for N3C.
  - M. Haendel noted that hospitals are generally less concerned about overall data quality except as it relates to implementation programs related to the primary medical record.
  - K. Johnston agreed hospitals tend to be less interested in quality issues associated with data mapped to research databases or datasets.
  - R. Wright noted the amount of work required to harmonize non-standard data from electronic health records.
  - L. Sinoway commented use of electronic medical record data without other longitudinal claims or medication data is problematic.
- Several participants noted they have a separate data warehouse for research data.

Presentation Summary:

D. McPherson (UT-Health Science Center at Houston) provided a summary report for the Pod including members from the University of Kentucky, University of Alabama-Birmingham, Boston University, and UT-SW.

1. The Pod reviewed Steering Committee presentations from May meetings, and questions related to social determinants of health arose:
   a. What was the purpose of collecting data on social determinants of health?
      i. M. Haendel explained the goal was to understand hypotheses relating to long COVID and work to recover from the condition. They reviewed risk factors, including social determinants of health, for long COVID and have published several papers. However, they only presented information on the technology involved from a coordination center perspective, not from a scientific perspective.
   b. Although Hispanics represent 17 percent of the U.S. population, the graphs displayed only 5 percent representation in the data. Does N3C collect data, and what steps are taken to include accurate demographic information?
      i. M. Haendel noted an N3C subset recovery program provided funding for inclusion of social determinants of health, and the data was collected from COVID positive cases and controls, so there was a narrow inclusion bias.
   c. What are the use cases for social determinants of health data?

        i.   M. Haendel stated the team can present in the future on the inclusion of social determinants of health in the OMOP common data model and their use of machine learning and statistical analyses of data to reveal risk assessments. They have templates for various uses.

Questions and Discussion:

- L. Sinoway asked how N3C's definition of social determinants of health differs from CDC's Social Vulnerability Index.
  - o K. Gersing noted N3C has public datasets, including social deprivation indexes, pollution indexes, and census data that link to patient data via codes. He also noted in the Chat that missing data in electronic health records is a known issue.
  - o M. Haendel noted in the Chat that the social vulnerability index and some constituent data sources are included in https://discovery.biothings.io/dataset?template=n3c. She also noted they have implemented some geocoding strategies to assign risk to patients in different locations.
- M. Haendel posted several additional links in the Chat:
  - o https://discovery.biothings.io/dataset/aaebb7ab9ac4d513
  - o https://covid.cd2h.org/social-determinants
  - o https://pubmed.ncbi.nlm.nih.gov/36093345/ (example of using social determinants of health data in N3C)
  - o https://pubmed.ncbi.nlm.nih.gov/37205340/
  - o https://pubmed.ncbi.nlm.nih.gov/35308947/

Presentation Summary:

R. Wright (Mount Sinai) provided a summary report for the Pod including members from the University of Illinois, Vanderbilt, Rockefeller, Northwestern, and Rutgers.

1. The Pod would like Steering Committee feedback on whether Pods are functioning as needed and whether there are specific insights the Pod should provide to the Steering Committee.
2. They suggested leveraging the Hub expertise of Pod members to stimulate collaborative projects and noted the need for an action item reminder to prepare for the Steering Committee meeting.
3. They discussed the Fall meeting topic of use of artificial intelligence (AI) in translational science, ethics, and education.
4. They suggested several potential speakers for the Fall meeting to participate in sessions on AI, ethics, and informatics.
5. They discussed training programs on AI and data science, noting focuses on building core competencies and an existing CTSA informatics competencies training.
6. The Pod would like NC3 to present to the Pod information on how they support and access and whether NCATS can estimate basic funding needed as a budget target.
7. The Pod would like the Steering Committee to discuss whether there is a potential for revising FOA, the differences between translational research and science, ways it can

provide guidance to Hubs as they develop frameworks, the possibility of sharing successful examples of funding applications with the consortium,

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Crowd Sourced Agenda Topic: How do you Construct Your EAB/EAC and Meetings? (Slides 10-11)

Speaker: Randy Urban

Presentation summary:

R. Urban shared 6 questions and requested feedback from the participants based on experience at everyone's individual institutions.

1. How long should be the duration of a meeting with the involvement of community members? What is a reasonable length of time?
   a. D. Mitchell stated groups have been experimenting with using a shorter meeting format, but it has been a challenge to convey the full breadth of information in a shortened format. Content should fit the allowed timeframe
   b. T. Johnson agreed it is important to be selective about information conveyed but noted community members are engaged and enjoy the program meeting. If anyone is thinking of a shorter duration, be mindful that it likely not be that helpful to the EC or community members.
   c. D. Rubio noted some hubs still do EAB via Zoom. Two days is too much. Meetings should be more focused and discuss fewer topics. However, frustration may also arise if there is not enough time for discussion, which often generates resutls and benefits.
   d. R. Wright agreed it is import to avoid overwhelming attendees with non-essential information. She suggested splitting training programs with other EABs.
   e. L. Sinoway noted networking can occur at dinners. Some discussion of clinical research at different institutions can occur over a meal. He suggested introducing general themes and obtaining views about things needing work. He also approves of breakout discussions and then summary review by the full group.
   f. J. Kahn noted they invite EAB members to join a networking dinner the evening before and then complete the EAB meeting the next day, ending mid-afternoon. They also shared information ahead of meetings to avoid spending time reviewing that at the actual meeting.
   g. D. McPherson said his group has three interim EABs. Each group focuses on a different topic and meets virtually or in person before the full group meeting.
2. How much and what type of information should the Pod send the EAB before the meeting?
   a. L. James commented she recently participated in an Oregon EAB meeting where they effectively shared a one page document related to each core topic, providing big metrics at a glance. This left plenty of time for discussion.
   b. T. Wun noted in the Chat they distribute presentation slides the week before a meeting.

3. What is the best way to structure the EAB meeting? Virtual versus in-person versu Hybrid? Do breakout groups work for the meeting? How do you structure an EAB meeting with multi-institutional partners?
    a. D. McPherson said EABs should be allowed to present as equal partners.
    b. K. Johnston recommends rotating meetings around different sites to allow for fuller participation. Virtual meetings are also helpful because they reduce travel costs, but the Board is asking for more in-person meetings that will provide more time with scholars.
    c. D. Rubio noted she had never attended a meeting with breakout sessions, but agrees discussion is the most beneficial part of a meeting.
    d. D. Ford noted Johns Hopkins is moving away from holding breakout sessions due to timing issues. They have found it challenging to reconvene and have useful full group discussion in the time remaining.
    e. R. Urban commented everyone seems to be taking different approaches.
    f. T. Wun noted in the Chat his group does not do breakout seessions because they received negative feedback from the EAB when they did hold them previously.
4. What is the ideal number of members to serve on the EAB? Do you continue to communicate with EAB members throughout the year?
    a. D. Rubio noted it varies; some have 5-6 members and others have around 15, but she recommends 6-8 as a good range.
    b. R. Wright agreed 8 should be the maximum, but noted the number might need to expand depending on the topic and presentation.
    c. T. Johnson noted her board is larger because they have CTSA representation as well as university deans and health system leaders. They have found it useful to have the additional representation since many of the questions relate to the institutions.
    d. D. Ford noted in the Chat his group originally did not include members from other CTSAs, but they now realize CTSA members contribute value and thus include CTSA principal investigators to their EAB.
5. Should EAB members be paid an honorarium?
    a. D. McPherson noted they offer everyone the same honorarium with the expectation that they will attend and participate. Surprisingly, roughly half return the honorarium.
    b. T. Johnson noted pre-pandemic CTSA honoraria ranged between $1,000.00 for one-day meetings to $2,500.00 for longer meetings. She is unaware of any EAB that does not pay an honorarium.
    c. D. Ford agreed participants should be compensated.
6. What are the expectations for the EAB report? Who writes it, what is contained in the report, what is the timeline for return to the hub?
    a. K. Johnson noted in the Chat compensating the lead writer of the report would be appropriate.
    b. R. Wright agreed in the Chat there should be more compensation for report writers.

Reminders

2023 Fall Program Meeting

- Meeting Information (agenda, FAQs, etc.) is available on CCOS website
- November 6-8, 2023, at Double Tree (Crystal City) in Washington, DC
- Registration is now open! A confirmation email including room block information will be sent after registration is complete.
- Send questions to mailto:FallMtg@ccos.ctsa.io

Meeting Action items

Date	Action	Person Responsible	Status
6/26/2023	CCOS to notify The Advancing Dissemination and Implementation Science Working Group: Advancing Equity-focused Dissemination & Implementation Sciences in clinical research, clinical practice, and communities that they have been approved as a Cycle 10 working group. and forward responses to SC.	L. Fitzharris	In progress
6/26/2023	Create a summary table.	K. Johnston and J. Fessel	In progress

Next Steering Committee Meeting: Monday, September 11, 2023, at 2:30-3:30 PM ET