CTSA Program Steering Committee

July 24, 2023

2:30 – 3:30 ET

Agenda July 24ᵗʰ, 2023

Time	Topic	Speaker(s)
2:30 – 2:35	Welcome and Update on Working Group Proposals	Michael Kurilla & Duane Mitchell
2:35 – 2:55	Pod Feedback	Erica Rosemond
2:55 – 3:30	How do you construct your EAB/EAC and Meetings	Randy Urban

Update of Working Group Proposals: Cycle 10

Should The Advancing Dissemination and Implementation Science Working Group: Advancing Equity-focused Dissemination & Implementation Sciences in clinical research, clinical practice, and communities be approved as a new working group?

91% Yes

9% Reject

CCOS will follow-up with the group.

Pod Feedback

Erica Rosemond

Date Received: May 24, 2023
Pod Lead: Jessica Kahn, University of Cincinnati
Pod Membership: Purdue, Minnesota, Madison, Florida, Iowa

Pod Meeting Summary Report:

1. N3C Discussion
- Christopher, Melissa, and Emily (N3C team) presented a PowerPoint which was followed by a discussion.

Discussion
- It can be **resource-intensive for teams at sites to do the data cleaning** – how can this be supported?
  - N3C team acknowledged that it **is challenging to maintain staff on informatics teams**.
  - **N3C team has attempted to minimize additional work** and build on areas that hubs are working on already (e.g. maintaining the same data models) – did not want N3C to add to the sites' work. So they have been able to take data from any model and ingest it with almost no change. Only if there are major data quality issues do they go back to the sites. N3C was agnostic to which data model the sites use. If there are data quality issues, then data cleaning may lead to improvements in that quality which is a benefit to sites.
  - In **N3C-Clinical,** the **team will return data in OMOP** if the sites don't already have data in OMOP which is a benefit to the sites.
  - It may be that the way that the CTSA program is organized, there is **not enough funding for informatics work,** so it will be important for sites to identify and ask for what they need. Consensus recommendations from sites for support may be helpful.
  - The N3C's experience is that those sites that use **common data model research networks do not incur substantial additional costs,** and they also benefit from the improvement in data quality.
- **Where does responsibility lie** in terms of **interpretation of findings?** These are data captured primarily in hospital settings, and **hospital settings have biases** (structural, who comes to a hospital, etc.) which means that any information coming out of that may maintain or amplify those biases. From an ethical standpoint, where does the accountability lie that the data that come out of this system do not create more harm than benefit?
  - N3C is looking at **ways to mitigate intrinsic bias** in the estimations. Each site includes different populations – e.g. Hopkins cares for large proportions of individuals living in poverty as well as those who present for care from around the world.
  - The dataset also includes non-hospital data to improve generalizability.
  - We have **no centralized healthcare in the US** so we have no centralized healthcare data – the **N3C is the closest** we have come.

Continued on next slide…

Date Received: May 24, 2023

Pod Lead: Jessica Kahn, University of Cincinnati

Pod Membership: Purdue, Minnesota, Madison, Florida, Iowa

Pod Meeting Summary Report:

- **How can we address these challenges?**
  - When N3C team notes that a site is collecting data in a way that appears biased (e.g. in the way that race was assessed at one site), the publications committee has often been able to catch that and advise them.
  - They have been tapped to examine disparities in outcomes (e.g. by government) using the N3C database.
  - There is a governance meeting weekly and it is open to anyone.
- **What have been the experiences of the informatics teams working with N3C?**
  - N3C focused on establishing a **"white glove" service** – wanted to be very hands-on and establish good lines of communication. They brought together the informatics teams in a way that they had not been brought together before, and this was a community-building experience.
  - **There are "haves" and "have-nots" across the CTSAs when it comes to informatics** – the resources vary greatly across the CTSAs. The "have-nots" are the ones that had the most challenges with data quality issues because of competing priorities. N3C did not release data into the enclave until they were cleaned, but did not set deadlines for sites to address quality issues so that they did not add to the sites' workload.
  - Some sites don't have as much influence or control with respect to the institution. There were some **concerns about joining N3C being required for participation in the CTSA**. The N3C team clarified that participation is voluntary, including N3C-clinical and the **data are in an enclave** so it is a highly protected environment. It **does not allow data exfiltration** (cannot download data).
  - Some hospitals have their own data feed into N3C.

2. Reflections on ACTS spring meeting
- **Discussed Joni Rutter's vision with respect to data science**
  - Discussion of alignment with FOA (well-aligned)
  - Are resources aligned currently? Not necessarily but once the vision is articulated, it will become more clear what resources may be needed.
  - Sites may need to de-prioritize some work in order to devote attention to this area.

Date Received: June 1, 2023
Pod Lead: David D. McPherson, UT-Health Science Center at Houston
Pod Membership: U of Kentucky, U of Alabama-Birmingham, Boston U, UT-SW

Pod Meeting Summary Report:

Crowd Sourced Agenda – Social Determinants of Health

- The POD reviewed both SC meetings in May

- Of note, for SDoH a number of questions arose

Questions:

- What was the purpose of collecting these data?

  - – ie what is the hypothesis for the collection – not presented

- Hispanics represent 17 percent of the population of the United States – however, the graphs show they were about 5% each.

  - Does N3C non-representative of the country collect the data?

  - If so what are they doing to collect data that better represents the country's demographics?

- How will they use data (if accurately representing the country)?

  - – ie what "case use" can they or will they show for SDoH?

Date Received: June 16, 2023

Pod Lead: Rosalind Wright, Mount Sinai

Pod Membership: U. of Illinois, Vanderbilt, Rockefeller, Northwestern, Rutgers

Pod Meeting Summary Report:

Topics of Discussion

- Feedback on **how the POD's are going/other ways of structuring?**
  - *Are we getting out of this what we need?*
  - *Are there any specific highlights we need to take to the steering committee?*

- **Possibly leverage the broader hub expertise** of the POD members to seed/stimulate collaborative projects
  - (Maybe set aside 15mins on some interval?)
  - **Action Item:** Would need to be reminded of these tasks a few weeks before for preparation for the meeting

- Discuss **fall face-to-face meeting**
  - How can CTSA lead the way in advancing use of AI/RWD in translational science/equity and ethics/and education

- **Who should we have speak at the fall meeting?** Who will bring new ideas?
  - Potential speakers discussed on planning calls - inviting someone for the AI presentation
    - (**Friedman** (UMich, national scalable LHS), possibly
    - **Sam Altman** (CEO OpenAI)
  - **Other ideas** for national level speakers
    - Who should we consider?
      - Think about the interface with AI/pathology/algorithms/etc and the AI for Messaging/delivering results/ethics/etc. Would be nice to balance out the full continuum.
      - **Peter Embi**, chair at Vanderbilt (Part of CTSA) – speaks on importance of algorithm of vigilance in evaluating AI tools for healthcare utilization https://www.vumc.org/dbmi/person/peter-j-embi-md-ms-facp-facmifamia-fiahsi
      - **Tina Hernandez-Boussard** from Stanford, addressing bias and promoting fairness in AI for healthcare; https://med.stanford.edu/boussardlab/research.html
      - Maybe someone who can talk about the effect of wildfires showing the potential for AI to address challenges facing translational science/medicine related to emerging climate change issues (bringing environment into translational science more broadly)

Date Received: June 16, 2023

Pod Lead: Rosalind Wright, Mount Sinai

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- Ideas from the **informatics** side?
  - **Zak Kohane**, Harvard, good at making waves in algorithmic space (not involved in CTSA)
- Think more about **ethics**, what are the nuances around AI?
  - **Ellen Clayton** at Vanderbilt (Highly regarded) https://law.vanderbilt.edu/bio/ellen-clayton
- There was great interest in an AI lecture on privacy issues when using AI and inputting health data. There is a steep learning curve on understanding the risks and data compliance.

- What is everyone thinking about with their **training programs on AI and data science?**
  - **Focus on building some basic competencies**, but unrealistic to expect that someone would get the skills of a PhD. They should be able to discuss concepts and be competent to implement in TS.
  - Team science and building in the core competencies as a focus
  - Reminded by the group that **there is already informatics competencies training** developed through the CTSA for investigators, it's at the lower end (Knowledgeable consumer skills). It was through the network. https://academic.oup.com/jamia/article/23/4/835/2201104 . **Are we leveraging this** in the consortium?

- Anything else you would like to discuss?
  - A lot of PODs are having people from **NC3 come talk** with them, are we interested in this - **YES?**
    - The important thing is access, and **how do you support access**. These are expensive endeavors. How to find a solution to sustain this work in the consortium
    - Would be helpful to understand **whether NCATS can give an estimate on what the expected unfunded mandate is** (either in FTEs or Dollars); would be helpful to build a budgeting target.
    - How can NCATS guide us in this direction
  - What would you like us to discuss at the **Steering Committees**
    - Wondering if there is a vision for **revision of future FOA**
    - How much do we need to talk about the **difference between translational research and translational science?** Do we want to designate face-to-face time in the fall to discuss?
    - The **RC2** is very complex as it leans heavily on the translational science part of it.
    - **Guidance on scope** as each hub comes up with own sense/framework
    - **Examples** of successful ones would be helpful – make them available to the consortium

Crowd Sourced Agenda Topic:
How do you construct your EAB/EAC and Meetings

Randy Urban

EAB Discussion

Randy Urban

1. How long a duration for the meeting with the involvement of community members?

2. How much information and what type of information to send the EAB before the meeting?

3. What is the best way to structure the EAB meeting? Virtual vs In-person vs Hybrid? Do break out groups work for the meeting? How do you structure an EAB meeting with multi- institutional partners?

4. Who best to serve on the EAB? How many EAB members is ideal? Do you continue to communicate with EAB members throughout the year?

5. Should EAB members be paid an honorarium?

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?

2023 Fall Program Meeting

- Fall Meeting Registration Open:
  - **https://cvent.me/v9nqPx**
  - A confirmation email will be sent after registration is complete and will include room block information

- Meeting webpage available on CCOS website**:**
  - **https://ccos-cc.ctsa.io/groups/program-meetings**

- Date and Location: November 6-8 in Washington, DC
  - Please see website for more details, including agenda and FAQs

- Questions: FallMtg@ccos.ctsa.io

Next SC Meeting:

September 11th , 2:30-3:30 PM ET