

NCATS

COLLABORATE. INNOVATE. ACCELERATE.

CTSA Program Steering Committee

October 28, 2024

2:30-3:30pm ET

CTSA Clinical & Translational
Science Awards Program



NIH National Center
for Advancing
Translational Sciences

October 28, 2024 Steering Committee Meeting: Agenda

| Time | Topic | Presenter(s) |
|----------------|--|--|
| 2:30-2:35pm ET | Welcome | Michael Kurilla Ruth O'Hara |
| 2:35-2:50pm ET | Update: Real-World Data Task Force, followed by discussion | Josh Fessel Ruth O'Hara Karen Johnston |
| 2:50-3:10pm ET | Report Out: Integration Across Lifespan EC, followed by discussion | Karen Wilson Mark Schleiss |
| 3:10-3:30pm ET | Informatics vs. Data Science Discussion | Joni Rutter Michael Kurilla |
| 3:30pm ET | Adjourn | |



Real-World Data Task Force Update

Josh Fessel

Director, NCATS Office of Translational Medicine

Very Brief Outline

- How it started
- How it's gone so far
- Key outputs
- What's next?

Genesis of the Task Force

- Initial goal came from two separate places that seemed to be closely related
 - From the SC side, help the CTSAs get a handle on the various NCATS-supported data assets
 - From the NCATS side, help understand what the CTSAs most want to do in the realm of data sciences related to RWD
- Fairly quickly discovered that the TF mission needed modification
 - It's not the “what” but rather the “who” and the “how”
 - There are basic language barriers to this kind of transdisciplinary team science
 - Some silos existed
- Focus shifted
 - Needs assessment
 - 3 impactful areas – education, democratization of data sciences, community engagement



Real World Data Task Force

Arleen Brown

Manisha Desai (co-chair)

Melissa Haendel

Tesheia Johnson

Karen Johnston (co-chair)

Jareen Meinzen-Derr (co-chair)

Ruth O'Hara

Muredach Reilly

Steve Reis

Ken Gersing

Jim Dickens

Josh Fessel

CCOS Team

- Serve to help focus the CTSAs' data science goals and needs
- Communicate those goals and needs to the Steering Committee and to NCATS leadership
 - “We’re not looking for the roadmap. We’re looking for the destinations.” – Mike Kurilla
- Meet monthly on Mondays at 4pm ET
- “Wait, wasn’t this the EHR/RWD Task Force?”
 - Yes, and still is. But we’ve learned a lot about how we all think and use words in this space....



National Center
for Advancing
Translational Sciences

Major Deliverable #1 - Education

- First major goal identified and the one most consistently topping the list
- Shared vocabulary needed
 - Development of an open access living glossary for data sciences terms and concepts
- Training materials needed
 - Course materials developed for a host of data sciences topics - machine learning, good algorithmic practices, artificial intelligence, and many others
 - Designed to be a living resource
 - All available to the entirety of the CTSA via the CCOS website
- Training space needed to actually practice
 - National Clinical Cohort Collaborative Education Tenant
 - Synthetic datasets with complete functionality of N3C
 - Designed to be as frictionless as possible to access



Major Deliverables #2 & 3 – Democratization and Community Engagement

- Recognized that the CTSAs collectively are leaders in data sciences
 - Experts and areas of expertise are unevenly distributed
- Recognized that data sciences is and needs to be a big, inclusive tent
 - There is no “One Ring to rule them all” and shouldn’t be
- Many parallels to clinical trials... so what about a “TIN-like structure for data sciences”?
 - Consider the CClA mechanism for now
 - How to build out further?
- Community engagement → communities engagement
 - Many communities to consider and to engage
 - Have only really just begun, and lots of opportunities remain



“Where Do We Go? Where Do We Go Now?”

- RWD TF could go on indefinite hiatus as other groups take up the charge
 - Workforce Development WG
 - Enterprise Committee(s)
- RWD TF could refocus to augment efforts to engage communities
 - This could include efforts to identify and to bridge silos within the CTSAs, as the CTSAs are one of the communities most important to engage
 - Could involve creative thought around how to have impactful conversations about data sciences and RWD with the communities from which those RWD come, the goal being to have communities become partners
- How can the data sciences and technology needs of the CTSAs be best served by this group?



NCATS

COLLABORATE. INNOVATE. ACCELERATE.

Now YOU talk!



NIH National Center
for Advancing
Translational Sciences

Integration Across the Lifespan Report Out

Lead Team Members



Karen Wilson, University of Rochester (Co-Chair)



Mark Schleiss, University of Minnesota (Co-Chair)



Elisabet Børsheim, University of Arkansas



Amanda Dettmer, Yale School of Medicine



Susanna McColley, Lurie Childrens Hospital



Mark Supiano, University of Utah

Non-Voting Members

- **Rashmi Gopal-Srivastava**, NIH/NCATS Representative
- **Melissa Brady**, CCOS Coordinator
- **Daniel Hanley**, TIN Representative

Goals



The Integration Across the Lifespan Enterprise Committee ensures translational science is integrated across its multiple phases and disciplines within complex populations' lifespan.

Its goals are to:

- Integrate translational science across all stages of life, with the ultimate goal of improving the health of all individuals
- Launch initiatives to investigate disparities in disease progression and treatment among special and complex populations
- Develop an integrated and cohesive approach to translational science that spans across all phases of research

Lead Team Activities

- Spring 2024 CTSA Group Meeting
- Monthly meeting presentations
- “Engaging Individuals with Disabilities in the Research Process” approved as a Working Group
- Social Determinants of Health Subcommittee
- Pediatric Clinical Trials Subcommittee
 - Working Group Proposal Submitted
- PAS Scholarly Session submission



Future Directions

- Support Social Determinants of Health Subcommittee Working Group proposal submission
- Partnerships/programs with other ECs:
 - Workforce
 - Informatics (Harmonizing longitudinal datasets across the lifespan)
 - DEIA
 - Community Engagement
- Expanding EC membership and participation



We are looking for new members!

- Need to encompass the entire lifespan/life-course
 - A little pediatrics heavy!
- We still need representation from:
 - Harvard Medical School
 - Icahn School of Medicine at Mount Sinai
 - Tufts University
 - University of Florida
 - University of Wisconsin, Madison
 - UT Southwestern Medical Center
 - Vanderbilt University Medical Center



Questions?

Contact: integrationacrosslifespan@ccos.ctsa.io
schleiss@umn.edu

Karen_Wilson@urmc.rochester.edu



Questions for the Steering Committee

- How does lifespan research fit in with the new NCATS strategic plan?
<https://ncats.nih.gov/about/ncats-overview/strategic-plan>
- Many academic societies represent different components of our lifecourse groups (pediatrics - Pediatric Academic Societies; pregnancy - American College of Obstetrics and Gynecology; geriatrics - American Geriatrics Society). Should efforts be made by our committee to form liaisons with these societies, particularly for programming for annual meetings?
- Many of the challenges with recruitment in different lifecourse groups (pediatrics, pregnancy, geriatrics) are similar across groups- in the spirit of translational science how can we more intentionally share information on overcoming these barriers across the lifespan?

Informatics vs. Data Science Discussion

- Joni Rutter
- Michael Kurilla



National Center
for Advancing
Translational Sciences

The relationship between Data Science and Biomedical Informatics in CTR & CTS

Presentation and discussion of the Venn diagram

Virtual CTSA Steering Committee Meeting

October 28, 2024

Meredith Zozus, PhD

Co-Chair, Informatics Enterprise Committee
Professor, Division Chief Clinical Research Informatics
Joe R. and Teressa Lozano Long School of Medicine
University of Texas Health Science Center at San Antonio

Thomas R. Campion, Jr., PhD, FACMI

Co-Chair, Informatics Enterprise Committee
Associate Professor of Research
Population Health Sciences
Weill Cornell Medical College

We agree the intersection on the slide is Data Science.
However, the intersection does not represent biomedical informatics.
For example, the domain knowledge, expert systems, and usability testing
are Biomedical Informatics as is Ontology.

For reference, our last discussion left off after discussion about the slide to the right and the name change from Informatics to Data Science.

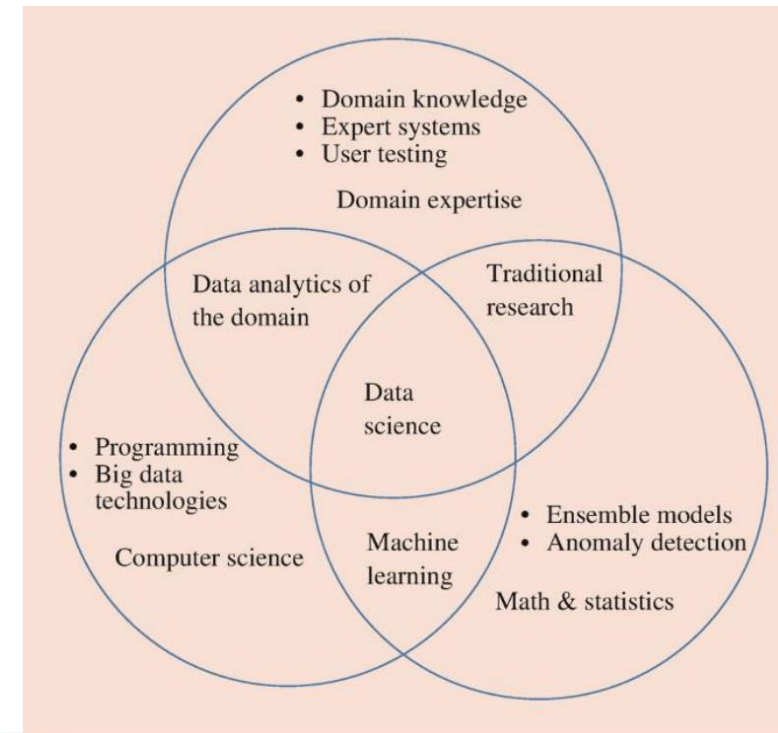
We were asked to bring back a Venn diagram showing the relationship between the two.

Slide from September 9, 2024 CTSA Steering Committee Meeting →

Data Science

- Computer science
- Math & statistics
- Domain expertise

Chiang, KL., Huang, CY. (2023). Precision Medicine and Telemedicine. In: Nof, S.Y. (eds) Springer Handbook of Automation. Springer Handbooks. Springer, Cham. https://doi.org/10.1007/978-3-030-96729-1_58



Adjourn

The next Steering Committee Meeting will be on November 13, 2024, 1:30-6:00pm ET in Bethesda, MD.

REMINDER: Please review the working group proposals!!!

