



Cancer Research Data Exchange Summit

Date: May 8 - 9, 2024

Agenda

(Please note, the following times are approximate, and all times are ET)

Day 1 – Wednesday, May 8th 10:00 am – 4:45 pm

10:00 AM - 10:15 AM

Welcome and Opening Remarks (Plenary)

- Jennifer Goldsack, CEO, Digital Medicine Society (DiMe)
- Avinash Shanbhag, Executive Director, Office of Technology, ONC

10:15 AM - 10:30 AM

Keynote Speakers (Plenary)

- Micky Tripathi, PhD, MPP, National Coordinator for Health Information Technology, ONC

10:30 AM - 11:35 AM

Session 1 (Plenary): Stories from the Field

- Technical foundational support for standardized health data exchange via open, consensus-based standards
 - Stephen Konya (Moderator)
 - **Group 1 – Federal**
 - Liz Turi, ONC
 - Anne-Marie Meyer, NCI
 - Kathleen Blackwell, CMMI, EOM
 - **Group 2 - Industry and CC-DIRECT**
 - Su Chen, MD, CodeX
 - Amy Cramer, Vulcan
 - Warren Kibbe, Duke
 - **Wrap-up**
 - Umit Topaloglu, NCI

11:35 AM – 11:50 AM

Session 2 (Plenary): Introduction to the use cases and user perspectives

- Overview and Goals for the USCDI+ Cancer Data Exchange Summit
- USE CASES & PERSPECTIVES
- Liz Turi, ONC

11:50 AM - 12:50 PM	Lunch
12:50 PM – 2:30 PM	Session 3 (Breakout): Questions in facilitation guide <ul style="list-style-type: none"> • Group I: Data Generators • Group II: Clinical Care Teams • Group III: Specialty Groups that Inform Care • Group IV: Middleware & Data Vendors • Group V: Standards & Semantic Experts • Group VI: Specialty Groups that inform Data Exchange & Sharing • Group VII: Patients, Caregivers, & Advocates • Group VIII: Researchers & Data Scientists RWD • Group IX: Regulators/Policy/Governance, Payers & Public Health with RWD • Group X: Senior Executives from the RWD ecosystem
2:30 PM - 2:40 PM	Break and move back to TE406
2:40 PM – 3:00 PM	Keynote Speaker (Plenary) <ul style="list-style-type: none"> • Keynote: View from NCI <ul style="list-style-type: none"> ○ Kimryn Rathmell, PhD, Director, National Cancer Institute
3:00 PM - 4:45 PM	Session 4 (Plenary): User Perspective Report outs <ul style="list-style-type: none"> • In this session, we will hear a summary of the issues from the User's Perspective
5:15 PM - 7:15 PM	After Hours Networking Event <ul style="list-style-type: none"> • The Bistro - 2nd floor • Courtyard Marriott, 2500 Research Blvd, Rockville, MD 20850
Day 2 – Thursday, May 9th 10:00 am – 4:45 pm	

10:00 AM - 10:15 AM	Welcome and Opening Remarks (Plenary) <ul style="list-style-type: none"> • Dr. Jill Barnholtz-Sloan, Associate Director of Informatics and Data Science Program, Center for Biomedical Informatics and Information Technology, NCI
10:15 AM - 10:45 AM	Keynote Speaker (Plenary) <ul style="list-style-type: none"> • View from the White House <ul style="list-style-type: none"> ○ Dr. Danielle Carnival Chairwoman, Deputy Assistant to the President for the Cancer Moonshot and Deputy Director for Health Outcomes, White House Office of Science and Technology Policy • View from a patient perspective <ul style="list-style-type: none"> ○ Ms. Amanda Borens, patient advocate, cancer survivor, and data scientist

10:45 AM - 11:00 AM	Break and move into Use Case Groups
11:00 AM - 11:20 AM	Session 5 (Plenary): Introduction to the Use Cases <ul style="list-style-type: none"> The goals and details of each Use Case will be presented at this session. <ul style="list-style-type: none"> CTM irAE Cancer Registries
11:20 AM - 12:20 PM	Session 6 (Breakout): CURRENT & FUTURE STATE AND INTRO TO ELEMENTS <ul style="list-style-type: none"> For each of the 3 Use Cases – CTM, irAE, Cancer Registries: <ul style="list-style-type: none"> Review the current state Create the desired future state Review higher-level classifications Introduce data-elements
12:20 PM - 1:20 PM	Lunch <ul style="list-style-type: none"> Lunch & Transition to Break-out Session 4 Rooms
1:20 PM - 2:10 PM	Session 7 (Plenary): Use Case Report outs. (CURRENT & FUTURE): <i>(15 minutes each, 5 minutes discussion)</i> <ul style="list-style-type: none"> Summary of the Use Case discussions from Session 6 <ul style="list-style-type: none"> CTM irAE Cancer Registries
2:10 PM - 2:25 PM	Break <ul style="list-style-type: none"> Stay in break-out rooms
2:25 PM - 3:25 PM	Session 8 (Breakout): DATA ELEMENTS PT 2, ACTIONS, TIMELINES <ul style="list-style-type: none"> Develop actions, priorities, and a timeline for each of the 3 Use Cases – CTM, irAE, Cancer Registries: <ul style="list-style-type: none"> Determine which concrete elements are generalizable and can be repeated in other areas of oncology and disease What data is available in the short term that provides broader value to the current state What data will be available from a long-term broader outlook?
3:25 PM - 3:40 PM	Break <ul style="list-style-type: none"> Break & Transition to the Plenary Session
3:40 PM - 4:30 PM	Session 9 (Plenary): Report Outs (TIMELINES/ACTIONS) <ul style="list-style-type: none"> Report out the common actions, priorities, and timeline views across each use case.

- CTM
- irAE
- Cancer Registries

4:30 PM – 4:45 PM

Session 10 (Plenary): USCDI+ Cancer Next Steps

- In this session, we will summarize the progress made and what that means to widespread adoption, including potential regulatory implications, and work that must be continued in other venues/initiatives after the Summit.