

National Cancer Institute

Childhood Cancer Data Initiative Symposium

July 29 – 31, 2019

Marriott Marquis, Washington, D.C.

DRAFT AGENDA & SESSION GOALS

MONDAY, JULY 29TH

- 4:30 p.m. – 5 p.m. **Registration & Gathering**
- 5 p.m. – 5:25 p.m. **Welcome & Opening Remarks**
Doug Lowy, M.D.
National Cancer Institute, NIH
- 5:25 p.m. – 5:50 p.m. **Keynote Address**
- 5:50 p.m. – 7:10 p.m. **Envisioning a National Childhood Cancer Data Initiative** *(Panel discussion)*
Goal of this session:
- To provide participants with perspectives from the government and private pediatric cancer research and care stakeholders for the CCDI
- 7:10 p.m. – 7:30 p.m. **Patient-Centered Data Management for Discovery** *(10 minutes each)*
- **Ethics Around Data Science & Sharing**
 - **Meeting Patient Needs through Data**
- 7:30 p.m. – 9:30 p.m. **Poster & Networking Reception**
- 9:30 p.m. Adjourn
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TUESDAY, JULY 30TH

- 8 a.m. – 8:30 a.m. **Registration & Gathering**
- 8:30 a.m. – 10 a.m. **Setting the Stage Presentations for Implementation of Vision**
(Panel discussions for each area of focus; 45 minutes each)
Goal of this session:
- This session will outline each of the focus areas of the NCI Childhood Cancer Data Initiative to provide a more comprehensive overview for broad discussion
 1. **Prioritizing scientific and clinical research data needs for therapeutic progress**
 2. **Creating meaningful datasets for clinical care and associated research progress**
- 10 a.m. – 10:15 a.m. **Break**

10:15 a.m. – 11:45 a.m. **Setting the Stage Presentations for Implementation of Vision – *continued***
(Panel Discussions, 45 minutes each)

3. Infrastructure to enable federation among pediatric data repositories

4. Development of tools and methods to extract knowledge from data

11:45 p.m. – 12: 30 p.m. **Roundtable Discussion – Governance and authorities associated with establishing a pediatric data ecosystem**

Goal of this session:

- To facilitate large group discussion around the themes that are cross-cutting from the morning session

12:30 p.m. – 1:30 p.m. **Networking Lunch & Poster Viewing**

1:30 p.m. – 5:30 p.m. **Breakout Track Sessions**

Goal of this session:

- Attendees will be broken out into focus groups along primary areas of focus. Each group should outline a set of recommendations for implementing approaches (can consider the following perspectives for each):
 - **Prioritizing scientific and clinical research data needs for therapeutic progress**
 - **Creating meaningful datasets for clinical care and associated research**
 - **Infrastructure to enable federation among disparate pediatric data repositories**
 - **Development of tools and resources to extract knowledge from data**

5:30 p.m. Adjourn for the day/Dinner on your own

WEDNESDAY, JULY 31ST

8 a.m. – 8:30 a.m. **Networking & Gathering**

8:30 a.m. – 10:30 a.m. **Recommendations from Breakout Track Sessions (30 minutes each)**

Goal of this session:

- A representative from each area of focus (breakout groups) will present an outline for a plan of action/set of recommendations for implementing approaches.
 - **Prioritizing scientific and clinical research data needs for therapeutic progress**
 - **Creating meaningful datasets for clinical care and associated research**
 - **Infrastructure to enable federation among disparate pediatric data repositories**
 - **Development of tools and resources to extract knowledge from data**

10:30 a.m. – 10:50 a.m. **Break**

10:50 a.m. – 11:50 a.m. **Roundtable Discussion with NCI Leadership**

Goal of this session:

- To allow research community interaction with NCI leadership to ask questions and receive feedback on perspectives for CCDI.

11:50 a.m. – 12 p.m. **Final Thoughts and Charge for Future**

Doug Lowy, M.D.

National Cancer Institute, NIH

12 p.m. Adjourn