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

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