



Summary of Meeting Goals and Objectives

Overarching Objective

This workshop was developed to help the larger pediatric oncology research community

1. Understand the critical need to share data – as no single country has sufficient numbers of these rare and ultra rare cancers to permit answering critical research questions
2. Make these data available to the broader international research community through mechanisms that are acceptable to all the international partners
3. That there may not be a single “one size fits all” solution hence our need to assess multiple options and solutions



Over the next 1.5 days we hope to have robust discussions on each of the topics for the workshops.

The 4 workshops include:

1. Harmonization of Clinical and Biological Data
2. Interoperability
3. Data Governance and Data Exchange
4. Innovative Models and Data Management

There is likely to overlap across many of the workshops, but it is our hope that

- each will represent a slightly different perspective on the topic and
- address concepts unique to the workshop topics.

Conference Goals and Objectives

- 1. Develop a report that summarizes the key barriers and possible solutions for data sharing with**
 - Focus on international regulations/laws and how these might support or prevent data sharing
 - Identify and discuss possible solutions leveraging examples that are presented at this workshop
 - Identify a set of partners- countries, organizations and individuals who will continue to be engaged as we move forward with this initiative
 - Identify in the report 2-3 key research questions that could lead to pilot projects
 - Include in the report short, medium and long-term goal

- 2. Within the work and examples from Workshop 3- Capture and share documents that have been leveraged for international data sharing including**
 - DUAs
 - Consent forms
 - Other relevant documents

- 3. Maintain a list of interested partners who might be willing to help with developing the matrix, working on pilot collaborations etc.**

Conference Goals and Objectives

4. Develop a data matrix or fabric that

- a. Captures data currently being collected across many countries/institutions that could serve as a core set of data on which to build additional new data systems
- b. Identify what data sources might be available in addition to the core data (e.g. detailed treatment, genomic information, outcomes other than survival such as recurrence, capture of subsequent primary cancers in this population)
 - i. And identify potential data sources from which there might be a common model/structure or opportunity to share across more than one organization
- c. Include the data standards or models under which these data are collected .

5. Identify and create a listing of successful tools/methods or projects that have successfully shared data internationally including

- a. The methods used (ie anonymized, encrypted with PPRL)
- b. Federated queries and nodal structure
- c. Other methods or tools which will be described over the next day and a half

Conference Goals and Objectives

6. Based on the discussions in the workshops identify a set of 2-3 pilot studies that could serve as demonstrations to:

- a. Illustrate the potential for data sharing or data access for researchers internationally (could be few to many countries)
- b. Options might include anonymization/federation (maintaining data behind institutional firewalls (research nodes)
- c. The purpose for these pilots, in addition to demonstrating capability would be to build **collaborative efforts**,
 - i. ensuring data sharing while upholding security and integrity – in accordance with each country's specific legislation.
 - ii. Pilot approaches should focus on ensuring that this data sharing initiative becomes an enduring and dependable resource, rather than a one-time effort.
 - iii. The creation of **dedicated, time-bound, shared databases tailored to the specific issue at hand** could be a potential solution.
 - iv. Working to collectively identify these key research question that can help us decide on how/where to scale



In conclusion



This effort of sharing data on childhood cancer

- can provide sufficient numbers to help address important research questions on ultra rare pediatric cancers
- May represent a critical solution to
 - improve outcomes from pediatric cancer and
 - Understand the long term impact of these diseases on children and their families.

It is our hope that

- This conference and the resulting work and task forces would be developed and organized in the context of the G7 goals
- With participation as well as participation from other organizations such as the EU governing bodies
- This is a **true, sustainable collaboration** which will need to be promoted and nurtured
- Needs to be embedded into a policy framework such as the G7 to assure that this can move forward
- As a reminder- this is important effort may serve as an example/demonstration for other rare diseases in which data sharing is essential