

Clinical Trial and Research Data Breakout Group

Tailoring your solution to scientific goals:

- Resource/data sharing is most successful when tailored to meet specific scientific goals.

Data sharing incentives and challenges:

- Publicly stated commitments, publication or journal requirements, funder requirements, ethical commitments to participants, and to drive new science are all effective ways of incentivizing researchers to share data.
- Utilization has lagged behind data contribution, data harmonization, and general awareness of data sharing initiatives proved to be challenges in data sharing.

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Data Discovery and Use:

- Upfront planning of clinical trials to promote re-use of data by first performing research to understand if similar trials have been conducted and leverage the data collected.
- Current inventory of clinical trials (such as clinicaltrials.gov) contain summary data for clinical trial results but not the raw individual participant level data.
- Many clinical trials are funder based. Technology companies can play a large role in making these datasets more universally findable.
- Being more open to where we have invested in technology to understand what part of the solution should be retired or built upon to best drive platform and tool development.

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Curation and Harmonization:

- How do we balance the value of collecting data now vs. planning for future collection?
- Endorse the concept of re-using large clinical trial studies and providing resources and showing deliverables to drive momentum forward.
- Effort across platforms to set core sets of metadata to facilitate metadata sharing and discovery across platforms.
- Understanding where to find platforms and data is a hurdle to data sharing for clinical trial and research data.