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.
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.