

Big Data Sharing Meeting Agenda

Day 1: Pre-Meeting Reception

We hope to see you at the **pre-meeting reception on Monday, September 18, 2017 at 6:00 p.m.** at the Shirley Ryan AbilityLab, one of the foremost rehabilitation hospitals in the country.



Shirley Ryan
AbilityLab

355 East Erie Street, Chicago, IL 60610, Reception on the 10th Floor

During the reception, you will have the opportunity to meet presenters and attendees of the Big Data Sharing Meeting as well as enjoy a guided tour of the Shirley Ryan AbilityLab. Tours begin at 6:30 p.m. If you have not yet registered, but would like to attend the reception, please RSVP to allison@cosfoundation.org.

Reception Sponsors:



American
Brain Tumor
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CIRCLE OF SERVICE FOUNDATION

Supporting great organizations to enhance community, opportunity and well-being

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Day 2: Big Data Sharing Meeting

Meeting mission statement / objectives

1. To reinforce funders' pre-existing inclination toward the importance of data sharing and to present some success stories.
2. To disambiguate the confusion around data sharing today, especially differentiating "data" from "big data", and "data sharing" from "Data Commons."
3. To educate funders about options available for sharing large research datasets and to provide a preliminary plan / roadmap for setting up data sharing within your foundation and options for funders to promote or enable data sharing.
4. To provide a forum at which funders can talk among themselves about jointly sponsoring platforms for data sharing (for example, Data Commons that are shared and funded by multiple HRA members).
5. Conclude with commitments from membership to assess data sharing needs, in order to establish data sharing platforms and/or work with existing platforms to host member data.

Audience

Representatives of private funding organizations supporting biomedical research that results in imminently shareable data. Specifically, organizations that are already inclined toward data sharing, and have moved on to getting more details about the issues and understanding how to do it.

Assumptions about you (and your organization) as a participant on September 19

- You have already decided that you want the investigators you support to share data.
 - Some of the investigators you support generate "Big Data".
- You may not yet:
 - Have developed formal data sharing policies for the foundation.
 - Require investigators to have a data sharing plan.
 - Score applications based in part on an investigator's data sharing plan.
- You may have:
 - A lot of questions about what is data sharing.
 - Confusion about the boundaries between a technology platform vs. the policies that govern data on that platform.
 - Vague information, or even misinformation, about existing data sharing platforms.
 - Lack of understanding about the implications of sharing data vs. sharing "big" data.
- You are here to learn more, hear some ideas, but probably not make any significant decisions immediately.

Meeting Sponsors:



The Health Research Alliance (www.healthra.org) is a nonprofit collaborative member organization of almost 80 members whose mission is to maximize the impact of biomedical research to improve human health. To achieve its mission, HRA employs working groups, including the Open Science Task Force which aims to help HRA members: 1) inform their decision-making processes in the implementation of open science policies, 2) facilitate implementation of open science policies and 3) influence the advancement of open science.



The Circle of Service Foundation (www.cosfoundation.org) is a private foundation supporting organizations in Community Services, Education, Jewish Communities and Medical Research.

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Day 2: Big Data Sharing Meeting

Location: Shirley Ryan AbilityLab
355 East Erie Street, Chicago, IL 60610
10th Floor, Conference Rooms A & B

Breakfast will be served from 8:00 – 8:30 a.m.

Welcome & Introduction	<ul style="list-style-type: none">Maryrose Franko (Health Research Alliance)Joanne Smith (Shirley Ryan AbilityLab)Adam Levine (Circle of Service Foundation)Robert Grossman (University of Chicago)	8:30 a.m. – 9:00 a.m.
Session One: What is Data Sharing, and Who Has Done It	<ul style="list-style-type: none">Maryrose Franko (Health Research Alliance) - ModeratorWarren Kibbe (Duke University School of Medicine)Brian Nosek (Center for Open Science)	9:00 a.m. – 10:15 a.m.
<i>Break</i>	<i>Refreshments will be served</i>	<i>10:15 a.m. – 10:30 a.m.</i>
Session Two: Data Sharing From Multiple Perspectives	<ul style="list-style-type: none">Martin Ferguson (Independent) - ModeratorMagali Haas (Cohen Veterans Bioscience)Kenna Shaw (MD Anderson Cancer Center)	10:30 a.m. – 11:30 a.m.
<i>Lunch</i>		<i>11:30 a.m. – 12:00 p.m.</i>
Session Three: Data Sharing Platforms Today	<ul style="list-style-type: none">Meghan Byrne (PLOS ONE) - ModeratorVincent Ferretti (Ontario Institute for Cancer Research (OICR), Cancer Genome Collaboratory)Michael Fitzsimons (University of Chicago, Genomic Data Commons – GDC Gen3)Justin Guinney (Sage Bionetworks, Synapse)Erik Lehnert (Seven Bridges Cancer Genomics Cloud)Benedict Paten (University of California, Santa Cruz, Human Cell Atlas Data Coordination Platform and UCSC Computational Genomics Platform)Anthony Philippakis (Broad Institute, Google Ventures, FireCloud)	12:00 p.m. – 1:45 p.m.
<i>Break</i>	<i>Refreshments and snacks will be served</i>	<i>1:45 p.m. – 2:00 p.m.</i>
Session Four: Establishing Data Commons	<ul style="list-style-type: none">Salvatore La Rosa (Children’s Tumor Foundation) - ModeratorMaryrose Franko (Health Research Alliance)Robert Grossman (University of Chicago)	2:00 p.m. – 3:30 p.m.