HRA Data Sharing Working Group
(part of OSTF)

Chair: Salvatore La Rosa, PhD, VP, Research & Development, Children’s Tumor Foundation
Intern: Heather McCartney
HRA Data Sharing Working Group

- Chair: Salvatore La Rosa  *(Children’s Tumor Foundation)*
- Intern: Heather McCartney  *(Vanderbilt University)*
- Members:
  - Jan Baranski  *(Lung Cancer Research Foundation)*
  - Sindy Escobar-Alvarez  *(Doris Duke Charitable Foundation)*
  - Laura Mayka, Josh McGowan, Pat Yuzawa-Rubin  *(Circle of Service Foundation)*
  - Kristen Mueller  *(Melanoma Research Alliance)*
  - Erik Nelson  *(The Leukemia and Lymphoma Society)*
  - Chris Percopo  *(The Helmsley Charitable Trust)*
  - Heather Snyder  *(Alzheimer’s Association)*
  - Emily White  *(Focused Ultrasound Foundation)*
  - Liz Jackson  *(St. Baldrick’s Foundation)*
  - Maryrose Franko  *(HRA)*

Thank you to all member organizations who have already submitted data sharing policies!
HRA Data Sharing Working Group

- Developed as a subgroup within the OSTF focused on collecting and generating helpful resources to advance the data sharing conversation

- Previous activities
  - Intro to Data Sharing Webinar (June 2017)
  - Intro to Sharing Big Data Webinar (August 2017)
  - In-person Big Data Meeting (Sept 2017)
  - Collection of HRA member (and other) data sharing policies* (continuing)

- Aims:
  - **Research policies and resources** *(what has worked, what hasn’t, what is already out there, what can we develop to change behavior)*
  - **Develop rubric for successful data sharing practices along a spectrum** *(including enforcing compliance)*
  - **Share resources with the broader community to increase data sharing** *(including collecting data on policies and practices and modifying resources as needed)*

*Send your policies! (Any wording that addresses member organization’s data sharing policies, where the policies are used, and if there is a mechanism in place to enforce or follow up on compliance)*

to heather.j.mccartney@vanderbilt.edu
Data Sharing Working Group
Process Framework
Drafted 03-05-2018

Stage One
Product: Aggregated set of data sharing policies

Key Activities:
- Collect data sharing policies
- Get permission to share them
- Create aggregate document
- Disseminate document

Resources:
- HRA Intern - Heather
- Working Group

Stage Two
Product: Codified set of data sharing policies; taxonomy to sort through policies

Key Activities:
- Create a mapping scheme/taxonomy against which we can codify policies (maybe via focus groups, survey, etc.)
- Codify policies
- Or do these two in reverse order
- Disseminate materials

Resources:
- HRA Intern - Heather
- Working Group
- Consultant to help determine taxonomy

Stage Three
Product: Codified set of organizational practices around data sharing

Key Activities:
- Collect information about organizational practices related to data sharing – i.e., practices that reinforce the data sharing policies, like providing funding, checking on whether a researcher shares data, etc.
- Codify these practices

Resources:
- HRA Intern - Heather
- Working Group
- Consultant to help determine taxonomy of org. practices
- Broader foundation participation

Stage Four
Product: Recommendations for creating a culture of data sharing that consider both data sharing policies and organizational practices

Key Activities:
- Assign a value to each of the practices – e.g., what’s a strong practice or strong set of practices?
- Create a toolkit with recommendations for organizations who are looking to create a data sharing policy

Resources:
- HRA Intern - Heather
- Working Group
- Consultant to help evaluate policy and practice elements
- Broader foundation participation