HRA Data Sharing Working Group
(part of OSTF)

Chair: Salvatore La Rosa, PhD, VP, Research &
              Development, Children's Tumor Foundation

Intern: Heather McCartney

Health Research Alliance

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