# Data Sharing: A Roadmap



Is your organization considering adopting a data sharing policy (DSP), but you're not sure where to begin? HRA members have built this guide to provide an overview of the process and highlight available resources.

Note: The steps outlined below are not necessarily linear – you may find that a different sequence is more conducive to your organization's goals, requirements, or timeline.

#### **Explore and research**

**Determine whether it's the right time.** Do you have the resources and support to undertake a large organizational change?

- Do the grants your organization fund generate big data (e.g. genomic databases, clinical trial databases, imaging databases, computational models)?
- Do you have enough administrative and programmatic support to adjust your grant practices to incorporate a DSP?

Consider taking incremental steps before/while your organization develops its own policy:

- Ask awardees to submit a data sharing plan absent of incentive and without encouragement in a particular direction.
- Add encouragement by stating that the organization wants data sharing, and that applications including data sharing plans that promote broad, rapid sharing will be scored favorably.
- Ultimately, your organization may require, score, and benchmark applications based on strong data sharing plans.

Notes & comments: -		

#### **Resources:**

#### Introduction to Data Sharing

- HRA webinar (July 2017)
- <u>Summary</u> with links to additional resources

# (Re)Introduction to Data Sharing

HRA webinar (March 2019)

#### Efforts to Implement a Data Sharing Policy: Lessons Learned (So Far)

Presentation by Jason Gerson, PCORI

#### Implementation of a Data Sharing Policy

Presentation by Belinda Orland, AHA

Explore and research

Pursue Create a draft DSP

Create a educational materials

Create procedures

Monitor compliance

# Pursue "buy-in"

**Discuss data sharing with leaders and stakeholders in your organization.** Have high-level conversations to ensure they are committed to the idea of data sharing and willing to invest the time and resources into implementing a policy. It is possible that your organization may need a third party expert to help steward this conversation.

#### **Resources:**



#### **Create a draft DSP**

#### Based on your organization's mission and goals, define parameters such as:

- The type(s) of data your grantees will be expected to share
- · The time frame expected for release of data
- Criteria for acceptable data sharing <u>repositories</u>, if not mandating a repository (e.g. permanent, well-curated), as well as the duration over which shared data will be maintained, if applicable
- Budget support, if any, grantees will receive for data sharing services (e.g. bioinformatics, harmonization, storage)
- Whether you will encourage or require grantees to get a <u>Creative Commons Attribution license</u> to allow others to use their data
- Will you require data sharing plans for of all grantees/grants or only some (new/junior vs. senior/tenured; small lab vs. big team science)? If not required, will it affect the way proposals are scored? Will you consider and allow exceptions on a case by case basis?

_ Notes & comments:		

#### **Resources:**





## **Engage**

**Discuss your DSP draft with key stakeholders in your organization** (e.g. scientific advisors, researchers, grantees). In some cases, this step may come *after* the creation of educational content (educational materials, templates) so that those can be shared as well.

Notes & comments:

#### **Resources:**

**The State of Open Data** 

Figshare annual report (2017)

Curated articles & analyses

### **Create educational materials**

When you publish the DSP on your foundation's website, also ensure you have media to educate relevant audiences. Consider:

- **Applicants:** Provide *specific* resources for applicants; for example, links to useful websites (e.g. <u>BioArchiv</u>, Creative Commons Attribution license). Consider providing an FAQ page with tips for navigating the data sharing portion of the grant application.
- **Reviewers:** Explain how reviewers should interpret the data sharing expectations as they review new grant applications. Determine if specific reviewer expertise might be required, and perhaps add those reviewers.
- **Institutions:** Attach or link the DSP to each applicable request for proposal (RFP), so administrators are aware of the new data sharing requirements.
- · Consider creating a glossary of data sharing and technical terms.

#### **Resources:**





management plans

Definitions and links to additional resources

**National Network of** 

**Libraries of Medicine** 

**Data Thesaurus** 

"Best Practices for Biomedical Research Data Management"

Harvard Biomedical Library online course

### **Revise grant procedures**

Modify grant application templates to add specific data management questions, such as:

- What data will be produced during the course of research, and where will it be shared? Who will be in charge of preparing the data to share?
- What data standards will be used, and why? Which metadata will be released?
- · What are the expected costs of preparing and sharing data?

**Modify reviewer templates** to include questions about how well data management (collection, annotation, sharing of data outputs) was incorporated into the study.

- Is your review committee equipped to assess and score data sharing plans?
- Are clearly stated plans for each step included? Did they address specific/required questions?

**Modify the grant contract.** Include the DSP as an appendix to the contract to facilitate institutional awareness and compliance.

Pursue "buy-in"

Create a draft DSP

Engage

Create educational materials

Revise grant procedures

Monitor compliance

### **Monitor compliance**

**Develop processes to determine if compliance has been achieved.** Even if you do not have a strict requirement, it may be useful to gather information on how many of your grantees do share data in some capacity. For example, you could fact check whether <u>Digital Object Identifiers</u> (DOIs) exist, and that data is 'discoverable' in the platform of choice.

If your organization uses **progress report questionnaires**, consider adding questions about data sharing progress:

- · What data has been produced, and has it been shared/is there a planned release date?
- · Are appropriate measures in place to protect confidentiality of subjects, if applicable?
- · What platform and/or data standards are being used?

Notes & comments: