

# **Encouraging Data Sharing Outside of Mandates**

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Maximizing the Impact of Research to Improve Human Health

## **HRA Members are Diverse**











































Advancing Treatment | Finding Cures

**Rheumatology Research Foundation** 











THE

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Alzheimer's

Foundation

LUNGEVITY

**Drug Discovery** 





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FOUNDATION



FOUNDATION OF AMERICA









Tourette

of America

Association

Awareness, Research, Support,







DAMON RUNYON

FOUNDATION

CANCER RESEARCH



American

Heart Association<sub>®</sub>

JAMES S. McDONNELL FOUNDATION







THE



for Cancer Research



The Gerber Foundation

Enhancing the quality of life of infants and young children

Melan<sub>o</sub>ma



American

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**Brain Tumor** 



FOUNDATION

AUTISM

SCIENCE





















CROHN'S

&COLITIS FOUNDATION



BREAST CANCER

RESEARCH FOUNDATION













American Society of Hematology

Helping hematologists conquer blood diseases worldwide

















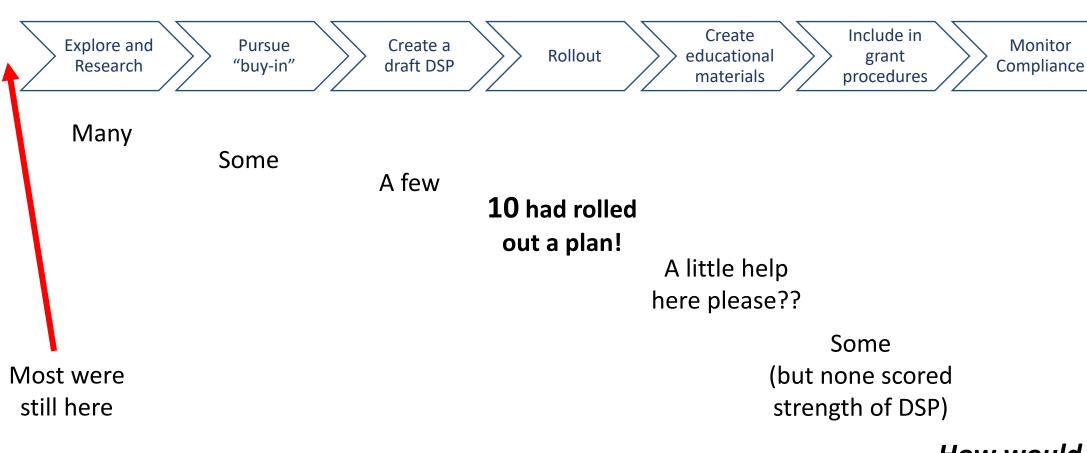




## 2018 Survey of Membership



Where are HRA Members on this Continuum of Data Sharing Policies?



How would you even do that?

## **Data-Sharing Working Group**



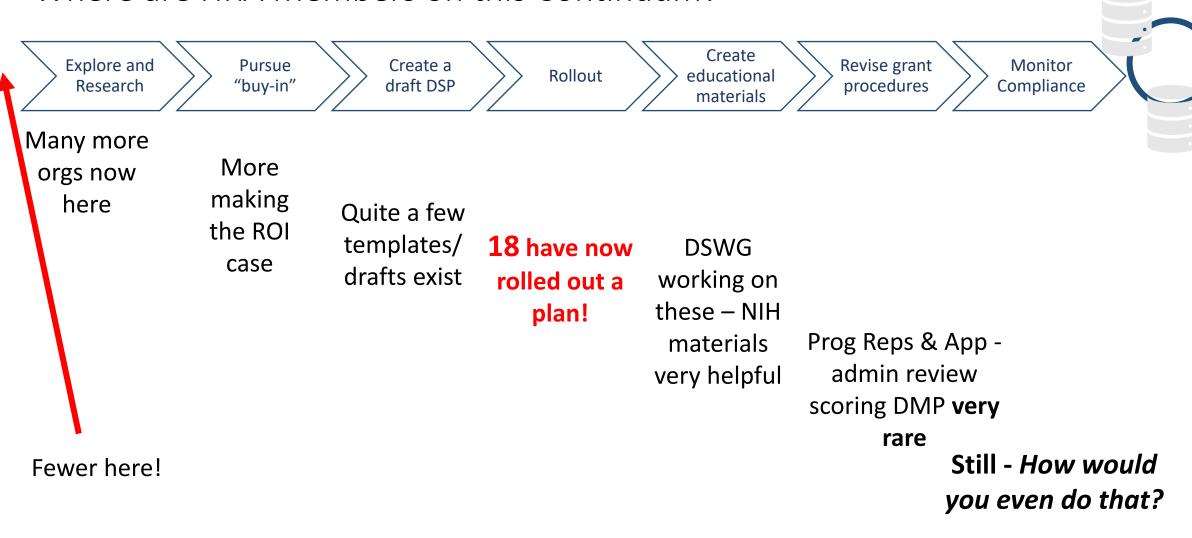
#### Goals

- Inform HRA members about the issues (what is FAIR, DMP/DSP/ DAS) and tools (e.g. DMP tool) to facilitate data sharing
- Help members communicate the value proposition of implementing policies
- Help members identify elements of a policy that fit their mission and resources
- Create a learning community to share successes, challenges and resources – clear and consistent expectations help make sharing normative

# 2021 Survey of Membership



Where are HRA Members on this Continuum?



## We Need "FAIR Resources"



- Success stories to demonstrate ROI to leadership, researchers, etc.
- What data & outputs and important to share, when, where, and how
  - Elements of an optimal repository, critical metadata, other outputs, timing, etc
  - Use of DOIs/PID, importance of citations
- **Elements** of a robust DM&SP or DAS (FAIR, Machine readable?)
- Template language for policies, grant agreements, etc.
- Reviewer training to enable scoring as part of the external review
- How to adequately resource an effective data sharing policy
  - Personnel and resource costs to development, implement, and enforce policies
  - Researchers need ADDITIONAL resources

# We Need Technology & Partnerships



- Technology that links data generation to critical outputs (protocols, code, etc)
- A system to track and evaluate data sharing behavior (applicants & grantees)
  - What data have you shared?
  - How have others used it?
  - Have **you used others' data** to advance the field?

- It's about RE-USE!
- A system to publicly commend grantees for "good behavior" (DS Index? badges?) (since no leverage or reward after the grant term)
  - Subsequent funders, reviewers, hiring and P&T committees can "see" evidence of prior good or bad data sharing
- Partnering with various sectors (nonprofits, government, academia, repositories, publishers) to set consistent expectations for data sharing

## Maryrose's Takeaways



#### "FAIR" Resource Library

Success stores – demonstrate ROI

Effective DM Policy and Plan elements

Tools and guidances ("Selecting a Repository for Data")

**Reviewer Training** 

Cost estimator

Template Terms and Conditions language

### Technology

**Monitor Compliance** 

"Badge" good behavior

Partnerships with nonprofits, government, universities, repositories, publishers