Data-Sharing and Data Management Plans

March 25, 2021

Introduction

At various points in the last five years, we have come together to discuss the notion, value proposition and complexities around data-sharing.

Today's Agenda:

- Survey Recap

- Hear from Members about their experience with designing and implement data-sharing policies

- Questions/Conversation Encouraged!

What is the Government Doing?

In February, we heard from two federal agencies at different points on the path to implementing robust data-sharing policies.
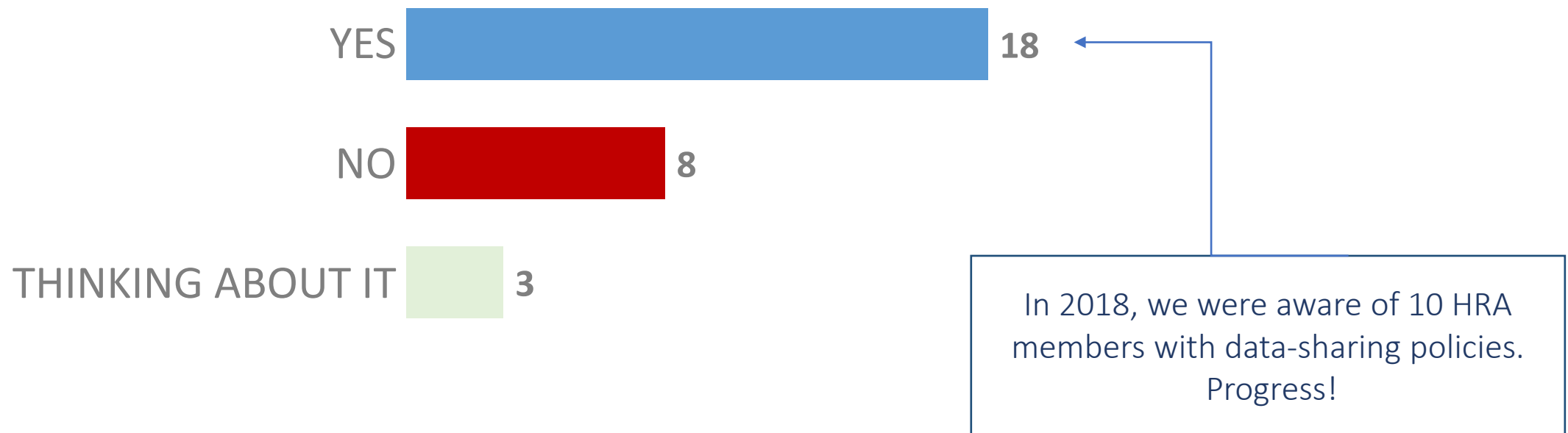
Highlights:

- Data-sharing should be the default practice

- Data-sharing is complex – a one-size-fits-all approach might not work immediately at scale

- It costs money and resources to share data – funding this work should be a part of the conversation

- To have a robust data-sharing policy, you need the knowledge of what "good" is, how to incorporate an evaluation into peer review, and how to track compliance

What About HRA Members?

In January 2021, HRA conducted a survey of its members to understand the current state of data-sharing policies. We received 29 responses.

Do you have a data sharing policy (formal or informal) for your awardees?

YES — 18

NO — 8

THINKING ABOUT IT — 3

In 2018, we were aware of 10 HRA members with data-sharing policies. Progress!
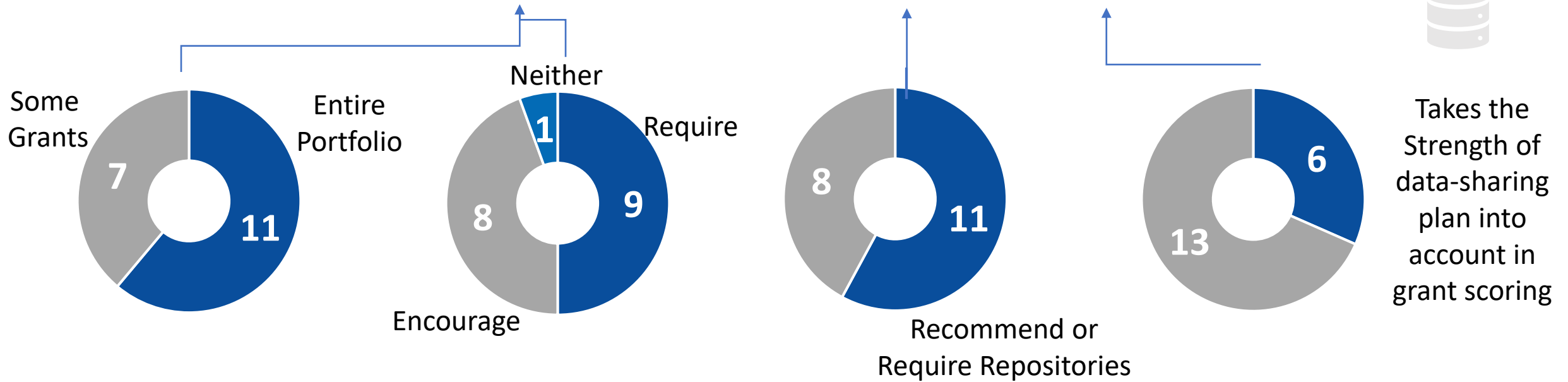
Understanding the "No's"

- Not Ready for Undertaking
- Funding Shareable Data (big v. small data)
- Lack of Internal Expertise
- Lack of Enforcement/Compliance and Staff Capacity

Thinking About It

- Finding the best way to "soften the ground"
- No wanting to rush through this to prevent making a misstep that could come back later
- Currently encouraging, but nothing formal yet
- Thinking of fostering discussions between researchers who might benefit from complementary datasets

Yes!

Health Research Alliance

Across the 18 organizations that report having a data-sharing plan, most are at different parts of the process:

Explore and Research → Pursue "buy-in" → Create a draft DSP → Engage → Create educational materials → Revise grant procedures → Monitor Compliance

Some Grants — 7 | 11 — Entire Portfolio

Neither — 1 | 9 — Require | 8 — Encourage

8 | 11 — Recommend or Require Repositories

6 | 13 — Takes the Strength of data-sharing plan into account in grant scoring

Data-Sharing Working Group

Health Research Alliance

DSWG Goals

- Inform HRA members about the issues and leading thinking surrounding data sharing.
- Help members in their decision-making processes regarding the creation of data sharing policies.
- Support HRA members with resources and insights as they develop and implement data-sharing policies.

Cochairs

Salvatore La Rosa, Children's Tumor Foundation

Carole Wegner, The V Foundation for Cancer Research

JOIN US!