Data Sharing
Nonprofit Nongovernmental Funders' Perspective

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November 2, 2017

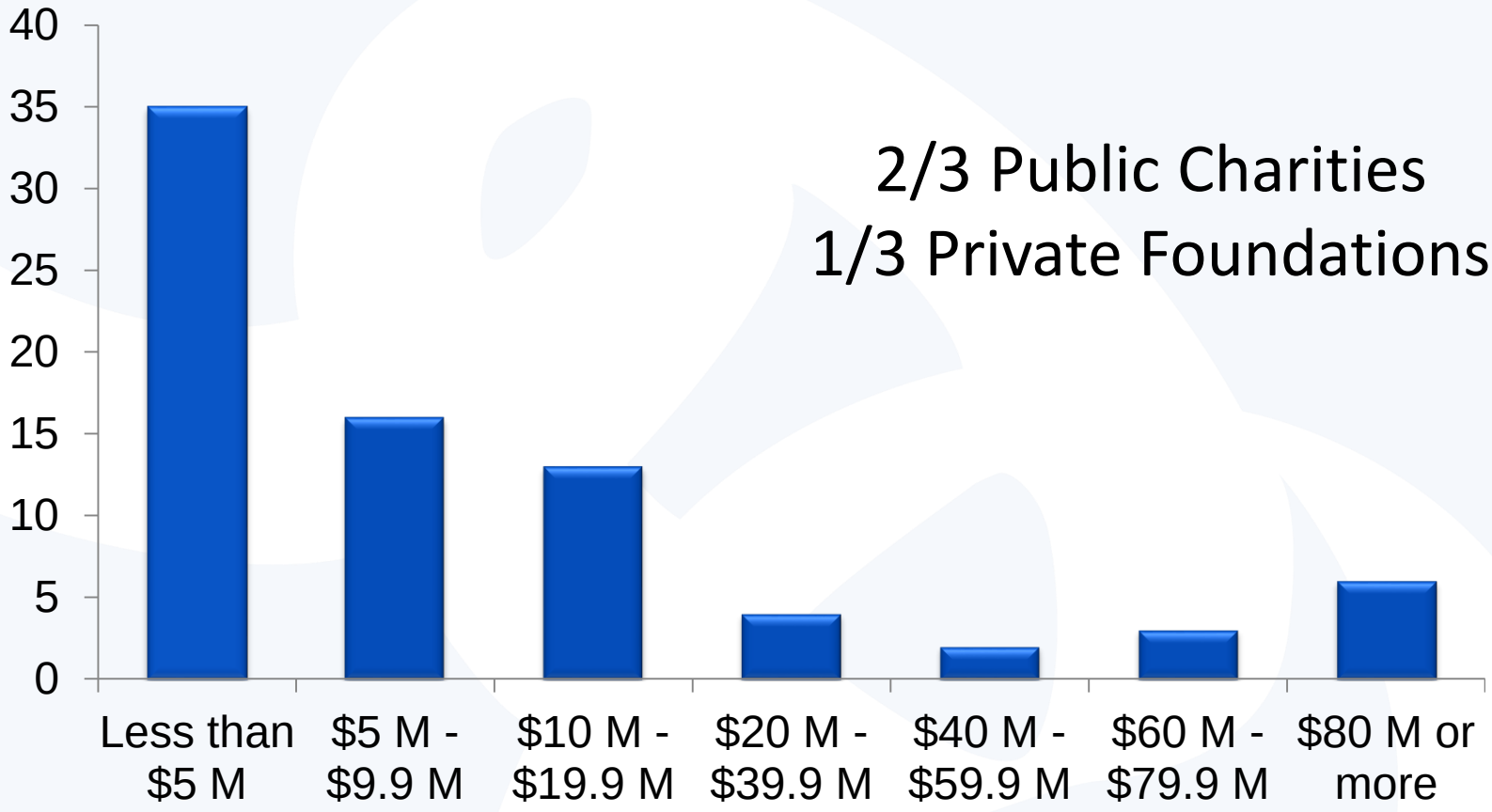
Health Research Alliance Mission

HRA, a collaborative member organization of nonprofit research funders, is committed to maximizing the impact of biomedical research to improve human health

IMPACT COLLABORATE INNOVATE


susan g. komen
PEW Scholars Program in the Biomedical Sciences
PEW Latin American Fellows Program in the Biomedical Sciences
American Diabetes Association
AACR American Association for Cancer Research FOUNDATION FINDING CURES TOGETHER
FLINN FOUNDATION
SIMONS FOUNDATION
THE KAVLI FOUNDATION
Alzheimer's Drug Discovery Foundation
American Brain Tumor Association
Providing and pursuing answers
AUTISM SCIENCE FOUNDATION
DORIS DUKE CHARITABLE FOUNDATION
march of dimes
The Donaghue Foundation
afar american federation for aging research
LUNGEVITY Find it. Treat it. Live.
ARTHRITIS FOUNDATION www.arthritis.org
St. Baldrick's FOUNDATION Conquer Childhood Cancers
Sarnoff Cardiovascular Research Foundation
Inspiring the Physician-Scientists of Tomorrow
Melanoma Research Alliance
Fondation Leducq
MYOTONIC DYSTROPHY FOUNDATION
Damon Runyon Cancer Research Foundation
FOUNDATION FIGHTING BLINDNESS
AUTISM SPEAKS It's time to listen.
Tuberous Sclerosis Alliance
RONNIE J. ADDARIO LUNG CANCER FOUNDATION
Bladder Cancer Advocacy Network BCAN Leading the way to awareness and a cure
American Heart Association Learn and Live
MPN RESEARCH FOUNDATION advancing research · empowering patients
WESTON BRAIN INSTITUTE
THE IACOCCA FAMILY FOUNDATION
Lung Cancer Research FOUNDATION
Parkinson's Disease Foundation
THE LEONA M. AND HARRY B. HELMSLEY CHARITABLE TRUST
RITA ALLEN FOUNDATION
Help Us Solve The Cruel Mystery LUPUS FOUNDATION OF AMERICA
alzheimer's association the compassion to care, the leadership to conquer
CANCER RESEARCH INSTITUTE The Leader in Immunotherapy
AMERICAN EPILEPSY SOCIETY
LEUKEMIA & LYMPHOMA SOCIETY fighting blood cancers
The Medical Foundation A division of Health Resources in Action
THE LAWRENCE ELLISON FOUNDATION A Nonprofit Corporation
THE KLARMAN FAMILY FOUNDATION
CURE Citizens United for Research in EPILEPSY
ARTHRITIS NATIONAL RESEARCH FOUNDATION
MMRF MULTIPLE MYELOMA Research Foundation
FOCUSED ULTRASOUND FOUNDATION
JDRF IMPROVING LIVES. CURING TYPE 1 DIABETES.
PSI FOUNDATION
Foundation for Physical Therapy Funding Research to Optimize Movement and Health
ljaf laura and john arnold foundation
MT. SINAI HEALTH CARE FOUNDATION
BCRF BREAST CANCER RESEARCH FOUNDATION
PANCREATIC CANCER ACTION NETWORK
W.M. KECK FOUNDATION
NYSCF The New York Stem Cell Foundation Research Institute
BURROUGHS WELLCOME FUND
hhmi Howard Hughes Medical Institute
AVON BREAST CANCER CRUSADE
THE V FOUNDATION for Cancer Research
NATIONAL PSORIASIS FOUNDATION
CONQUER CANCER FOUNDATION of the American Society of Clinical Oncology
CHILDREN'S TUMOR FOUNDATION ENDING NF THROUGH RESEARCH
John Templeton Foundation
Kenneth Rainin FOUNDATION
PERSHING SQUARE SOHN CANCER RESEARCH ALLIANCE
pcori PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE
Parent Project Muscular Dystrophy LEADING THE FIGHT TO END DUCHENNE
Rheumatology Research Foundation Advancing Treatment | Finding Cures
American Cancer Society
GLENN FOUNDATION FOR MEDICAL RESEARCH
BrightFocus Foundation Cure in Mind. Cure in Sight.
LYMPHOMA RESEARCH · FOUNDATION
Hydrocephalus Association
The Gerber Foundation Enhancing the quality of life of infants and young children

Who are HRA's 80 Members?



2/3 Public Charities
1/3 Private Foundations

Annual Grant Budgets

Clinical Trials: Candidate Alzheimer's Disease Compounds (2002-2012)

413 Total Clinical Trials (clinicaltrials.gov)

- 124 Phase I
- 206 Phase 2
- 83 Phase 3

244 Compounds Tested

- 72% Failure Rate Phase 1
- 92% Failure Rate Phase 2
- 98% Failure Rate Phase 3

244 compounds tested only ONE was approved for marketing

99.6% FAILURE IS UNACCEPTABLE

Alzheimers Res Ther. 2014; 6(4): 37. doi: 10.1186/alzrt269

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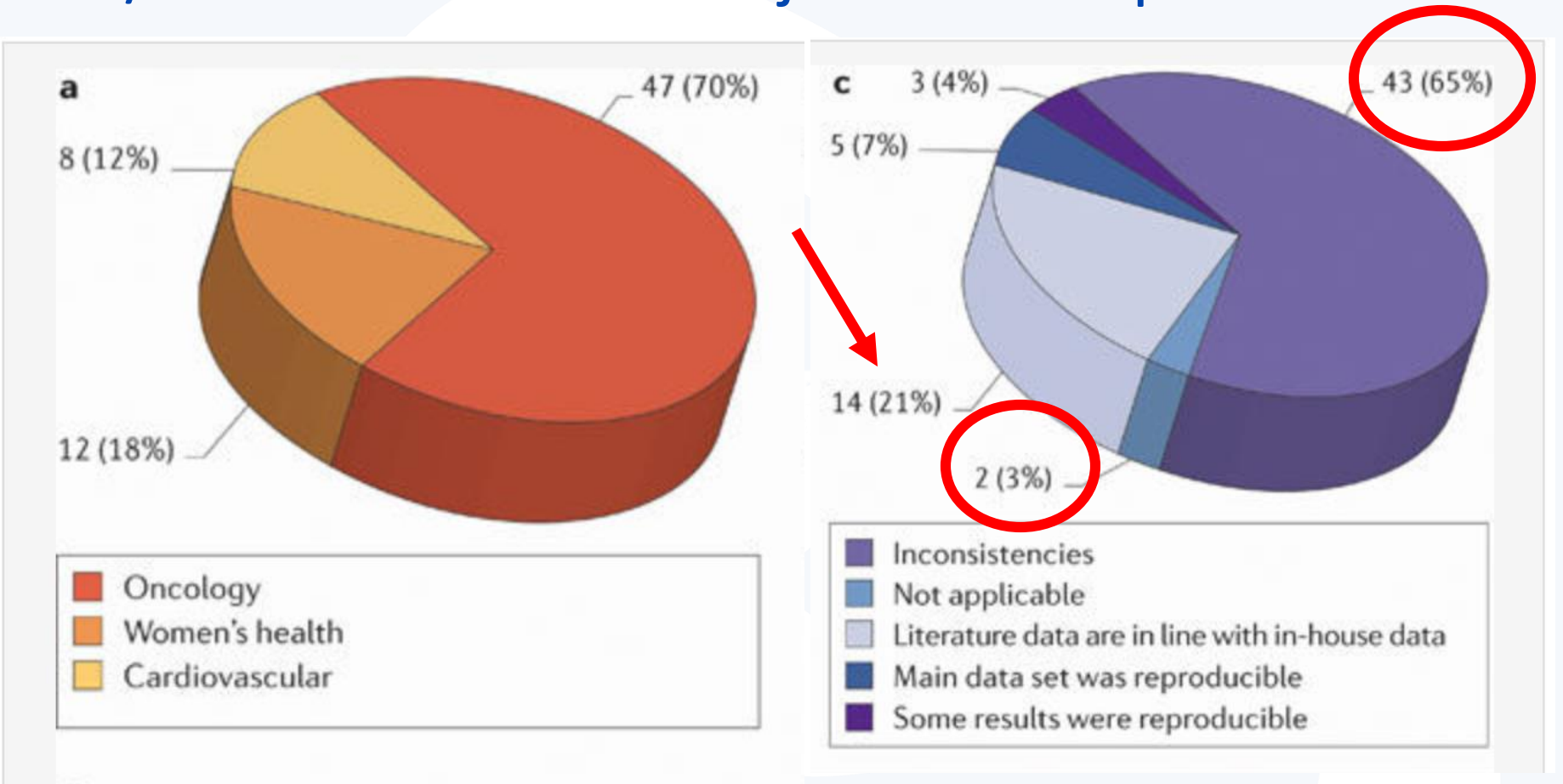
2/3 of Studies in 67 Projects Not Reproducible



From Bayer Healthcare: Nature Reviews Drug Discovery 10, 712 (September 2011) doi:10.1038/nrd3439-c1

Open, Transparent, Rigorous Science Accelerates Research and Improves Human Health

Require Open Access to publications

Encourage use of interim research products

(preprints, preregistration)

Require collaboration with biostatisticians

~~**Require data management plans**~~

Require collaboration with data stewards

Require awardees "share their data"

(What does that mean?)

From Hand Wringing to Taking Action

- Created an Open Science Task Force
- Task Force Developed a Topic List
- Found Partners
- Learn from others – webinars/workshops

CENTER FOR OPEN SCIENCE

PMC
US National Library of Medicine
National Institutes of Health

SCIENTIFIC DATA

figshare

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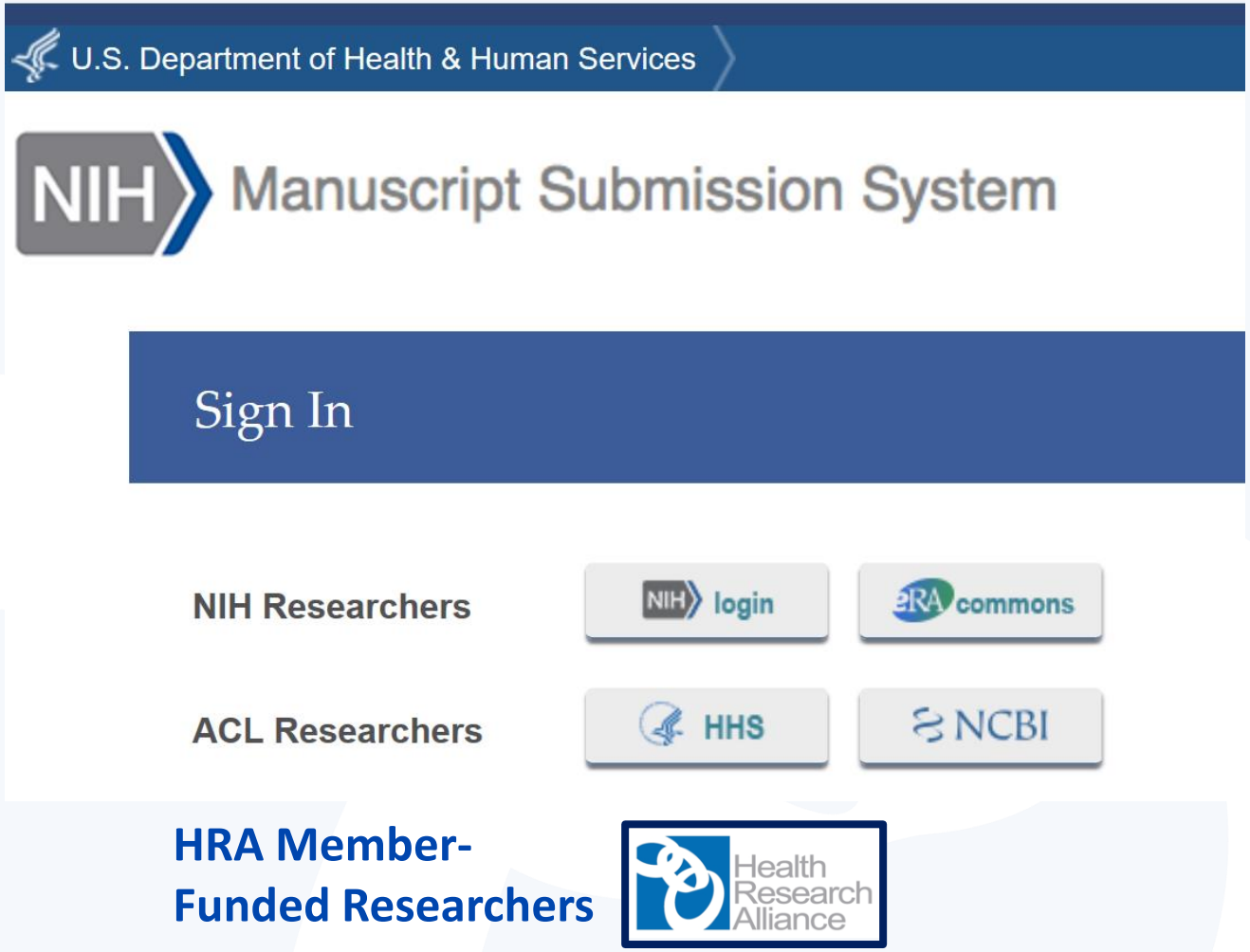
OSTF's "To-Do" List

- **Create infrastructure to comply with NIH's Public Access Policy (PMC part of HRA OPEN)**
- **Create infrastructure to enable Open Data (Figshare part of HRA OPEN)**
- **Incentivize awardees to share data - linked to grant**
- Develop best practices in data sharing
- Create guidance for choosing an appropriate trusted repositories
- Create template data sharing policies (modular)
- Implement data sharing policies
- Share polices and experiences – what worked and why?

HRA OPEN



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HRA OPEN

Manage admins | Invite authors | Submit data | Curate submissions

Please select the funder associated with your research data

- alzheimer's association
- Alzheimer's Drug Discovery Foundation
- American Association for Cancer Research
- American Brain Tumor Association
- American Cancer Society
- American Epilepsy Society
- american federation for aging research
- American Heart Association
- American Lung Association

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What is Data Sharing?

Intro to Data Sharing Webinar:

- What do we mean by sharing?
- What do we mean by data?

Perspectives from:

- PLOS ONE
- Natures' Scientific Data

Topics:

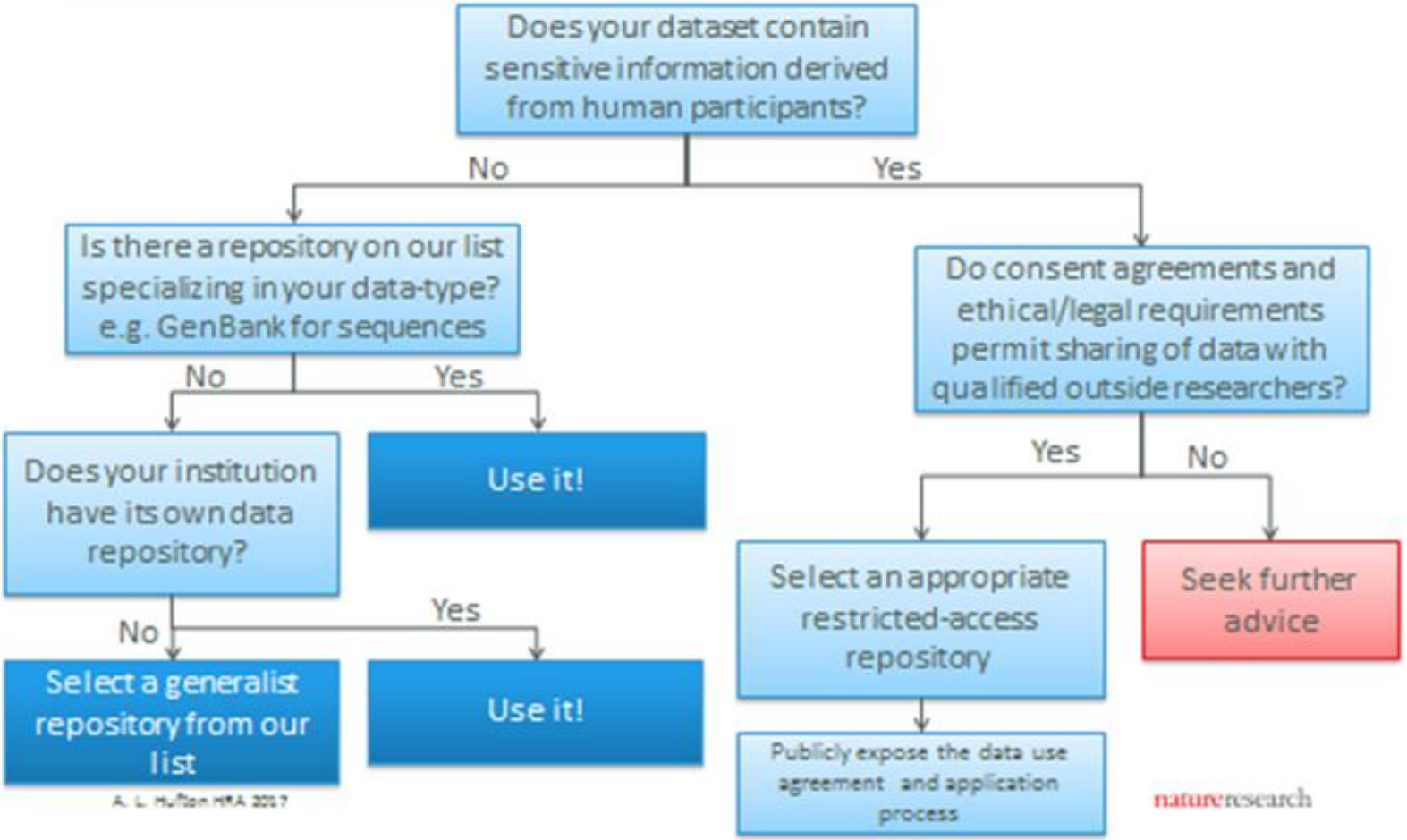
- FAIR Principles
- Trusted Repositories
- Data Availability Statements

Implementing Data Sharing

Harvard Dataverse	Contact repository for datasets over 1 TB	2.5 GB per file, 10 GB per dataset	No	view re3data entry
Open Science Framework	Free of charge	5 GB per file, multiple files can be uploaded	No	view FAIRsharing entry

An overly simple guide to picking the right data repository

https://www.nature.com/sdata/policies/repositories



Initial Best Practices for Sharing Data

- When citing data, state whether data are available, and, if so, where to access them *(transparency)*
- Data must be posted to a trusted repository (FAIR). Exceptions must be identified at article submission.
- Data analysis also must be posted to a trusted repository, and reported analyses should be reproduced independently prior to publication.

How to Share BIG Data or Sensitive Data?

Big Data Sharing Meeting - September 19, 2017

Session 1: What is data sharing and who has done it

- *Warren Kibbe (Duke University School of Medicine, formerly NCI)*
- *Brian Nosek (Center for Open Science)*

Session 2: Data sharing from multiple perspectives

- *Magali Haas (Cohen Veterans Bioscience)*
- *Kenna Shaw (University of Texas - MD Anderson Cancer Center, formerly Director NIH's The Cancer Genome Atlas)*

Sharing BIG Data? Sensitive Data?

Big Data Sharing Meeting - September 19, 2017 *(cont)*

Session 3: Data sharing platforms today

- Vincent Ferretti (Ontario Institute for Cancer Research - OICR)
- Michael Fitzsimons (University of Chicago, Genomic Data Commons – GDC
- Justin Guinney (Sage Bionetworks)
- Erik Lehnert (Seven Bridges Genomics)
- Benedict Paten (University of California, Santa Cruz)
- Anthony Philippakis (Broad Institute, Google Ventures)

Challenges to Open Data Sharing

- Not free - who pays?
- What are the relevant trusted repositories?
- Burden to researchers – data needs to be “sharable”
- Researchers *(and funders)* afraid to share sensitive data
- Administrative burden for funder – negotiate agreements, verify compliance, etc.
- Needs to be better aligned with reward structure
- Researchers want to mine their own data first, and spin off studies should be purview of postdocs etc.

Incentivizing Data Sharing

- Require (most are not there yet)
- Publicize – sharing increases research impact
- Give meaningful credit for sharing data
- Require DMP in proposal *(or data steward signoff?)*
- Evaluate extent of data sharing in renewals, applications, etc *(open data metric?)*
- Help cover costs – supplement grants, build infrastructure, ?

Health Research Alliance

Thank you

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www.healthra.org

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