



# **American Heart Association's Implementation of a Data Sharing Policy**

Tuesday, March 13, 2018

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American Heart Association

# AHA MISSION

**Building healthier lives,  
free of cardiovascular  
diseases and stroke.**

## GUIDING VALUES

- Improving & Extending People's Lives
- **Bringing Science to Life**
- **Speaking With A Trustworthy Voice**
- Building Powerful Partnerships
- Inspiring Passionate Commitment
- Meeting People Where They Are
- Making An Extraordinary Impact
- Ensuring Equitable Health For All

# OPEN SCIENCE MOTIVATION

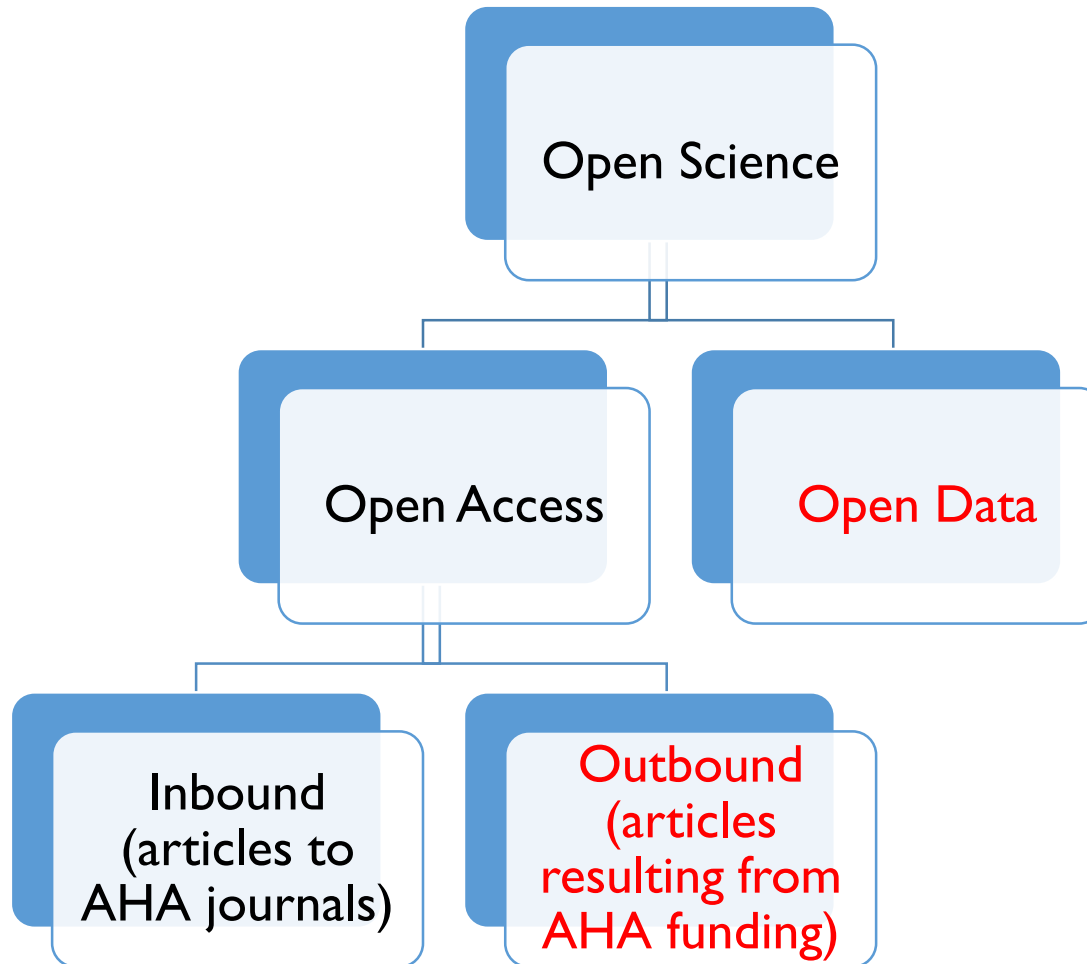
The AHA invests heavily in research in order to:

- **accelerate** the pace of scientific discovery,
- **encourage** innovation,
- **enrich** education, and
- to **improve** the public good.



We recognize that scientific investigation advances only through sharing of methods and results, and the value of an investment in research is only maximized through wide use of this information.

# OPEN SCIENCE POLICIES



# OPEN DATA POLICY

The AHA requires certain applicants to include a **data sharing plan** with the application. Any factual data that is needed for independent verification of research results must be made **freely and publicly** available in an **AHA-approved repository** within 12 months of the end of the funding period (and any no-cost extension).

# OPT-OUT AND RESEARCH TYPE

2017 Awards	Award Counts	Percent of Total Awards	Percent of Non Exempt Awards
	893	-	-
Non Exempt Awards	477	53%	-
Opt Out Requests	37		8%
Approved Opt Outs.	10		2%

**Basic**  
**68%**

**Clinical**  
**22%**

**Population**  
**10%**

# CHALLENGES TO GETTING STARTED

## *Getting everyone up to speed*

- Developed basic orientation materials on this complex topic and how it relates to the AHA
- Volunteers rotate in and out - -we must provide orientation on a continuous basis



# CHALLENGES TO GETTING STARTED

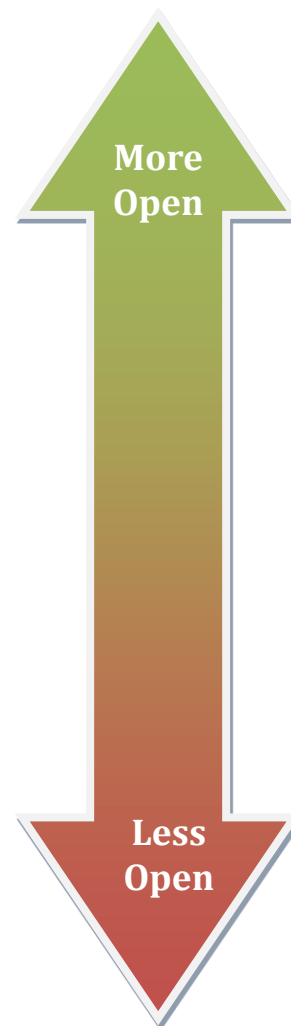
- Policies drafted by a committee over the course of about 3 meetings, refining gaining approval took about 18 months.
- THE GAP
- Initial resistance and confusion





# LESSONS LEARNED

- Developing a FAQ document early and add to it throughout the process
- Provide sample data plans
- Focus on **TRANSPARENCY** vs. **REPLICATION**
- Open science in a continuum



# ONGOING CHALLENGES

## *Keeping up to date and staying flexible*

- Monitoring what other organizations are doing relative to Open Science
- Established a permanent committee to monitor open science issues and recommend changes to our policy as needed

# AHA PRECISION MEDICINE PLATFORM



## The Institute

for Precision Cardiovascular Medicine™

# PRECISION MEDICINE PLATFORM



life is why™

es por la vida™

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