



# Open Science in Behavioral Medicine

Update to SBM Board

November 15, 2019

# Presidential Request: Working Group on Open Science



## Working Group on Open Science



2019-20 Presidential Initiative (Michael A. Diefenbach, PhD)

The "drive for open science" has increased over the past years and has reached heightened visibility in conjunction with the release of the "Cancer Moonshot Initiative." The movement to open science to everybody is not without controversy with opponents and allies exchanging deep-felt arguments. For some it is the end of an ordered status quo of discovery, whereas for others it is the promise of accelerated science and advancement. Up to recently, discussions have been confined to the basic and medical sciences, however, there have been some efforts to bring psychological science into the open science arena.

### CALL TO ACTION – A Working Group on Open Science

As the trend for more and more open science initiatives continues, it is time for the Society of Behavioral Medicine (SBM) to explore the implications of this movement for its members and others working in the behavioral medicine space. The working group, under the leadership of Bradford W. Hesse, PhD, has the following charges:

- Explore the likely implications of open science for behavioral scientists
  - What can behavioral scientists learn from the existing experience with open science?
  - Does open science affect collaborative efforts between behavioral scientists and basic science?
- Educate SBM members about open science
  - Are the implications of open science different for established versus beginning researchers?
  - Education efforts could include hosting SBM webinars and Annual Meeting sessions
- Develop recommendations that can be adopted on the SBM level, pending Board approval
  - Develop and publish in SBM's journal(s) position paper(s) that reflect the society's priorities with regard to open science
  - Develop and publish concrete steps that can be undertaken by the society to address the challenges of open science

The working group will operate for one year (April 2019 to April 2020), with a final report for the SBM Board delivered April 2020. Dr. Hesse can appoint up to five working group members (must be SBM members in good standing, and subject to approval by the SBM Executive Committee), and can call upon the expertise of other SBM members, councils, and committee as needed.



Join Me in Accelerating our Science

Michael Diefenbach, PhD, SBM President

## CALL TO ACTION

1. Explore implications for SBM scientists (and practitioners)
2. Educate SBM members about open science (across career stages)
3. Develop recommendations for Board approval in April 2020

# Formulating the Working Group



**Brad Hesse (Chair)**

National Cancer Institute (retired / affiliate)  
*Previous SBM Board member, has focused on digital platforms for science since 1984*



**Abby King**

Stanford University  
*Member of SBM Wisdom Council, recognized thought leader in "citizen science"*



**Eric Hekler**

UC San Diego  
*SBM's 2019 Program Chair, leadership in creating participative platforms for health*



**David Conroy**

Penn State  
*Chair of SBM's Publications & Communications Council, pioneer in translating open science to SBM publications*



**Dominika Kwasnicka**

SWPS University, Wrocław Poland  
*Leader within the Open Digital Health Initiative*



**Kenneth Tercyak**

Georgetown University  
*Is an NIH funded trailblazer in cross-disciplinary research: e.g., health genomics and behavioral medicine*



**Molly Waring**

University of Connecticut  
*Brings cutting-edge experience in statistical reasoning as applied to open, big data resources*



**Sarah Andrus**

Oxford University Press  
*Brings an expansive and strategic view of open science publishing across disciplines*

# Facets Relevant to SBM

Legislative  
Requirements



Fair Access to Science and  
Technology Research Act  
(FASTER), 2017



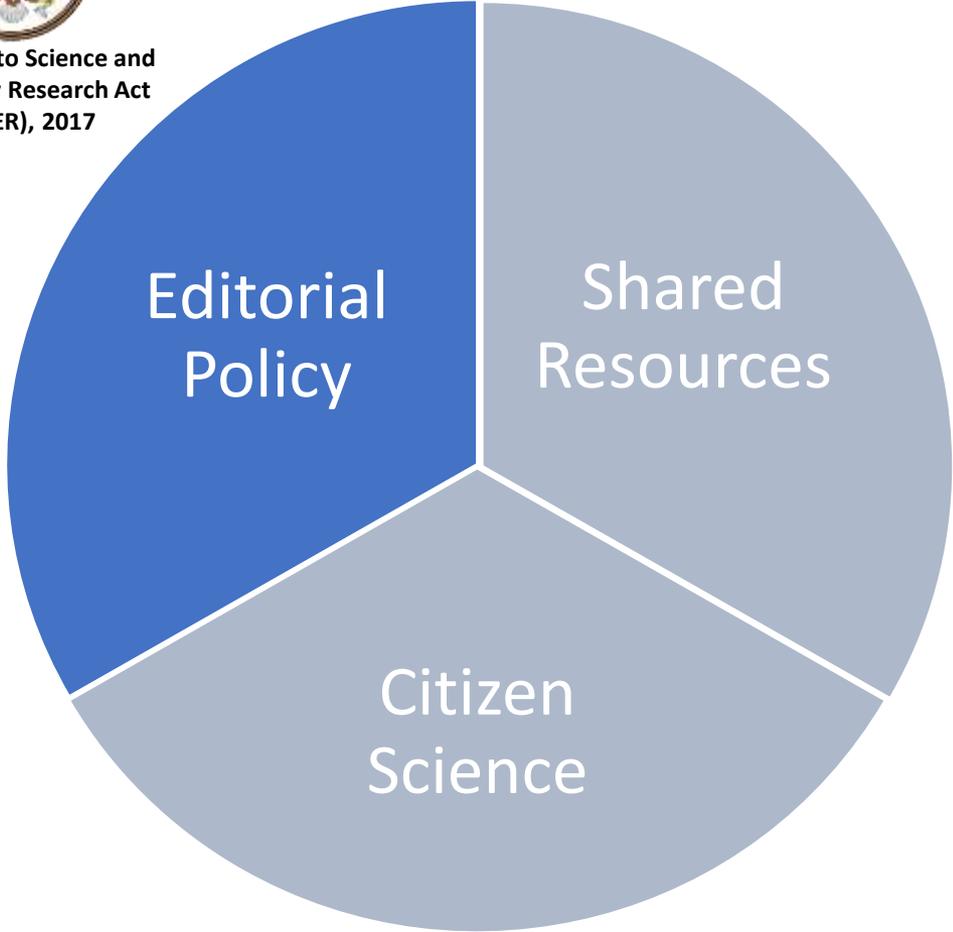
Digital Market  
Changes

It's time to change  
the way we do research!

zotero



Collect. Organize. Cite. Collaborate. Discover.  
Scientific  
Pressures



# Facets Relevant to SBM

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Open for Discovery

Digital Market Changes

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Scientific Pressures



Shared Resources in Medical Science: e.g., the BRAIN initiative, Cancer moonshot



Shared Code

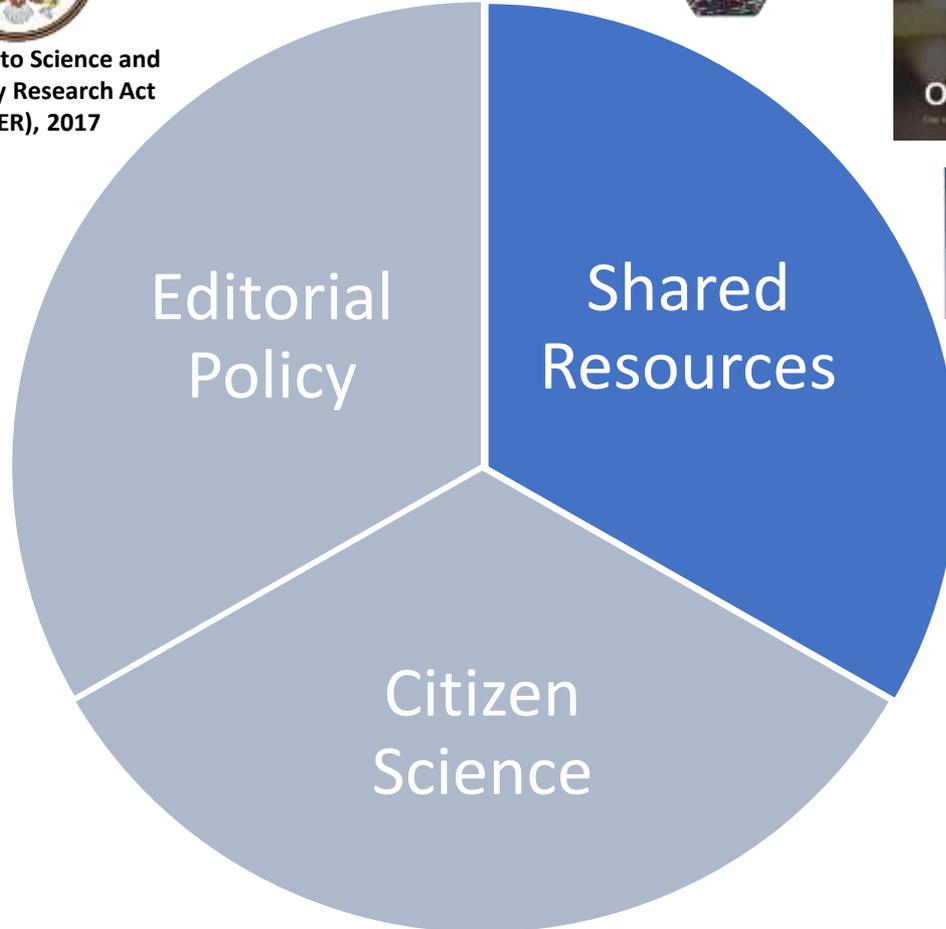


GitHub

Shared Data

HealthData.gov

Shared Data Resources



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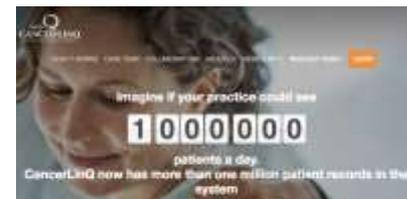


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**PLOS**  
Open for Discovery

Digital Market Changes

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Scientific Pressures

Participatory Public Health

Our Voice: Citizen Science for Health Equity

The Our Voice initiative empowers community members to drive change in their local environments. Using the Discovery Tool mobile app, these "citizen scientists" document features of their communities that impact their ability to lead healthy lives. They then review their own findings, prioritize areas for change, and mobilize to promote improvements that will support community health.

This 2-minute video describes the Our Voice approach.



Participatory Research



Data Altruism



Personal Data for the Public Good

Free Open Access to Health Research

Robert Wood Johnson Foundation



# Timeline



SOCIETY OF  
BEHAVIORAL  
MEDICINE

## Kickoff

7-19-19



## Deep Dives

8-16-19 to 12-19-19



Editorial  
Policy  
8-16-19



Shared  
Resources  
9-20-19



Citizen  
Science  
11-01-19



Synthesis &  
Conclusions  
12-19-19



## Deliverables

1-1-20 to 5-31-20

Recommendations



Annual  
Meeting



Papers



Seminars



Forming

Exploring

Transforming

June

July

Aug

Sept

Oct

Nov

Dec

Jan

Feb

Mar

April

May

2019

2020



# Editorial Policy & Publications

D. Conroy & K. Tercyak

# Transparency and Openness Promotion (TOP) Guidelines



## SCIENTIFIC STANDARDS

# Promoting an open research culture

Author guidelines for journals could help to promote transparency, openness, and reproducibility

By **B. A. Nosek**,\* **G. Alter**, **G. C. Banks**, **D. Borsboom**, **S. D. Bowman**, **S. J. Breckler**, **S. Buck**, **C. D. Chambers**, **G. Chin**, **G. Christensen**, **M. Contestabile**, **A. Dafoe**, **E. Eich**, **J. Freese**, **R. Glennerster**, **D. Goroff**, **D. P. Green**, **B. Hesse**, **M. Humphreys**, **J. Ishiyama**, **D. Karlan**, **A. Kraut**, **A. Lupia**, **P. Mabry**, **T. Madon**, **N. Malhotra**, **E. Mayo-Wilson**, **M. McNutt**, **E. Miguel**, **E. Levy Paluck**, **U. Simonsohn**, **C. Soderberg**, **B. A. Spellman**, **J. Turitto**, **G. VandenBos**, **S. Vazire**, **E. J. Wagenmakers**, **R. Wilson**, **T. Yarkoni**

**Summary of the eight standards and three levels of the TOP guidelines**  
Levels 1 to 3 are increasingly stringent for each standard. Level 0 offers a comparison that does not meet the standard.

	LEVEL 0	LEVEL 1	LEVEL 2	LEVEL 3
<b>Citation standards</b>	Journal encourages citation of data, code, and materials—or says nothing.	Journal describes citation of data in guidelines to authors with clear rules and examples.	Article provides appropriate citation for data and materials used, consistent with journal's author guidelines.	Article is not published until appropriate citation for data and materials is provided that follows journal's author guidelines.
<b>Data transparency</b>	Journal encourages data sharing—or says nothing.	Article states whether data are available and, if so, where to access them.	Data must be posted to a trusted repository. Exceptions must be identified at article submission.	Data must be posted to a trusted repository, and reported analyses will be reproduced independently before publication.
<b>Analytic methods (code) transparency</b>	Journal encourages code sharing—or says nothing.	Article states whether code is available and, if so, where to access them.	Code must be posted to a trusted repository. Exceptions must be identified at article submission.	Code must be posted to a trusted repository, and reported analyses will be reproduced independently before publication.
<b>Research materials transparency</b>	Journal encourages materials sharing—or says nothing.	Article states whether materials are available and, if so, where to access them.	Materials must be posted to a trusted repository. Exceptions must be identified at article submission.	Materials must be posted to a trusted repository, and reported analyses will be reproduced independently before publication.
<b>Design and analysis transparency</b>	Journal encourages design and analysis transparency or says nothing.	Journal articulates design transparency standards.	Journal requires adherence to design transparency standards for review and publication.	Journal requires and enforces adherence to design transparency standards for review and publication.
<b>Preregistration of studies</b>	Journal says nothing.	Journal encourages preregistration of studies and provides link in article to preregistration if it exists.	Journal encourages preregistration of studies and provides link in article and certification of meeting preregistration badge requirements.	Journal requires preregistration of studies and provides link and badge in article to meeting requirements.
<b>Preregistration of analysis plans</b>	Journal says nothing.	Journal encourages preanalysis plans and provides link in article to registered analysis plan if it exists.	Journal encourages preanalysis plans and provides link in article and certification of meeting registered analysis plan badge requirements.	Journal requires preregistration of studies with analysis plans and provides link and badge in article to meeting requirements.
<b>Replication</b>	Journal discourages submission of replication studies—or says nothing.	Journal encourages submission of replication studies.	Journal encourages submission of replication studies and conducts blind review of results.	Journal uses Registered Reports as a submission option for replication studies with peer review before observing the study outcomes.

# Reviewed Current Status of SBM Journals against Standards



## • Annals of Behavioral Medicine

- **Design & analysis transparency, Preregistration of studies, Preregistration of analysis plans:** As a condition of consideration for publication, clinical trials must be registered in a public registry (e.g., [www.clinicaltrials.gov](http://www.clinicaltrials.gov)) and the trial registration number must be reported in the Methods section of the manuscript as well as at the end of the abstract, e.g., (ClinicalTrials.gov number NCT#). Clinical trials are defined as studies that prospectively assign participants to either intervention or control conditions to study the cause-and-effect relationship between an intervention(s) and a health or behavioral health related outcome. This policy requires the registration of trial methodology but does not require registration of trial results. Although the journal does not advocate a particular registry, the registry must be accessible to the public at no charge, open to all prospective registrants, managed by a not-for-profit organization, and electronically searchable.
- **Data transparency and Analytic methods (code) transparency:** Upon request authors must be prepared to send relevant documentation or data in order to verify the validity of the results.... Sensitive information in the form of confidential proprietary data is excluded.
- Option to publish under Oxford Open initiative for a fee (\$2848-\$3560)
- Editor's Choice designation renders time-limited open access status for select papers

## • Translational Behavioral Medicine

- **Design & analysis transparency:** When possible, submissions to TBM should comply with the relevant reporting guidelines published by the Enhancing the QUALity and Transparency Of health Research (EQUATOR) Network (<http://www.equator-network.org>). Authors should include a completed checklist with their submission, Submissions that do not adhere to these guidelines are welcome and will receive full consideration provided the authors report their rationale for deviating from the guidelines in both the cover letter and manuscript.
- **Data transparency & Analytic methods (code) transparency:** Upon request authors should be prepared to send relevant documentation or data in order to verify the validity of the results. This could be in the form of raw data, samples, records, etc. Sensitive information in the form of confidential proprietary data is excluded.
- Option to publish under Oxford Open initiative for a fee (\$1050-\$2625)
- Editor's Choice designation renders time-limited open access status for select papers

# Evaluated Methods available for increasing transparency and openness

## Submission stage

- Author teams already disclosing funding, COI, and ethics
- Formalize expectation that authors disclose the level of transparency/openness for each standard. Propose Level 1 for each standard
- Encourage publication of replication studies (likely as a brief report)
- Create option for publishing registered reports using two-stage peer review

## Peer review stage

- Who shoulders burden? Limited to authors if disclosure only. Shared by editorial team if verification required. Propose limiting to disclosure for 5 year period and re-evaluating then (including as a part of next contract negotiation with publisher).

## Publication stage

- Badging on article PDF as recognition
- Post link on journal site for each article to any registry or repository with data, materials or code

## Dissemination stage

- OA available for fee (currently \$1050-\$3560 for ABM/TBM)
- Explicitly permit publication of author copy on preprint servers with expectation that authors add doi for journal version upon publication.
  - Question: would we want to recommend a BMed specific preprint server?
- Uploading final author version to MyNCBI for PubMed linking (required for NIH-funded studies; advantage is discoverability)

# Evaluated Pros & Cons Across Stakeholders

	Pros	Cons
Trainees	<ol style="list-style-type: none"> <li>1. Increased citations from increase in citable material</li> <li>2. Recognition for contributing at more points in research pipeline</li> </ol>	<ol style="list-style-type: none"> <li>1. Extra work (unfunded mandate risk)</li> </ol>
Jr Scientists	<ol style="list-style-type: none"> <li>1. Increased citations from increase in citable material</li> <li>2. Recognition for contributing at more points in research pipeline</li> </ol>	<ol style="list-style-type: none"> <li>1. Extra work (unfunded mandate risk)</li> </ol>
Established Scientists (midcareer, senior)	<ol style="list-style-type: none"> <li>1. Increased citations from increase in citable material</li> <li>2. Recognition for contributing at more points in research pipeline</li> </ol>	<ol style="list-style-type: none"> <li>1. Extra work (unfunded mandate risk)</li> </ol>
SBM	<ol style="list-style-type: none"> <li>1. Increases trust in field</li> </ol>	<ol style="list-style-type: none"> <li>1. Could impact value of journal in next publishing contract negotiation</li> </ol>

Incentives & disincentives to increasing transparency & openness



Social consequences of increasing transparency & openness



	Pro	Con
For patients	<ol style="list-style-type: none"> <li>1. Increased trust</li> <li>2. Opportunity to engage with primary data if desired and skilled</li> </ol>	<ol style="list-style-type: none"> <li>1. Potential to draw improper inference if unskilled and analyzing data</li> <li>2. Privacy risk if data are reidentified</li> </ol>
For industry	Increased trust	
For policy makers	Increased trust	
For faculty/ investigators (P&T)	<ol style="list-style-type: none"> <li>1. Increased trust</li> <li>2. Increased citation counts from having more citable material</li> <li>3. Increased work product to include in promotion &amp; tenure dossiers</li> </ol>	
For funders	<ol style="list-style-type: none"> <li>1. Increased trust</li> <li>2. More deliverables possible from grantees</li> <li>3. Research impact potential beyond initial grant</li> </ol>	

# Offered Specific Suggestions for Consideration by Working Group



Journals should adopt and formalize expectation of level 1 (disclosure) without verification.  
Revisit in 5 yrs.

Add OSF badges to title pages to convey value of transparency and openness

Explicitly permit prior publication on preprint servers not indexed by major search engines at time of submission (PubMed, WoS)

Add sections for replication studies (likely as brief report; would complement *TBM* section for null results).

Create option for two-stage peer review of registered reports

# Concretized Recommendations for Consideration as Editorial Policy



## Proposed addition to Instructions to Authors (Level 1 TOP Guidelines)

The policy of **Translational Behavioral Medicine** is for authors to disclose the level of transparency and openness for all submissions, but not to require a certain level of transparency or openness. All submissions will be considered regardless of the level of transparency and openness. Badges will be added to the title page for accepted articles that disclose the use of transparent research practices (i.e., open data, open materials, preregistration).

All data, program code and other methods should be appropriately cited. Such materials should be recognized as original intellectual contributions and afforded recognition through citation.

The policy of **Translational Behavioral Medicine** is to publish papers where authors:

- indicate whether the data, methods used in the analysis, and materials used to conduct the research will be made available to any researcher for purposes of reproducing the results or replicating the procedure. Authors must, in acknowledgements, indicate if they will or will not make their data, analytic methods, and study materials available to other researchers. If an author agrees to make materials available, the author must specify where that material will be available.
- follow standards for disclosing key aspects of the research design and data analysis. Authors are encouraged to review the standards available for many research applications from <http://www.equator-network.org/> and use those that are relevant for the reported research applications.
- indicate whether the conducted research was preregistered in an independent, institutional registry (e.g., <http://clinicaltrials.gov/>, <http://socialscienceregistry.org/>, <http://openscienceframework.org/>, <http://egap.org/design-registration/>, <http://ridie.3ieimpact.org/>). Preregistration of studies involves registering the study design, variables, and treatment conditions prior to conducting the research.
- indicate whether or not the conducted research was preregistered with an analysis plan in an independent, institutional registry (e.g., <http://clinicaltrials.gov/>, <http://socialscienceregistry.org/>, <http://openscienceframework.org/>, <http://egap.org/design-registration/>, <http://ridie.3ieimpact.org/>). Preregistration of studies involves registering the study design, variables, and treatment conditions prior to conducting the research. Including an analysis plan involves specification of sequence of analyses or the statistical model that will be reported.

The policy of **Translational Behavioral Medicine** is to encourage submission of replication studies, particularly of research published in this journal.



## Transparency and openness in behavioral medicine research

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<sup>2</sup>Department of Kinesiology, The Pennsylvania State University, State College, PA, USA

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Behavioral medicine aims to improve the health of individuals and communities by addressing behavioral, psychosocial, and environmental contributors to health. Succeeding in this endeavor requires rigorous research and effective communication of this research to relevant stakeholders and the public at large [1]. Both research rigor and effective communication of research may benefit from adopting transparent and open research practices [2–4], sometimes called “open science.” Such practices include preregistering designs, hypotheses, and data analysis plans; making publically available study materials, data, and analytic code; sharing preprints (works-in-progress) of articles; and publishing open access [2]. In this commentary, we describe the evolving pressures to increase the transparency and openness of research, examine the status of open science practices in behavioral medicine, and recommend a path forward to find the right fit for these practices in behavioral medicine research.

### PRESSURES TO INCREASE OPENNESS AND TRANSPARENCY

In the past decade, several fields have confronted high-profile failures to replicate prominent findings [5–9]. These failures gave rise to what was initially identified as a “replication crisis” [6,10]. Questionable research practices have been attributed as a prominent cause of the crisis [11,12]. These practices include selective reporting of studies, collecting additional data after analyzing results, presenting post hoc hypotheses as if they had been generated a priori, and even falsifying data [11,13]. Although there are differences of opinion in the depth of the problems of questionable research practices [14], it is clear that strategies to reduce questionable research practices will strengthen science. Transparent and open research practices are advocated as a powerful way to address questionable research practices, as well as a pathway to democratize access to research. As a result, the adoption of transparent and open research practices is being stimulated by rapidly evolving funding, publishing, institutional, and research landscapes.

Funders, such as the National Institutes of Health (NIH), have expressed clear interests in supporting research that is reproducible [15]. NIH grant applications are now required to address rigor and

reproducibility in their research strategy and to provide a resource sharing plan (e.g., a plan on how data will be shared) if costs exceed \$500,000 annually [16]. New data-sharing policies are being developed and will apply more broadly to NIH-funded research [17,18]. Once funded, clinical trials are required by the Public Health Service Act (42 U.S.C. 282 sec. 801) to be registered on [www.clinicaltrials.gov](http://www.clinicaltrials.gov) within 21 days of the first participant enrolling. Publications funded by grants from NIH, National Science Foundation, and other federal agencies must be deposited in public access repositories (e.g., PubMed Central).

Journal editors play a role by setting policies regarding the use of open science practices. Transparency and Openness Promotion (TOP) guidelines (<https://cos.io/top/>) are a set of standards for journals developed by an interdisciplinary group of journal editors, funding agency representatives, and researchers [19]. TOP guidelines include eight areas of standards for journal articles: citation standards (relating to citation of data, codes, and materials); data transparency; analytic methods transparency (relating to sharing of analytic code); research materials transparency; design and analyses transparency (relating to following reporting standards, such as CONSORT); preregistration of studies; preregistration of analysis plan; and replication (relating to journals’ support for publishing replication studies). Each standard can be described according to specific levels of stringency, from requiring author disclosure related to the standard (Level 1) to journal verification of standard (Level 3). Journal editors can choose different levels of adoption across standards, providing flexibility in adapting the standards to the context of their journals and fields. Over 1,000 journals across scientific disciplines—including *Translational Behavioral Medicine* and the *Annals of Behavioral Medicine*—have expressed their support for transparency and openness in science by becoming signatories of TOP guidelines. Open science practices have also been recommended by the International Committee of Medical Journal Editors, which, for example, asks that signatory journals require detailed data-sharing statements from study authors. (<http://www.icmje.org/icmje-recommendations.pdf>).

Academic publishers have played a role in promoting open science. Many publishers offer an open



# Resource Sharing

D. Kwasnicka & M. Waring

# Resource Sharing



## What resources?

- Research data
- Data collection tools (e.g., REDCap/Qualtrics data dictionaries/templates)
- Statistical code (e.g., SAS programs/Stata do files/R scripts/SPSS syntax files to score measures and to conduct specific analyses)
- Intervention content/manuals/materials
- Digital health tools (e.g., apps, websites, wearables)

## Why share?

- Transparency and reproducibility
- Efficient use of resources and efforts – (re)use existing resources, better use of governmental funds
- Increasingly, required/encouraged by funders
  - <https://grants.nih.gov/policy/sharing.htm>

# Open Digital Health initiative

## [www.opendigitalhealth.org](http://www.opendigitalhealth.org)

- Evidence-based tools (apps, websites, wearables)
- Facilitating not-for-profit sharing

### Concerns to address:

- Building a **database of tools** and directory of digital health researchers
- Education on **licensing**; licensing may not seem “open” – protection – control/concern with others running wild with intervention or tools
- How to protect **intellectual property** and original investigators’ research productivity?

## OPEN DIGITAL HEALTH

Our mission is to share evidence-based digital health tools.

OPEN DIGITAL HEALTH

Home Story Team Contact

WHAT IS IT ALL ABOUT?

### Accelerating digital health

If you are a health researcher, practitioner, programmer or technology developer, we would love to hear from you.

We want digital health to grow faster, be cheaper and more transparent across the countries. We want to move health science forward by advancing the progress of evidence-based digital health technologies.



# Sharing research data/code

- Platform for sharing?
  - Center for Open Science [www.osf.io](http://www.osf.io)
  - [www.nlm.nih.gov/NIHbmic/nih\\_data\\_sharing\\_repositories.html](http://www.nlm.nih.gov/NIHbmic/nih_data_sharing_repositories.html)
  - Server hosted by SBM (at sbm.org)?
- Publishing datasets
  - People can cite this publication and investigators can add to their CV (then easier to count towards promotion/tenure)
  - Recommendation: develop list of journals relevant to behavioral science that offer this article type
    - Could SBM journals offer this article type (online-only)?
- Challenges
  - Effort to clean data enough – **shifting standard – does not have to be perfect**
  - Investigator sense of responsibility if others publish crap science using their data? - **collaboration with original investigator so original team has influence on how data is used**



# Ideas for encouraging resource sharing



## Funding opportunities

- Proposals representing new collaborations between investigators to conduct secondary analyses – reuse existing data to answer new and innovative questions
- Proposals to adapt/reuse/repurpose existing digital health tools – **implementation science focused**
- Suggest NIH funding opportunity
  - Also offer through SBM?

# Implications

## Research Methods

- Recommend that investigators think about sharing data when designing data collection tools through data management through statistical analyses
- Recommend that investigators check if digital health tool exists before proposing to create a new tool

## Academic incentives

- Extend impact of research – “credit” for research using shared resources
- Suggest where shared sources could be listed on CV
- Educate promotion/tenure committees

## Societal impact

- More efficient use of research
- Potential for unsupervised/bad science



# Evaluated Pros & Cons Across Stakeholders

	Pros	Cons
Trainees	<ol style="list-style-type: none"> <li>1. Increased citations from increase in citable material</li> <li>2. Recognition for contributing at more points in research pipeline</li> <li>3. Avoid duplicating efforts/more efficient use of time/resources</li> </ol>	<ol style="list-style-type: none"> <li>1. Extra work (unfunded mandate risk)</li> </ol>
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Established Scientists (midcareer, senior)	<ol style="list-style-type: none"> <li>1. Increased citations from increase in citable material</li> <li>2. Recognition for contributing at more points in research pipeline</li> <li>3. Avoid duplicating efforts/more efficient use of time/resources</li> </ol>	<ol style="list-style-type: none"> <li>1. Extra work (unfunded mandate risk)</li> <li>2. Bad science done with their data</li> <li>3. Depending on timeline for sharing, decreased time to conduct secondary analyses of own data</li> </ol>
SBM	<ol style="list-style-type: none"> <li>1. Increases trust in field</li> <li>2. Seen as hub for data &amp; resources</li> </ol>	<ol style="list-style-type: none"> <li>1. Dissemination of low-quality materials or resources with errors</li> </ol>

## Incentives & Disincentives with Resource Sharing



## Social consequences of Resource Sharing



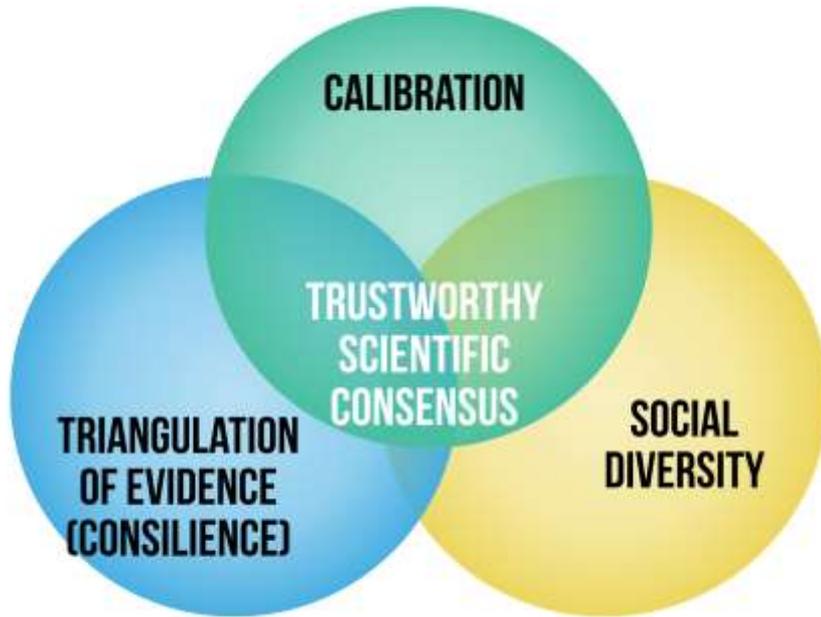
	Pro	Con
For patients	<ol style="list-style-type: none"> <li>1. Opportunity to engage with primary data if desired and skilled</li> </ol>	<ol style="list-style-type: none"> <li>1. Potential to draw improper inference if unskilled and analyzing data</li> <li>2. Privacy risk if data are reidentified</li> </ol>
For industry	<ol style="list-style-type: none"> <li>1. Ability to re-use/build upon existing digital tools</li> <li>2. Ability to access relevant and informative data</li> </ol>	<ol style="list-style-type: none"> <li>1. Loss in profits if evidence-based tools and free government funded solutions are more effective than commercially available ones.</li> </ol>
For policy makers	<ol style="list-style-type: none"> <li>1. Potential for faster breakthroughs and more efficient and cost-efficient science that can inform policy</li> </ol>	<ol style="list-style-type: none"> <li>1. Confusion, information overload, how to select most relevant evidence, best solutions, interventions</li> </ol>
For faculty/ investigators (P&T)	<ol style="list-style-type: none"> <li>1. Ability to re-use/build upon existing digital tools; reuse, reanalyze datasets, reuse codes etc</li> <li>2. Increased citation counts from having more citable material</li> <li>3. Increased work products &amp; impact to include in promotion &amp; tenure dossiers</li> </ol>	<ol style="list-style-type: none"> <li>1. Promotion &amp; tenure committees not valuing these activities; efforts taken to share resources seen as detracting from productivity</li> <li>2. University intellectual property rules?</li> <li>3. Licensing rules?</li> </ol>
For funders	<ol style="list-style-type: none"> <li>1. More deliverables from grant funding – longer-term impact of any grant</li> <li>2. Research impact potential beyond initial grant</li> </ol>	<ol style="list-style-type: none"> <li>1. No clarity on how the 'product' of the grant will be used in the future</li> <li>2. Limited protection of the 'product' IP if we are heading towards truly Open Science</li> </ol>



# Citizen Science

Eric Hekler & Abby King

# Reviewed Evolution in Scientific / Medical Thought



Boaz Miller (2013) When is consensus knowledge based?  
Distinguishing shared knowledge from mere agreement.  
*Synthese* 190(7):1293-1316.



## Hume's Is/Ought Problem (Fact/Value Gap)

### Is

- Oriented towards fact
- Science
- Oriented towards the past and present

### Ought

- Oriented towards values
- Morality, ethics
- Oriented towards the future

[https://en.wikipedia.org/wiki/Is%E2%80%93ought\\_problem](https://en.wikipedia.org/wiki/Is%E2%80%93ought_problem)

## Original Hippocratic Oath

- Guild Oath to “share scientific knowledge *only* with other physicians.”

## Millennial Hippocratic Oath

- The community of stakeholders to benefit from “hard-won scientific knowledge” includes researchers, patients, and the public.

# Scientific Community is Striving to Rebuild Trust



FIND YOUR EVENT ORGANIZE VOLUNTEER SHOP [DONATE](#)

## Unite Behind The Science

We are the world's largest grassroots community of science advocates, organizing for a more sustainable and just future.



# Genuine Participation Rebuilds Trust

Our Voice: Citizen Science for Health Equity

The Our Voice Initiative empowers community members to drive change in their local environments. Using the knowledge that public agencies have "hidden scientific" about the health of their communities that impact their ability to lead healthy lives. They then review their own findings, provide areas for change, and mobilize to provide improvements that will support community health.

This 2-minute video describes the Our Voice approach.

**HEALTH EQUITY**  
Everyone can live a healthy and vibrant life, regardless of economic or social status.

**OUR VOICE CITIZEN SCIENTIST**  
Ordinary people who use community data to activate change.

NATIONAL CANCER INSTITUTE  
Division of Cancer Control & Population Sciences

Behavioral Research Program

L.A.U.N.C.H. (Linking & Amplifying User-Centered Networks through Connected Health): A Demonstration of Broadband-enabled Health for Rural Populations in Appalachia

**PURPOSE**

The purpose of the initiative is to develop a public-private demonstration platform following basic principles of human-system integration to support:

- patient management of symptoms as experienced during cancer treatment;
- opportunities for developing enabling technologies, services, and connected health solutions to improve remote cancer care; and
- patient engagement in community-oriented education.

Initial project goals will focus on addressing symptom management needs among cancer patients in rural Kentucky.

How can we make San Diego a more sustainable city?

San Diego is an amazing place to live, work, and visit. But like many cities, San Diego faces a number of difficult challenges—around mobility, climate, housing, public health, and economic growth—that could affect the long-term sustainability of the region. Want to make a difference in our community? Join the Design for San Diego (D4SD) initiative to help address the city's most pressing challenges using human-centered design. Scroll down to see some sample challenges for this year's theme.

Get our mailing list

## Opening Pathways for Innovation

Opening Pathways

Opening pathways for discovery, research, and innovation in health and healthcare

Dana Lewis, Principal Investigator (PI)

After building her own DIY "artificial pancreas," Dana Lewis helped found the open source artificial pancreas movement (known as "OpenAPS"), making safe and effective artificial pancreas technology available (sooner) for people with diabetes around the world. She is part of the #WeAreWaking movement & engages with patient communities globally to solve healthcare problems in new and innovative ways. She's working to scale patient-led innovation and scientific discovery in more patient communities. She is active on Twitter at @DanaLewis.

This project is a collaboration between patients and traditional researchers to explore the processes around discovery, research, and innovation in health and healthcare. The project is unique because it is led by a patient as Principal Investigator. The project is supported with grant funding by the Robert Wood Johnson Foundation.

Support provided by Robert Wood Johnson Foundation

<http://openingpathways.org/>

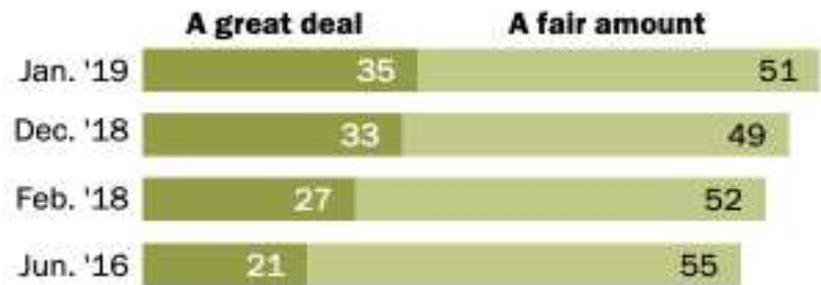
# National Trends

Public confidence in scientists to act in the public interest has increased in recent years.

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## Americans' confidence in scientists to act in the public interest up since 2016

*% of U.S. adults who say they have \_\_\_ amount of confidence in scientists to act in the best interests of the public*



Note: Respondents who gave other responses or who did not give an answer are not shown.

Source: Survey conducted Jan. 7-21, 2019.

"Trust and Mistrust in Americans' Views of Scientific Experts"

**PEW RESEARCH CENTER**

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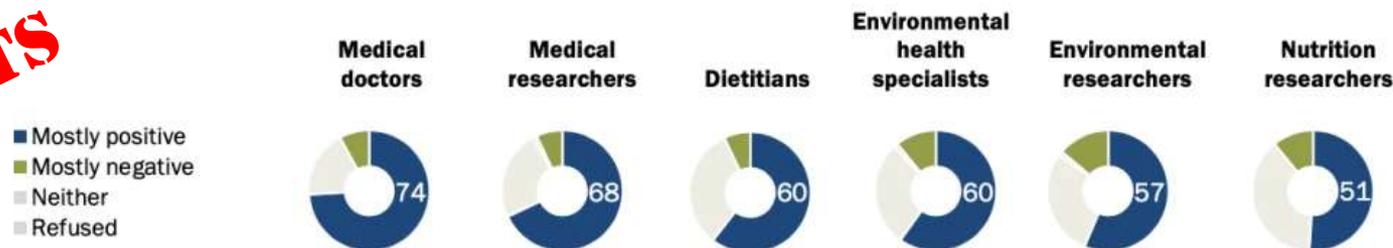
# National Trends

Majorities trust medical doctors and dietitians to care about their patients' best interests, but trust in other scientists is lower.

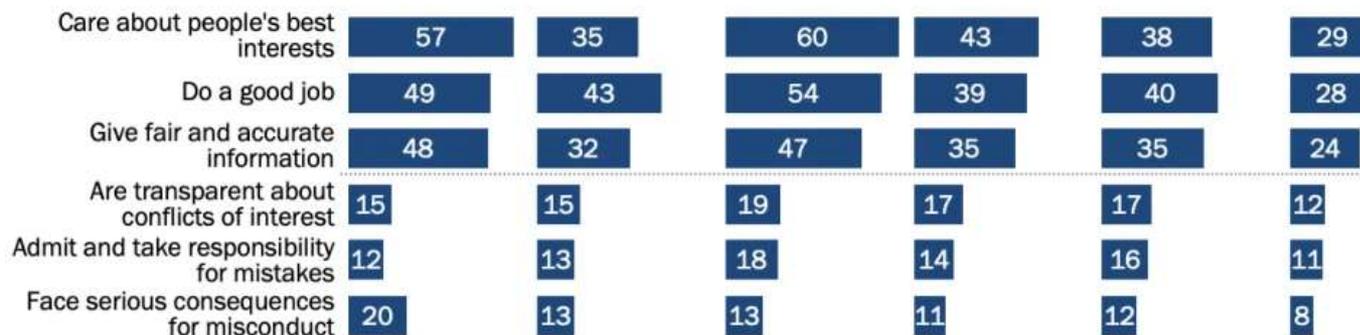
## Trust in medical doctors and dietitians is higher than for researchers in these areas

% of U.S. adults who say their view of each of these groups is ...

**SBM ASSETS**



% of U.S. adults who say each of these groups \_\_\_ all or most of the time



Note: Respondents who gave other responses or who did not give an answer are not shown.

Source: Survey conducted Jan. 7-21, 2019.

"Trust and Mistrust in Americans' Views of Scientist Experts"

PEW RESEARCH CENTER

# Types of Citizen Science

	Professional-led	Co-led	Citizen-led
Health care	<p>Support historically marginalized groups</p> <ul style="list-style-type: none"> <li>• Clinics targeting underserved populations (e.g., refugee clinic on Southern Border)</li> </ul> <p>Targeting resourced groups (e.g., 1/9%)</p> <ul style="list-style-type: none"> <li>• Fold-IT (Game)</li> <li>• PatientsLikeMe</li> </ul>	<p>Support historically marginalized groups</p> <ul style="list-style-type: none"> <li>• CBPR</li> <li>• C. Daniel Mullins work</li> </ul> <p>Targeting resourced groups (e.g., 1/9%)</p> <ul style="list-style-type: none"> <li>• MakerNurse</li> <li>• OpeningPathways of Innovation</li> </ul>	<p>Support historically marginalized groups</p> <ul style="list-style-type: none"> <li>• Society for Participatory Medicine</li> </ul> <p>Targeting resourced groups (e.g., 1/9%)</p> <ul style="list-style-type: none"> <li>• #WeAreNotWaiting</li> <li>• OpenAPS</li> <li>• Biohacking</li> </ul>
Pop. Health	<p>Support historically marginalized groups</p> <ul style="list-style-type: none"> <li>• Promotoras model</li> </ul> <p>Targeting resourced groups</p> <ul style="list-style-type: none"> <li>• Peer coaching</li> </ul>	<p>Support historically marginalized groups</p> <ul style="list-style-type: none"> <li>• LAUNCH</li> </ul> <p>Targeting resourced groups (e.g., 1/9%)</p> <ul style="list-style-type: none"> <li>• Project Apollo</li> </ul>	<p>Support historically marginalized groups</p> <ul style="list-style-type: none"> <li>• Self-organized disaster relief</li> </ul> <p>Targeting resourced groups (e.g., 1/9%)</p> <ul style="list-style-type: none"> <li>• Community-organizing</li> <li>• Neighborhood associations</li> </ul>
Public health	<p>Support historically marginalized groups</p> <ul style="list-style-type: none"> <li>• OurVoice</li> <li>• Gates Foundation efforts (e.g., sanitation in under-resourced countries)</li> </ul> <p>Targeting resourced groups (.g., 1/9%)</p> <ul style="list-style-type: none"> <li>• Townhall meetings</li> <li>• Providing disaster relief</li> </ul>	<p>Support historically marginalized groups</p> <ul style="list-style-type: none"> <li>• TBD</li> </ul> <p>Targeting resourced groups (e.g., 1/9%)</p> <ul style="list-style-type: none"> <li>• Design for San Diego</li> </ul>	<p>Support historically marginalized groups</p> <ul style="list-style-type: none"> <li>• ?</li> </ul> <p>Targeting resourced groups (e.g., 1/9%)</p> <ul style="list-style-type: none"> <li>• Quantified Self</li> </ul>

# Recommendations

## Study design Methods Recs

- Support a broader array of methods, beyond “big data”/nomothetic (i.e., most of what we currently do) approaches
- Develop respected pathways for the insights from “citizen scientists” at whatever capacity (through providing their voice to advancing fundamental science) be included in scientific discourse
- Find ways to bridge “is” and “ought” arguments
  - How do evidence and values interact effectively?

# From “Protecting”



# To “Participating”



- “Protecting” mentality can have unintended consequences
- Psychological biases may play a role
  - Stereotyping
  - Omission bias
  - Learned helplessness for those “protected”
- How power works is changing, we need everybody
  - People are diverse in skills & knowledge
  - Knowledge is distributed across lay and expert sources
  - Partnerships increase reach over time and geography
  - “Many eyes” can stave off error
  - Common goals lead to policy and public support

# Evaluated Pros & Cons Across Stakeholders

	Pros	Cons
Trainees	<ul style="list-style-type: none"> <li>Many students I talk to are hungry for this stronger "ought" lens" to our work, suggesting a pro is that they would find this valuable and fulfilling</li> <li>If we could make this acceptable, their work could be more directly linked to impact</li> </ul>	<ul style="list-style-type: none"> <li>Many students don't feel comfortable, nor have the requisite privileges, power, and rights to do this type of work</li> <li>Definitely not incentivized to do any of this</li> </ul>
Jr Scientists	<ul style="list-style-type: none"> <li>Building a research process that is more directly linked with benefit to people</li> </ul>	<ul style="list-style-type: none"> <li>Not incentivized for this</li> <li>Doesn't fit into current culture on "good science" as part of study section</li> </ul>
Established Scientists (midcareer, senior)	<ul style="list-style-type: none"> <li>Creates more pathways for robust science to move into practice and to benefit people</li> </ul>	<ul style="list-style-type: none"> <li>Not incentivized to do this</li> <li>Might feel counter to "true science"</li> </ul>
SBM	<ul style="list-style-type: none"> <li>Could play a leadership role on articulating an broad, encompassing vision of open science</li> </ul>	<ul style="list-style-type: none"> <li>Would be a fairly major cultural shift if we fully moved in this direction</li> </ul>

## Incentives & Disincentives with Citizen Science



## Social consequences of Citizen Science



	Pro	Con
For patients	<ol style="list-style-type: none"> <li>Would have a voice in defining priorities and efforts across healthcare, population health, and public health</li> <li>Honors the agency of people to meaningfully influence understanding of issues they care about</li> <li>May support more rapid translation of research to practice</li> </ol>	<ol style="list-style-type: none"> <li>People who may want to engage like this, currently do not have a role, funding, or other support</li> <li>If done wrong, it could easily result in groups being taken advantage of (tokenism)</li> <li>It could also be a pathway for "pseudo-science" to gain traction</li> </ol>
For industry	<ol style="list-style-type: none"> <li>Could feasibly be used to align pace and success criteria between groups</li> </ol>	<ol style="list-style-type: none"> <li>Might create a wider realm on what counts as "evidence," which could be used by some to justify a tool as "evidence-based" when its not</li> </ol>
For policy makers	<ol style="list-style-type: none"> <li>If done well, policy-makers could more directly link their work and commitment to science to public benefit</li> </ol>	<ol style="list-style-type: none"> <li>If not done well, could result in confusion on what is "known."</li> </ol>
For faculty/ investigators (P&T)	<ol style="list-style-type: none"> <li>Create more robust linkages between the science that is needed and the science that is produced, thus increasing likelihood that each investigator will have impact</li> </ol>	<ol style="list-style-type: none"> <li>Definitely not part of current T&amp;P</li> <li>Will require investigators to learn how to interact with non-scientists</li> <li>For some, may perceived as a reduction of power and privilege</li> </ol>
For funders	<ol style="list-style-type: none"> <li>Feasibly greater connection between science and impact</li> </ol>	<ol style="list-style-type: none"> <li>"Peer review" would not really work for this, as currently conceived.</li> </ol>



Next Steps

# Operationalize Within Context of Provocative Questions

How can we use artificial intelligence to improve the health of all individuals?

How can emerging technologies be leveraged to positively impact behavioral medicine interventions and overall population health?

How can behavioral medicine eliminate health inequalities and advance social justice?

How can behavioral medicine solve sociopolitical issues like climate change, gun violence, and fake science?

How do we better tailor and scale behavioral medicine interventions for sustained behavior change?

How do we better integrate behavioral medicine into the healthcare system and personalized medicine approaches?

How do we improve our scientific methodologies and research translation?

# Synthesize and Conclude

## Editorial Policy & Publication

- Discuss & ratify recommendations
- Align with feedback from SBM editors, publisher, and publications / communications council

## Resource Sharing

- Vote on proposal from the Digital Health Council regarding endorsement of resource sharing sites such as [opendigitalhelth.org](https://opendigitalhelth.org)
- Work with SIG & Education Councils to bring opportunities for resource sharing to the fore.

## Citizen Science

- Coordinate with Health Policy Council to endorse/instantiate a participative mission.
- Promote membership awareness through publication, webinars, and programmatic content in annual meeting.