Evidence Mobilization Action Collaborative Fall 2021 Webinar

Stewarding Public Trust in Biomedical Science and Research

November 4, 2021 | 12:00 PM – 4:00 PM EST

Share your thoughts!

@theNAMedicine
Welcome & Introduction

Michael McGinnis
Leonard D. Schaeffer Executive Officer
Stakeholder leaders in private, public, and independent organizations from key health sectors, collaborating under the auspices of the National Academy of Medicine for action on their common interests in advancing effectiveness, efficiency, equity, and continuous learning in health, medical care, and biomedical science.
A learning health system is one in which science, informatics, incentives, and culture are aligned for continuous improvement, innovation, and equity—with best practices and discovery seamlessly embedded in the delivery process, individuals and families active participants in all elements, and new knowledge generated as an integral by-product of the delivery experience.

Leadership Consortium Charter 2006
focus:

COLLABORATION FOR ACTION
COLLABORATIVE ACTION

**SCIENCE:** Evidence Mobilization Action Collaborative  
FOCUS: *continuous learning through real-world evidence*

**INFORMATICS:** Digital Health Action Collaborative  
FOCUS: *digital infrastructure & data as a core utility*

**INCENTIVES:** Value Incentives & Systems Action Collaborative  
FOCUS: *payment based on health outcomes for people and populations*

**CULTURE:** Culture, Inclusion & Equity Action Collaborative  
FOCUS: *full and equitable health engagement for people and communities*
CORE ELEMENTS FOR EACH COLLABORATIVE

ORGANIZATIONAL NETWORKS

ANCHOR PRINCIPLES

KEY PROGRESS INDICATORS

COLLABORATIVE PROJECTS
Trust as a Common Theme in the COVID-19 Sector Impact Assessments

Emerging Stronger After COVID-19: Priorities for Health System Transformation

Clinicians
Health care payers
Research

Patients, families, and communities
Public health
Digital health

Care systems
Quality, safety and standards organizations
Health product manufacturers and innovators

Emerging Stronger After COVID-19: Priorities for Health System Transformation - National Academy of Medicine (nam.edu)
Evidence Mobilization Action
Collaborative Co-Chairs

Richard Kuntz
Medtronic

Richard Platt
Harvard University
Agenda

Welcome, Introductions & Meeting Overview 12:00 – 12:15 PM
Michael McGinnis, National Academy of Medicine
Richard Kuntz, Medtronic
Richard Platt, Harvard University

Overview of Trust and Distrust in Biomedical Research 12:15 – 1:00 PM
Moderator: Richard Kuntz, Medtronic
Speakers: Cary Funk, Pew Research Center
        Sudip Parikh, American Association for the Advancement of Science
        Sandra Quinn, University of Maryland School of Public Health

Transparency, Independence, and Innovation in Science 1:00 – 1:45 PM
Moderator: Richard Platt, Harvard University
Speakers: Ramona Burress, Janssen, Pharmaceutical Companies of Johnson & Johnson
        Lisa Fitzpatrick, Grapevine Health
Reactors: Gwen Darien, National Patient Advocate Foundation
        Joseph Ross, Yale University Open Data Access (YODA) Project
Agenda Continued

**Society, Science, and Social Media**
1:45 – 2:45 PM

Moderator: Richard Kuntz, Medtronic
Speakers: Robin Vanderpool, National Cancer Institute
Jay van Bavel, New York University
Jeremy Greene, Johns Hopkins Medicine
Katherine Ognyanova, Rutgers University
Reactors: Wendy C. King, University of Pittsburgh
Tara Haelle, Freelance Journalist

**Strategies & Solutions for Closing the Trust Gap**
2:45 – 3:30 PM

Moderator: Richard Platt, Harvard University
All panelists are welcome to join

**Call to Action**
3:30 – 4:00 PM

Moderator: Richard Platt, Harvard University
All panelists are welcome to join

**Adjourn**
4:00 PM

Michael McGinnis, National Academy of Medicine
**Zoom Instructions**

**Panelists**
- Always keep your line muted unless you are called on to speak.
- If possible, turn on video while speaking to the group. To enable video click the ‘start video’ option at the bottom left of your screen.
- If you would like to say something, use Zoom’s “Raise Hand” feature by clicking the “Participants” button and then pressing “Raise Hand” at the bottom of the participants tab.

**Attendees - Q & A**
- Please type in questions into the Q&A located at the bottom of the screen on your zoom interface.
- Question format:
  - Your name and organization
  - To whom
  - Question
Overview of Trust and Distrust in Biomedical Research
Public Trust in Biomedical Science and Research

Cary Funk, Ph.D.
Director, Science and Society Research
Strong confidence in vaccine research and development process increases

U.S. adults who say they have ____ of confidence in the research & development process for COVID-19 vaccines

<table>
<thead>
<tr>
<th></th>
<th>Sept '20</th>
<th>Nov '20</th>
<th>Feb '21</th>
<th>Aug '21</th>
</tr>
</thead>
<tbody>
<tr>
<td>A great deal</td>
<td>19</td>
<td>30</td>
<td>33</td>
<td>39</td>
</tr>
<tr>
<td>A fair amount</td>
<td>45</td>
<td>45</td>
<td>40</td>
<td>33</td>
</tr>
</tbody>
</table>

Note: Respondents who gave other responses or did not give an answer are not shown.
Vaccinated adults highly confident in COVID-19 vaccine R&D process

U.S. adults who have ___ confidence in the research & development process for COVID-19

- **A great deal**: 39
- **A fair amount**: 33
- **Not too much**: 15
- **None at all**: 12

### COVID-19 vaccination status ...

- **Vaccinated (1+ dose)**:
  - A great deal: 52
  - A fair amount: 39
  - Not too much: 7
  - None at all: 2

- **Not vaccinated**:
  - A great deal: 3
  - A fair amount: 18
  - Not too much: 37
  - None at all: 41

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

61% say changing COVID-19 recommendations from public health officials made sense, but 51% also say they made them feel less confident in guidance

U.S. adults who’ve had each reaction to changes in public health officials’ recommendations on how to slow the spread of the coronavirus

<table>
<thead>
<tr>
<th>POSITIVE REACTIONS</th>
<th>NET 66% had at least one positive reaction</th>
</tr>
</thead>
<tbody>
<tr>
<td>It made sense because scientific knowledge is always being updated</td>
<td>61</td>
</tr>
<tr>
<td>It reassured me that public health officials are staying on top of new information</td>
<td>51</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>NEGATIVE REACTIONS</th>
<th>NET 63% had at least one negative reaction</th>
</tr>
</thead>
<tbody>
<tr>
<td>It made me wonder if public health officials were holding back important information</td>
<td>55</td>
</tr>
<tr>
<td>It made me less confident in public health officials' recommendations</td>
<td>51</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>CONFUSION</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>It made me feel confused</td>
<td>53</td>
</tr>
</tbody>
</table>

Note: Respondents who gave other responses or did not give an answer are not shown. Survey of U.S. adults conducted Aug. 23-29, 2021.
About four-in-ten Americans have a great deal of confidence in scientists, medical scientists

Confidence in scientists to act in the best interests of the public

<table>
<thead>
<tr>
<th>Year</th>
<th>A fair amount</th>
<th>A great deal</th>
<th>Not too much/none at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jun '16</td>
<td>55</td>
<td>21</td>
<td>23</td>
</tr>
<tr>
<td>Feb '18</td>
<td>52</td>
<td>27</td>
<td>21</td>
</tr>
<tr>
<td>Dec '18</td>
<td>49</td>
<td>33</td>
<td>17</td>
</tr>
<tr>
<td>Jan '19</td>
<td>51</td>
<td>35</td>
<td>13</td>
</tr>
<tr>
<td>Apr '20</td>
<td>48</td>
<td>39</td>
<td>12</td>
</tr>
<tr>
<td>Nov '20</td>
<td>45</td>
<td>39</td>
<td>15</td>
</tr>
</tbody>
</table>

Confidence in medical scientists to act in the best interests of the public

<table>
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<tr>
<th>Year</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Jun '16</td>
<td>60</td>
<td>24</td>
<td>15</td>
</tr>
<tr>
<td>Jan '19</td>
<td>52</td>
<td>35</td>
<td>13</td>
</tr>
<tr>
<td>Apr '20</td>
<td>46</td>
<td>43</td>
<td>11</td>
</tr>
<tr>
<td>Nov '20</td>
<td>45</td>
<td>40</td>
<td>14</td>
</tr>
</tbody>
</table>

Note: Respondents who did not give an answer are not shown.
Since the pandemic, Democrats but not Republicans have more trust in medical scientists. U.S. adults who have ___ of confidence in medical scientists to act in the best interests of the public

<table>
<thead>
<tr>
<th>U.S. adults</th>
<th>Rep/lean Rep</th>
<th>Dem/lean Dem</th>
</tr>
</thead>
<tbody>
<tr>
<td>A fair amount</td>
<td>60 52 46 45</td>
<td>65 56 54 55</td>
</tr>
<tr>
<td>A great deal</td>
<td>24 35 43 40</td>
<td>18 32 31 26</td>
</tr>
<tr>
<td>Not too much/none at all</td>
<td>15 13 11 14</td>
<td>16 12 15 18</td>
</tr>
</tbody>
</table>

Note: Respondents who did not give an answer are not shown. Survey of U.S. adults conducted Nov. 18-29, 2020.
In 2019, Americans’ trust was higher for medical doctors than researchers but most were wary of scientific integrity

% of U.S. adults who say medical doctors or medical researchers do the following …

<table>
<thead>
<tr>
<th></th>
<th>Medical Doctors</th>
<th>Medical Researchers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care about people’s best interests</td>
<td>57%</td>
<td>35%</td>
</tr>
<tr>
<td>Do a good job</td>
<td>49%</td>
<td>43%</td>
</tr>
<tr>
<td>Provide fair and accurate information</td>
<td>48%</td>
<td>32%</td>
</tr>
<tr>
<td>Are transparent about conflicts of interest</td>
<td>15%</td>
<td>15%</td>
</tr>
<tr>
<td>Admit and take responsibility for mistakes</td>
<td>12%</td>
<td>13%</td>
</tr>
<tr>
<td>Face serious consequences for misconduct</td>
<td>20%</td>
<td>13%</td>
</tr>
</tbody>
</table>

Note: Respondents who did not give an answer are not shown. Respondents were asked about whether medical doctors and dieticians care about the best interests of “their patients.”

Source: Survey conducted Jan. 7-21, 2019.
Black adults are less likely to say science has a mostly positive impact on society than Hispanic and white adults

U.S. adults who say ...

<table>
<thead>
<tr>
<th>Statement</th>
<th>Black (%)</th>
<th>Hispanic (%)</th>
<th>White (%)</th>
<th>U.S. adults (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Science has had a mostly positive effect on society</td>
<td>59</td>
<td>66</td>
<td>78</td>
<td>73</td>
</tr>
<tr>
<td>Research misconduct by medical research scientists is a very/moderately big problem</td>
<td>42</td>
<td>60</td>
<td></td>
<td>48</td>
</tr>
<tr>
<td>They are very/somewhat interested in science news</td>
<td>60</td>
<td>72</td>
<td>73</td>
<td>71</td>
</tr>
</tbody>
</table>

Note: Respondents who gave other responses or did not give an answer are not shown. White and Black adults include those who report being only one race and are not Hispanic. Hispanics are of any race. Surveys of U.S. adults conducted Jan. 7-21, 2019 and May 30-Jun. 12, 2017.
Moving from Distrust to Trust to Trustworthiness

Sandra Crouse Quinn, PhD
Stewarding Public Trust in Biomedical Science and Research
National Academy of Medicine Leadership Consortium
Evidence Mobilization Action Collaborative
November 4, 2021
Engaging with Communities and Listening to Community Concerns

Kizzmekia S. Corbett, Ph.D.
National Institutes of Health

Dr. Kizzmekia S. Corbett is a research fellow and the scientific lead for the Coronavirus Vaccines & Immunopathogenesis Team at the National Institutes of Health (NIH), National Institute of Allergy and Infectious Diseases, Vaccine Research Center (VRC). She received a B.S. in Biological Sciences, with a secondary major in Sociology, in 2008 from the University of Maryland-Baltimore County, where she was a Meyerhoff Scholar and an NIH undergraduate scholar. She then enrolled at University of North Carolina at Chapel Hill, where she obtained her Ph.D. in Microbiology and Immunology in 2014.

A viral immunologist by training, Corbett uses her expertise to propel novel vaccine development for pandemic preparedness. Appointed to the VRC in 2014, her work focuses on developing novel coronavirus vaccines, including mRNA-1273, a leading candidate vaccine against the virus that causes COVID-19. In response to the ongoing global COVID-19 pandemic, the vaccine concept incorporated in mRNA-1273 was designed by Corbett's team from viral sequence data and rapidly deployed to industry partner, Moderna,
Reaching diverse audiences

- Use tools that will reach diverse audiences (Community Immunity)
Embed research in settings people trust and receive other services
Bringing health care to community settings

Tre Shadez Hair Studio in Capitol Heights, Md., recently hosted a Covid-19 vaccination clinic, with customers bringing their families.

HEALTH POLICY

Barbershops and Hair Salons Are Enlisted in Covid-19 Vaccine Push

Nurse Cindy House gives Clarence Cromer, 72, of Hyattsville, the Johnson & Johnson vaccine during clinic at The Shop Spa. Organizers hope the barbershop clinic will become a national model.
A Different Legacy for Tuskegee

They were denied treatment.

LET THEIR LEGACY BE OUR MOTIVATION
Sandra Crouse Quinn, Ph.D.
Senior Associate Director
Maryland Center for Health Equity
Professor and Chair, Department of Family Science
School of Public Health
University of Maryland
College Park, MD
scquinn@umd.edu
Building Trust Between Minorities and Researchers

Health disparities are a national problem, and in order to address health needs effectively, research must contribute to the health of future generations. Today, with this website, we can start building trust between communities and health researchers in an effort to inform health literacy and improve health outcomes across all of our health.

www.buildingtrustumd.org
Additional resources

- Buildingtrustumd.org
- https://youtu.be/B0Vb7O121_8
- https://getvaccineanswers.org/Legacy
- https://hhph.org/communityimmunity/
Acknowledgements

Building Trust was supported by Award Number 7RC2MD004766 from the National Institute on Minority Health And Health Disparities and the Office of the Director, NIH (Quinn and Thomas, PIs)
Transparency, Independence, and Innovation in Science
Ramona Burress
Janssen

Lisa Fitzpatrick
Grapevine Health
Living Up to Our Vision: ENSEMBLE

Intentional focus and purposeful tracking in ENSEMBLE’s clinical trial design and experience allowed us to achieve our enrollment targets within populations disproportionately affected by the COVID-19 pandemic.

The ENSEMBLE study design included both study-specific strategies along with best practices from previous Janssen clinical trials. These best practices, along with new learnings captured from ENSEMBLE, may be considered as options for future study design.

60+

34% of global participants are over the age of 60

Among participants in U.S.,
74% are White / Caucasian,
15% are Hispanic,
13% are Black / African American,
6% are Asian and
1% are Native American

45% of global participants identify as female, and 55% as male
Validating Our Approach: The Formula for Driving Inclusive Clinical Research

In order to achieve our vision, we are scaling our approach to deliver impact across Janssen’s entire portfolio to advance health equity, close gaps in care, and create a better future for our patients. To meet the unique needs of all patients, we must apply strategic operational practices to engage and increase racial and ethnic minorities in clinical trials.

Strategy + Operational Excellence + Community Engagement = Success

- Formalizing a strategy prior to execution
- Working as one to achieve the shared goal
- Creating closer engagements to build awareness and trust
- Driving inclusive clinical research
Research Includes Me: Community Engagement and Education Program

The program focused on reaching underrepresented communities by:

- Providing information on the clinical research process and why diversity and inclusion is so important
- Building trust in clinical research
- Offering resources related to clinical trials

Who must be included in clinical research? **Everyone.**

ResearchIncludesMe.com
launched in 2020
Gwen Darien
National Patient Advocate Foundation

Joseph Ross
Yale University Open Data Access (YODA)
Society, Science, and Social Media
Social Media and Health: Two sides of the same coin

Robin C. Vanderpool, DrPH
Chief, Health Communication and Informatics Research Branch
robin.vanderpool@nih.gov
(Positive) Impacts of Social Media

Benefits
- Social support
- Targeted & tailored information sharing
- Increased information access overall, equitable access
- Potential to impact digital divide
- Low-cost, real-time outreach & engagement
- Promotion of healthy behaviors
- Peer-to-peer interactions

Research Opportunities

**Observational studies**: SM data offer insights on knowledge, attitudes, behaviors; enables the collection of a large amount of surveillance data for relatively low cost, can be used to obtain data on “harder to reach” populations.

**Intervention studies**: SM can be used in health interventions to facilitate behavior change, provide information, increase knowledge and awareness, etc. SM can also be used to find and recruit study participants.
Data on social media use start to be collected (HINTS, PEW)

2003-present

Growing inclusion of social media in NCI/NIH portfolio & emergence of descriptive and intervention studies on SM and health

2009-present

Web 2.0 for Health: scoping reviews (AJPH, JCS)

2012-present

NCI Working Group meeting on health misinformation on SM

2018

CRAN RFA-14-008, Using Social Media to Understand & Address Substance Use and Addiction

2013-2017

2018

JAMA Viewpoint on misinformation (Chou et al.)

2003 - 2021

Measles outbreak / WHO lists vaccine hesitancy among top global health threats

"Misinformation" = "Word of the Year" (Dictionary.com)

COVID-19 pandemic & Misinfodemic

NIH COVID-19 Vaccination Communication report

Commentary on combating racism and xenophobia online

2020

NCI-sponsored AJPH Issue on SM Health Misinformation

2020

2021

"Misinformation" in view of COVID-19

2020

Facebook whistleblower

2021

COVID-19 Pandemic & Misinfodemic

2020

“Measles outbreak / WHO lists vaccine hesitancy among top global health threats

1997-1999

Advent of Social Media: blogging/online support groups

1997-2000

2004

Facebook

2005

YouTube

2006

Reddit

Twitter

PatientsLikeMe

2007

Tumblr

2010

Instagram

2011

Pinterest

Google+

Snapchat

2012

Twitter

2013

Facebook

2016

Cambridge Analytica harvests data from 87 million people using a third-party FB app

2015

JAMA Viewpoint on"Word of the Year"

2018

2019

2020

2021

Web 2.0 for Health: scoping reviews (AJPH, JCS)

2012-present

NCI Working Group meeting on health misinformation on SM

2018

CRAN RFA-14-008, Using Social Media to Understand & Address Substance Use and Addiction

2013-2017

2018

JAMA Viewpoint on misinformation (Chou et al.)
More Balanced View of Social Media

Benefits

- Social support
- Targeted & tailored information sharing
- Increased information access overall, equitable access
- Potential to impact digital divide
- Low-cost, real-time outreach & engagement
- Promotion of healthy behaviors
- Peer-to-peer interactions

- Research opportunities

Risks

- Cyber-aggression
- (Mis)information silos & echo chambers
- Risks posed by limited health literacy
- Low-cost, rapid spread of anecdotes & falsehoods
- Normalization of risky behaviors
- Lack of expert gatekeeping

- Ethics of online research
- Content moderation
“Misinfodemics” online: A perfect storm?

- Ubiquitous health content online
- Falsehoods spread faster than truths and garner more engagement and emotional reactions, whereas credible scientific information may more complex, nuanced, evolving, conflicting, and uncertain
- Ongoing disinformation campaigns erode a sense of consensus and drive divisions
- Growing mistrust (among some populations) in science, experts, government, and institutions
- Negative emotions (fear, anger), ideology, identity

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Dandelion Tea: The Cancer Killer

While it is often overlooked as just an annoying weed, dandelions happen to be one of the most incredible medicinal plants available with tons of healing abilities.

And now, studies have indicated that it kills cancer cells. One study at Windsor University found that cancer patients who drank dandelion tea were getting better. When they analyzed the results, it was found that the dandelions focused in on the cancer cells and killed them, while it left non-cancerous cells alone (Chemotherapy, on the other hand, kills all cells).

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NIH NATIONAL CANCER INSTITUTE
Online Cancer Misinformation Examples

1) Breast cancer prevention and treatment on Pinterest (Wilner et al. *AJPH*, 2020)
   - 11.4% of breast cancer pins in their sample were found to contain misinformation in text, image, or both (e.g., anticancer effects of probiotics/turmeric/dandelions; antiperspirants cause cancer)

2) Prostate cancer videos on YouTube (Loeb et al. *Eur Urol*, 2018)
   - 77% of videos contained misinformation/biased content in the video itself or the comments
   - Analysis of comments section suggests potential impact (e.g., decision to pursue an unproven tx)

3) Cancer misinformation on Facebook and other SM (Johnson et al. *JNCI*, 2021)
   - Experts reviewed the 50 most popular SM articles on each of 4 cancers (breast, prostate, colorectal, and lung) posted between January 2018 and December 2019
   - Out of the 200 articles reviewed, 32.5% (n=65) contained misinformation and 30.5% (n=61) contained harmful information.
   - Articles containing harmful information or misinformation garnered greater engagement
Online COVID-19 Misinformation Examples

- **Disease Characteristics**
  - Denial of pandemic ("overblown")
  - Downplaying susceptibility/severity/prevalence

- **Origins and spread of virus**
  - Conspiracy theories and xenophobic/stigmatizing rumors

- **Unproven treatments**
  - Promoting unproven drugs or dangerous products

- **Policy responses**
  - Casting doubt on effectiveness of mask and vaccination policies
  - Vilifying scientists and health professionals / questioning motives behind COVID-19 control measures

- **COVID-19 vaccines**
  - Doubts regarding the vaccine development process, risks, safety, efficacy, motives
  - Misleading legal arguments against vaccine mandates
  - Continued politization
Major knowledge gaps remain….

- False claims are **not easy to identify**
  - Nuanced, embedded in videos or images, visual images
- Beyond assessment of content accuracy:
  - The **sources of the spread** and their **motivations**:
    - For example, in the case of vaccines, a **small group of actors are responsible** for most of the misinformation being spread online
- **Repeated exposure over time** may increase misinformation impact
- Nature of **engagement** beyond quantitative metrics
- **Individual characteristics** that make some more susceptible to misinformation (e.g., lower educational attainment, conspiracy mentality, distrust, health literacy)
- **Differences** in misinformation sharing **across SM platforms** due to different user behaviors and platform policies/features
Potential Impact of Misinformation on Health

- Prevention, screening, and treatment adherence (e.g., decision-making, delays in care, use of unproven therapies)
- Patient-provider relationship (e.g., exposure to conspiracy theories might reduce trust in providers/medical system)
- Psychological and emotional effects (e.g., anxiety, confusion)
- Scams/financial loss (e.g., sales of products to vulnerable people)
- Exacerbation of health disparities (e.g., different content moderation enforcement for Spanish vs. English language posts could lead to unequal impact, especially if high quality information in Spanish is not available)
Whole-of-Society Approach

- Individuals, Families, and Communities
  - Learn how to identify and avoid sharing misinformation
- Educators
  - Educate students and the public on common tactics used by those who spread misinformation online
- Health Professionals and Organizations
  - Proactively engage with the public
  - Partner with community groups
- Journalists and Media Organizations
  - Recognize, correct, and avoid amplifying misinformation
  - Provide context to avoid skewing perceptions about ongoing debates - consider use of headlines and images
- Technology Platforms
  - Assess impact of current practices & share findings
  - Enable researchers access to data
  - Strengthen monitoring of misinformation
  - Prioritize early detection of “super-spreaders” & repeat offenders
  - Amplify trusted messengers & experts
- Researchers, Governments, and Foundations
  - Coordinated efforts to build long-term resilience
**Racism and Xenophobia in a Pandemic: Interactions of Online and Offline Worlds**

Wen-Ying Sylvia Chou, PhD, MPH, and Anna Gogoszynsky, MPH

“…demonstrating that social media platforms can also be powerful channels for condemning and countering racist rhetoric, expressing solidarity with minority communities, and providing support to those who have been targets of abuse.”


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**Reminder! Social media can be used for good!**

SM can also offer a space for real conversations to take place

E.g., *Vaccine Talk*, a Facebook group with more than 70,000 members, is open to pro- and anti-vaccine members but has strict rules, including requiring anyone who posts to provide citations within 24 hours for any claim they make.

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**Technology**

A group of moms on Facebook built an island of good-faith vaccine debate in a sea of misinformation

As social media giants struggle to crack down on false claims about covid, ordinary users are finding ways to reach vaccine skeptics — and win them over.
Polarization & misinformation during the pandemic

Jay Van Bavel, New York University @jayvanbavel
Lessons from behavioral science

Using social and behavioural science to support COVID-19 pandemic response


The COVID-19 pandemic represents a massive global health crisis. Because the crisis requires large-scale behaviour change and places significant psychological burdens on individuals, insights from the social and behavioural sciences can be used to help align human behaviour with the recommendations of epidemiologists and public health experts. Here we discuss evidence from a selection of research topics relevant to pandemics, including work on navigating threats, social and cultural influences on behaviour, science communication, moral decision-making, leadership, and stress and coping. In each section, we note the nature and quality of prior research, including uncertainty and unsettled issues. We identify several insights for effective response to the COVID-19 pandemic and highlight important gaps researchers should move quickly to fill in the coming weeks and months.
Collective behavior change

- Threat perception
  - Threat
  - Emotion and risk perception
  - Prejudice and discrimination
  - Disaster and panic

- Leadership
  - Trust and compliance
  - Identity leadership
  - Ingroup elevation

- Individual and collective interests
  - Zero-sum thinking
  - Moral decision-making
  - Cooperation

- Science communication
  - Conspiracy theories
  - Fake news
  - Persuasion

- Social Context
  - Social norms
  - Social inequality
  - Culture

- Stress and coping
  - Social isolation and connection
  - Intimate relationships
  - Healthy mind-sets

Van Bavel et al., NHB: https://www.nature.com/articles/s41562-020-0884-z
Partisanship

The emergence of out-party hate as a stronger force than in-party love

Finkel et al., 2020, Science: https://science.sciencemag.org/content/370/6516/533
Partisanship

Polarized movement

- Using geotracking of 15 million smartphones per day
- Counties that voted for Trump over Clinton in 2016, exhibited 14% more movement
- The reddest counties had the lowest spatial distancing, the bluest counties had the most

Gollwitzer et al., 2020, NHB: https://www.nature.com/articles/s41562-020-00977-7
Polarized movement

- The degree to which people in different counties watched Fox News over CNN and MSNBC was associated with highest levels of movement.

Gollwitzer et al., 2020, NHB: https://www.nature.com/articles/s41562-020-00977-7
Out-group animosity drives engagement on social media

Steve Rathje\textsuperscript{a,1}, Jay J. Van Bavel\textsuperscript{b}, and Sander van der Linden\textsuperscript{a,1}

Fig. 3. In A, the meta-analyzed effect sizes across all eight datasets are shown. The effect size of political out-group language was 4.7 times as large as that of negative affect language and 6.7 times as large as moral-emotional language. In B, the meta-analyzed effect sizes of in-group and out-group language on each of the Facebook reactions are shown. In-group language predicted “love” reactions, whereas out-group language strongly predicted “angry” reactions.

Rathje et al., 2021, PNAS: https://www.pnas.org/content/118/26/e2024292118
Online networks of vaccine confidence

Rathje et al., under review
Political rhetoric is key

- Polarization can undercut public health behavior, especially when identity leaders downplay risks
- Leaders who rally people around a common (“Us”) may be more effective in ensuring public health during a pandemic
Trust in science and medicine: Politics, misinformation, and health attitudes

Evidence Mobilization Action Collaborative
Rebuilding Public Trust in Biomedical Science & Research
Fall 2021 Webinar, National Academy of Medicine

Katherine Ognyanova • School of Communication & Information • Rutgers University
Email: katya@ognyanova.net • Web: www.kateto.net • Twitter: @ognyanova
The COVID States Project

- **20 surveys** April 2020-November 2021 (recruited by PureSpectrum)
- Covering all **50 states & DC** (N~300/500 per state per wave)
- Total respondents per wave: ~**20,000-25,000** (Quotas & weights for demographics)
- Social media data collection (consenting survey respondents)
- Browser add-on data

Research teams:
- Northeastern University
- Harvard University
- Rutgers University
- Northwestern University

Supported by funding from:
- National Science Foundation
- Knight Foundation
- Russell Sage Foundation
- Peterson Foundation

Any opinions, findings, or recommendations are those of the authors and do not necessarily reflect the views of the funding institutions.
Trust in social institutions
How much do you trust the following people and organizations to do the right thing to best handle the current coronavirus (COVID-19) outbreak?

Percent respondents who say "some" or "a lot"
Trust in Science and Medicine by Party

How much do you trust the following people and organizations to do the right thing to best handle the current coronavirus (COVID-19) outbreak? [Percent respondents who say "Some" or "A lot"]

<table>
<thead>
<tr>
<th>Organization</th>
<th>Total</th>
<th>Republican</th>
<th>Democrat</th>
<th>Independent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospitals and doctors</td>
<td>91%</td>
<td>88%</td>
<td>96%</td>
<td>87%</td>
</tr>
<tr>
<td>Scientists and researchers</td>
<td>85%</td>
<td>76%</td>
<td>94%</td>
<td>83%</td>
</tr>
<tr>
<td>Pharmaceutical companies</td>
<td>69%</td>
<td>64%</td>
<td>80%</td>
<td>62%</td>
</tr>
<tr>
<td>The CDC</td>
<td>75%</td>
<td>55%</td>
<td>92%</td>
<td>70%</td>
</tr>
<tr>
<td>The FDA</td>
<td>72%</td>
<td>57%</td>
<td>89%</td>
<td>66%</td>
</tr>
</tbody>
</table>

National sample, N = 21,079, Time period: 08/26/2021-09/27/2021

Source: The COVID-19 Consortium for Understanding the Public's Policy Preferences Across States (A joint project of: Northeastern University, Harvard University, Rutgers University, and Northwestern University) www.covidstates.org • Created with Datawrapper
## Trust in Science and Medicine by Race

How much do you trust the following people and organizations to do the right thing to best handle the current coronavirus (COVID-19) outbreak? [Percent respondents who say "Some" or "A lot"]

<table>
<thead>
<tr>
<th>Organization</th>
<th>African American</th>
<th>Asian American</th>
<th>Hispanic</th>
<th>White</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospitals and doctors</td>
<td>88%</td>
<td>94%</td>
<td>91%</td>
<td>92%</td>
</tr>
<tr>
<td>Scientists and researchers</td>
<td>83%</td>
<td>92%</td>
<td>86%</td>
<td>85%</td>
</tr>
<tr>
<td>Pharmaceutical companies</td>
<td>70%</td>
<td>77%</td>
<td>71%</td>
<td>68%</td>
</tr>
<tr>
<td>The CDC</td>
<td>80%</td>
<td>82%</td>
<td>76%</td>
<td>73%</td>
</tr>
<tr>
<td>The FDA</td>
<td>77%</td>
<td>79%</td>
<td>74%</td>
<td>71%</td>
</tr>
</tbody>
</table>

*National sample, N = 21,079, Time period: 08/26/2021-09/27/2021*

*Source: The COVID-19 Consortium for Understanding the Public's Policy Preferences Across States (A joint project of: Northeastern University, Harvard University, Rutgers University, and Northwestern University) www.covidstates.org • Created with Datawrapper*
Trust in Science and Medicine by Age

How much do you trust the following people and organizations to do the right thing to best handle the current coronavirus (COVID-19) outbreak? [Percent respondents who say "Some" or "A lot"]

<table>
<thead>
<tr>
<th></th>
<th>18 to 24</th>
<th>25 to 44</th>
<th>45 to 64</th>
<th>65 and over</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospitals and doctors</td>
<td>89%</td>
<td>87%</td>
<td>92%</td>
<td>97%</td>
</tr>
<tr>
<td>Scientists and researchers</td>
<td>85%</td>
<td>83%</td>
<td>85%</td>
<td>90%</td>
</tr>
<tr>
<td>Pharmaceutical companies</td>
<td>66%</td>
<td>63%</td>
<td>69%</td>
<td>82%</td>
</tr>
<tr>
<td>The CDC</td>
<td>78%</td>
<td>73%</td>
<td>74%</td>
<td>76%</td>
</tr>
<tr>
<td>The FDA</td>
<td>70%</td>
<td>70%</td>
<td>73%</td>
<td>77%</td>
</tr>
</tbody>
</table>

National sample, N = 21,079, Time period: 08/26/2021-09/27/2021
Source: The COVID-19 Consortium for Understanding the Public’s Policy Preferences Across States (A joint project of: Northeastern University, Harvard University, Rutgers University, and Northwestern University) www.covidstates.org • Created with Datawrapper
Trust in Science and Medicine by Education

How much do you trust the following people and organizations to do the right thing to best handle the current coronavirus (COVID-19) outbreak? [Percent respondents who say "Some" or "A lot"]

<table>
<thead>
<tr>
<th>Organization</th>
<th>Some high school</th>
<th>High School Graduate</th>
<th>Some College</th>
<th>Bachelor Degree</th>
<th>Graduate Degree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospitals and doctors</td>
<td>85%</td>
<td>89%</td>
<td>92%</td>
<td>94%</td>
<td>95%</td>
</tr>
<tr>
<td>Scientists and researchers</td>
<td>79%</td>
<td>81%</td>
<td>86%</td>
<td>90%</td>
<td>92%</td>
</tr>
<tr>
<td>Pharmaceutical companies</td>
<td>64%</td>
<td>68%</td>
<td>67%</td>
<td>72%</td>
<td>77%</td>
</tr>
<tr>
<td>The CDC</td>
<td>70%</td>
<td>71%</td>
<td>75%</td>
<td>78%</td>
<td>81%</td>
</tr>
<tr>
<td>The FDA</td>
<td>64%</td>
<td>69%</td>
<td>72%</td>
<td>77%</td>
<td>81%</td>
</tr>
</tbody>
</table>

National sample, N = 21,079, Time period: 08/26/2021-09/27/2021

Source: The COVID-19 Consortium for Understanding the Public's Policy Preferences Across States (A joint project of: Northeastern University, Harvard University, Rutgers University, and Northwestern University) www.covidstates.org • Created with Datawrapper
# Trust in Science and Medicine by Income

How much do you trust the following people and organizations to do the right thing to best handle the current coronavirus (COVID-19) outbreak? [Percent respondents who say "Some" or "A lot"]

<table>
<thead>
<tr>
<th>Organization</th>
<th>Under 50K</th>
<th>50K to under 100K</th>
<th>100K to under 150K</th>
<th>150K to under 200K</th>
<th>Over 200K</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospitals and doctors</td>
<td>89%</td>
<td>93%</td>
<td>93%</td>
<td>96%</td>
<td>95%</td>
</tr>
<tr>
<td>Scientists and researchers</td>
<td>83%</td>
<td>87%</td>
<td>88%</td>
<td>92%</td>
<td>91%</td>
</tr>
<tr>
<td>Pharmaceutical companies</td>
<td>67%</td>
<td>71%</td>
<td>72%</td>
<td>76%</td>
<td>76%</td>
</tr>
<tr>
<td>The CDC</td>
<td>73%</td>
<td>75%</td>
<td>76%</td>
<td>83%</td>
<td>78%</td>
</tr>
<tr>
<td>The FDA</td>
<td>70%</td>
<td>74%</td>
<td>76%</td>
<td>81%</td>
<td>79%</td>
</tr>
</tbody>
</table>

*National sample, N = 21,079, Time period: 08/26/2021-09/27/2021*

Source: The COVID-19 Consortium for Understanding the Public’s Policy Preferences Across States (A joint project of: Northeastern University, Harvard University, Rutgers University, and Northwestern University) www.covidstates.org • Created with Datawrapper
Predictors of public trust in doctors and hospitals

The numbers are coefficients from OLS regressions. Estimates are presented in red, confidence intervals in gray.
Outcome variable: Trust in doctors and hospitals to handle COVID-19.

Gender: Male (vs. Female)
Age: 25 to 44 (vs. 18-24)
Age: 45 to 64 (vs. 18-24)
Age: Over 65 (vs. 18-24)
Education (Low-High)
Income (Low-High)
Race: Asian (vs. White)
Race: Black (vs. White)
Race: Hispanic (vs. White)
Race: Other (vs. White)
Party: Democrat (vs. Republican)
Party: Independent (vs. Republican)
Residence: Suburban (vs. Rural)
Residence: Urban (vs. Rural)
Region: Northeast (vs. Midwest)
Region: South (vs. Midwest)
Region: West (vs. Midwest)

National sample, N = 21,079, Time period: 08/26/2021-09/27/2021
Source: The COVID-19 Consortium for Understanding the Public’s Policy Preferences Across States (A joint project of: Northeastern University, Harvard University, Rutgers University, and Northwestern University) www.covidstates.org • Created with Datawrapper
Predictors of public trust in scientists and researchers

The numbers are coefficients from OLS regressions. Estimates are presented in red, confidence intervals in gray. Outcome variable: Trust in scientists and researchers to handle COVID-19.

Gender: Male (vs. Female)
Age: 25 to 44 (vs. 18-24)
Age: 45 to 64 (vs. 18-24)
Age: Over 65 (vs. 18-24)
Education (Low-High)
Income (Low-High)
Race: Asian (vs. White)
Race: Black (vs. White)
Race: Hispanic (vs. White)
Race: Other (vs. White)
Party: Democrat (vs. Republican)
Party: Independent (vs. Republican)
Residence: Suburban (vs. Rural)
Residence: Urban (vs. Rural)
Region: Northeast (vs. Midwest)
Region: South (vs. Midwest)
Region: West (vs. Midwest)

National sample, N = 21,079, Time period: 08/26/2021-09/27/2021
Source: The COVID-19 Consortium for Understanding the Public's Policy Preferences Across States (A joint project of: Northeastern University, Harvard University, Rutgers University, and Northwestern University) www.covidstates.org • Created with Datawrapper
Misinformatuion and health attitudes
Trust is liked to **misperceptions**

Trust predicts **health** attitudes

Trust in **social ties vs. institutions**
COVID-19 vaccine misperceptions

COVID-19 vaccines can alter people’s DNA.

COVID-19 vaccines contain microchips that could track people.

COVID-19 vaccines contain the lung tissue of aborted fetuses.

COVID-19 vaccines can cause infertility, making it more difficult to get pregnant.
Vaccine misperceptions among Americans

[ Percent respondents who believe each false statement is accurate, inaccurate, or say they are not sure ]

- **The COVID-19 vaccines can cause infertility, making it more difficult to get pregnant.**
  - Accurate: 11%
  - Inaccurate: 52%
  - Not sure: 37%

- **The COVID-19 vaccines will alter people’s DNA.**
  - Accurate: 10%
  - Inaccurate: 63%
  - Not sure: 26%

- **The COVID-19 vaccines contain the lung tissue of aborted fetuses.**
  - Accurate: 9%
  - Inaccurate: 60%
  - Not sure: 32%

- **The COVID-19 vaccines contain microchips that could track people.**
  - Accurate: 8%
  - Inaccurate: 70%
  - Not sure: 22%

*National sample, N = 16,996, Time period: 06/09/2021-07/07/2021*

Source: The COVID-19 Consortium for Understanding the Public’s Policy Preferences Across States (A joint project of: Northeastern University, Harvard University, Rutgers University, and Northwestern University) www.covidstates.org • Created with Datawrapper
Misperceptions are linked to vaccine attitudes

COVID-19 vaccine status among respondents who said none, one, or more than one of the following false statements were accurate:
1. The COVID-19 vaccines will alter people’s DNA.
2. The COVID-19 vaccines contain microchips that could track people.
3. The COVID-19 vaccines contain the lung tissue of aborted fetuses.
4. The COVID-19 vaccines can cause infertility, making it more difficult to get pregnant.

<table>
<thead>
<tr>
<th>Vaccination Status</th>
<th>None</th>
<th>One</th>
<th>Two or more</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vaccinated</td>
<td>70%</td>
<td>43%</td>
<td>46%</td>
</tr>
<tr>
<td>May get vaccinated</td>
<td>15%</td>
<td>22%</td>
<td>13%</td>
</tr>
<tr>
<td>Vaccine resistant</td>
<td>15%</td>
<td>36%</td>
<td>42%</td>
</tr>
</tbody>
</table>

National sample, N = 16,996, Time period: 06/09/2021-07/07/2021

Source: The COVID-19 Consortium for Understanding the Public's Policy Preferences Across States (a joint project of: Northeastern University, Harvard University, Rutgers University, and Northwestern University) www.covidstates.org • Created with Datawrapper
Uncertainty also predicts vaccine attitudes

COVID-19 vaccine status among respondents who...
(1) Identify one or more misinformation statements about COVID-19 vaccines as true
(2) Do not identify misinformation statements as true, but select "Not sure" at least once
(3) Correctly identify all misinformation statements about COVID-19 vaccines as false

<table>
<thead>
<tr>
<th>Vaccinated</th>
<th>May get vaccinated</th>
<th>Vaccine resistant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Holds misperceptions</td>
<td>44%</td>
<td>17%</td>
</tr>
<tr>
<td>Uncertainty with no misperceptions</td>
<td>56%</td>
<td>20%</td>
</tr>
<tr>
<td>No uncertainty and no misperceptions</td>
<td>85%</td>
<td></td>
</tr>
</tbody>
</table>

National sample, N = 16,996, Time period: 06/09/2021-07/07/2021

Source: The COVID-19 Consortium for Understanding the Public's Policy Preferences Across States (A joint project of: Northeastern University, Harvard University, Rutgers University, and Northwestern University) www.covidstates.org • Created with Datawrapper
Vaccine misinformation on Twitter

Tweets about the following four false vaccine statements:
1. The COVID-19 vaccines will alter people’s DNA. / 2. The COVID-19 vaccines contain microchips that could track people.
3. The COVID-19 vaccines contain the lung tissue of aborted fetuses. / 4. The COVID-19 vaccines can cause infertility, making it more difficult to get pregnant.

[Shown as percent of all tweets about COVID-19 vaccines posted during the same time period]

Sample: 3,871,021 tweets about COVID-19 vaccines, 54,460 tweets about misinformation topics.
Source: The COVID-19 Consortium for Understanding the Public’s Policy Preferences Across States (A joint project of: Northeastern University, Harvard University, Rutgers University, and Northwestern University) www.covidstates.org • Created with Datawrapper
Predictors of vaccine resistance: Trust and misinformation

The numbers are standardized coefficients from logistic regressions. Estimates presented in red, confidence intervals in gray. Outcome variable: respondent reports they do not intend to get vaccinated.

Gender: Male
Age: 25 to 44 (vs. 18 to 24)
Age: 45 to 64 (vs. 18 to 24)
Age: 65+ (vs. 18 to 24)
Education: Some College (vs. high school or less)
Education: Bachelor Degree (vs. high school or less)
Education: Graduate Degree (vs. high school or less)
Income (min to max)
Race/Ethnicity: Asian (vs. White)
Race/Ethnicity: Black (vs. White)
Race/Ethnicity: Hispanic (vs. White)
Race/Ethnicity: Other (vs. White)
Party: Independent (vs. Democrat)
Party: Other (vs. Democrat)
Party: Republican (vs. Democrat)
Residential area: Suburban (vs. Rural)
Residential area: Urban (vs. Rural)
Region: Northeast (vs. Midwest)
Region: South (vs. Midwest)
Region: West (vs. Midwest)
Follow COVID-19 news (Not closely at all - Very closely)
Respondent had COVID-19
Family members had COVID-19

Trust in institutions (low to high)
Misperceptions about COVID-19 (0-4)
Uncertainty about COVID-19 (0-4)

National sample, N = 16,996, Time period: 06/09/2021-07/07/2021
Source: The COVID-19 Consortium for Understanding the Public's Policy Preferences Across States (A joint project of: Northeastern University, Harvard University, Rutgers University, and Northwestern University) www.covidstates.org - Created with Drawraper
Predictors of being vaccinated: Trust and misinformation

The numbers are standardized coefficients from logistic regressions. Estimates are presented in red, confidence intervals in gray. Outcome variable: respondent reports they have received at least one dose of the COVID-19 vaccine.

Gender: Male
Age: 25 to 44 (vs. 18 to 24)
Age: 45 to 64 (vs. 18 to 24)
Age: 65+ (vs. 18 to 24)
Education: Some College (vs. high school or less)
Education: Bachelor Degree (vs. high school or less)
Education: Graduate Degree (vs. high school or less)
Income (min to max)
Race/Ethnicity: Asian (vs. White)
Race/Ethnicity: Black (vs. White)
Race/Ethnicity: Hispanic (vs. White)
Race/Ethnicity: Other (vs. White)
Party: Independent (vs. Democrat)
Party: Other (vs. Democrat)
Party: Republican (vs. Democrat)
Residential area: Suburban (vs. Rural)
Residential area: Urban (vs. Rural)
Region: Northeast (vs. Midwest)
Region: South (vs. Midwest)
Region: West (vs. Midwest)
Follow COVID-19 news (Not closely at all - Very closely)
Respondent had COVID-19
Family members had COVID-19
Trust in institutions (low to high)
Misperceptions about COVID-19 (0-4)
Uncertainty about COVID-19 (0-4)

National sample, N = 16,996, Time period: 06/09/2021-07/07/2021
Source: The COVID-19 Consortium for Understanding the Public’s Policy Preferences Across States (A joint project of: Northeastern University, Harvard University, Rutgers University, and Northwestern University) www.covidstates.org • Created with Datawrapper
The role of **social media use**
Social media, trust, and misinformation

- Low trust and **news consumption** patterns
- Social media as a **misinformation** vector
- Associations with **anti-vaccine attitudes**
Vaccine misperceptions by news source

Respondents who said one or more of the following false statements were accurate:
1. The COVID-19 vaccines will alter people's DNA.
2. The COVID-19 vaccines contain microchips that could track people.
3. The COVID-19 vaccines contain the lung tissue of aborted fetuses.
4. The COVID-19 vaccines can cause infertility, making it more difficult to get pregnant.

[ Percent among respondents who said they got COVID-related news from each source in the past 24 hours ]

- Only Newsmax: 37%
- Multiple Sources (At least one of FB/Fox/Newmax): 32%
- Only Facebook: 22%
- Only Fox: 21%
- Only CNN: 15%
- No Provided Sources: 13%
- Only MSNBC: 11%
- Only Biden Administration: 10%
- Multiple Sources (None of FB/Fox/Newmax): 7%

Chart: National sample, N = 20,669. Time period: 06/09/2021-07/07/2021 • Source: The COVID-19 Consortium for Understanding the Public's Policy Preferences Across States (A joint project of: Northeastern University, Harvard University, Rutgers University, and Northwestern University) www.covidstates.org • Created with Datawrapper
Vaccination and news consumption

[ Percent among respondents who say they got COVID-related news from each source in the past 24 hours ]

<table>
<thead>
<tr>
<th>Source</th>
<th>Vaccinated</th>
<th>Might get vaccinated</th>
<th>Would not get vaccinated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Multiple Sources, (None of FB/Fox/Newmax)</td>
<td>87%</td>
<td>10%</td>
<td>10%</td>
</tr>
<tr>
<td>Only Biden Administration</td>
<td>79%</td>
<td>12%</td>
<td>9%</td>
</tr>
<tr>
<td>Only MSNBC</td>
<td>77%</td>
<td>15%</td>
<td>9%</td>
</tr>
<tr>
<td>Only CNN</td>
<td>73%</td>
<td>17%</td>
<td>10%</td>
</tr>
<tr>
<td>Multiple Sources, (At least one of FB/Fox/Newmax)</td>
<td>67%</td>
<td>21%</td>
<td>12%</td>
</tr>
<tr>
<td>No Provided Sources</td>
<td>62%</td>
<td>18%</td>
<td>21%</td>
</tr>
<tr>
<td>Only Fox</td>
<td>59%</td>
<td>19%</td>
<td>23%</td>
</tr>
<tr>
<td>Only Facebook</td>
<td>47%</td>
<td>29%</td>
<td>25%</td>
</tr>
<tr>
<td>Only Newmax</td>
<td>42%</td>
<td>18%</td>
<td>41%</td>
</tr>
</tbody>
</table>

National sample, N = 20,669, Time period: 06/09/2021-07/07/2021

Source: The COVID-19 Consortium for Understanding the Public's Policy Preferences Across States (A joint project of: Northeastern University, Harvard University, Rutgers University, and Northwestern University) www.covidstates.org • Created with Datawrapper
Predictors of vaccination: Media use

The numbers are coefficients from logistic regressions. Estimates presented in red, confidence intervals in gray. Outcome variable: respondent reports they do not intend to get vaccinated

National sample, N = 20,669, Time period: 06/09/2021-07/07/2021
Source: The COVID-19 Consortium for Understanding the Public's Policy Preferences Across States (A joint project of: Northeastern University, Harvard University, Rutgers University, and Northwestern University) www.covidstates.org • Created with Datawrapper
The End
MEDICAL
KNOWLEDGE
and the CHALLENGE
OF NEW MEDIA

Jeremy Greene, MD, PhD, FACP
Johns Hopkins University School of Medicine
Pharmaceutical Marketing and the New Social Media

Jeremy A. Greene, M.D., Ph.D., and Aaron S. Kesselheim, M.D., J.D., M.P.H.

Facebook and Twitter, the largest social media Web sites, have more than 350 million users worldwide, and surveys indicate that 60% of Americans turn first to the Internet when seeking health-related information. It is therefore surprising that the pharmaceutical and medical-device industries have been slow to establish a social media presence. The drug industry allocated less than 4% of the more than $4 billion it spent on direct-to-consumer advertising to Internet outlets in 2008, and only a tiny fraction of that was for social networking sites. In the next year, however, the proportion may change substantially.

Since the Pure Food and Drug Act was passed in 1906, control by the Food and Drug Administration (FDA) over drug labels has been one of its most powerful tools for protecting the public’s health. To encourage appropriate use of prescription drugs, the FDA has sought to ensure that promotional statements make claims about approved indications only and neither overstate the benefits nor underestimate the risks. A major concern has been finding ways to ensure “fair balance,” with adequate attention given to information about risks as well as benefits. When this balance is not achieved, inappropriate promotional statements can contribute to misuse of drugs, with dangerous consequences.

As communications media have evolved, manufacturers have tended to wait for the FDA to establish explicit codes of acceptable marketing practices before devoting substantial resources to a new medium. Direct-to-consumer advertising in print media proceeded tentatively until the FDA issued a guidance document in 1985 establishing a standard format for providing a “brief summary” of risks. Prescription-drug advertising in broadcast media was similarly minimal until the FDA’s guidance revised the definition of “adequate” risk information in 1997, and again in 1999, to permit broadcast media to include references to a toll-free number or Web site where consumers could obtain more detailed descriptions of a product’s adverse effects. In the wake of these FDA actions, spending on direct-to-consumer advertising mushroomed from $779 million in 1996 to $1.3 billion in 1998 and to over $4 billion in 2008.

In November 2009, the FDA...
Ivermectin
(ivermectin)
INJECTION FOR CATTLE AND SWINE
How Ivermectin Became The New Focus Of The Anti-Vaccine Movement

Facebook groups promoting ivermectin as a Covid-19 treatment continue to flourish.

Facebook has become more aggressive at enforcing its coronavirus misinformation policies in the past year. But the platform remains a popular destination for people discussing how to acquire and use ivermectin, a drug typically used to treat parasitic worms, even though the Food and Drug Administration has warned people against taking it to treat Covid-19.
Demand Surges for Deworming Drug for Covid, Despite Scant Evidence It Works

Prescriptions for ivermectin have jumped to more than 88,000 per week, some pharmacists are reporting shortages and people are overdosing on forms of the drug meant for horses.
Why You Should Not Use Ivermectin to Treat or Prevent COVID-19
You are not a horse. You are not a cow. Seriously, y'all. Stop it.

Why You Should Not Use Ivermectin to Treat or Prevent COVID-19
Using the Drug ivermectin to treat COVID-19 can be dangerous and even lethal. The FDA has not approved the drug for that purpose.

fda.gov
politics of trust and distrust in scientific knowledge

Alaska Legislature

Several Republican Alaska lawmakers push for easier access to ivermectin to ward off COVID

By Associated Press
Updated: October 12, 2021
Published: October 12, 2021

Ohio judge orders COVID-19 patient be treated with ivermectin — which no agency recommends

By Patrick Reilly
August 30, 2021 7:10pm Updated
Right-wing media pushed a deworming drug to treat Covid-19 that the FDA says is unsafe for humans

By Oliver Darcy, CNN Business
Updated 1:50 PM ET, Mon August 23, 2021
politics and the mediation of scientific knowledge
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old media, new media, and political polarization
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ideology and skepticism before social media: the case of Laetrile
Laetrile and the circulation of conspiracy logics

Backers of Laetrile Charge a Plot Is Preventing the Cure of Cancer

By Richard D. Lyons
Special to The New York Times

WASHINGTON, July 12—The leaders of the laetrile movement took their crusade to legalize the purported anti-cancer drug to a Senate hearing today, charged that an international conspiracy was preventing "the cure of cancer and heard themselves called purveyors of false hopes.

The hearing lasted four hours and was marked by raised voices and finger-pointing.

Senator Edward M. Kennedy, the Massachusetts Democrat who is leading the inquiry, charged that the laetrile movement was headed by "slick salesmen who would offer a false sense of hope" to people suffering from cancer.

Mr. Kennedy's Senate Subcommittee on Health and Scientific Research heard 10 other witnesses testify that laetrile was useless in the treatment of anything and that the three witnesses who supported the substance had made large amounts of money from its sale.

This was denied by Dr. John A. Richardson of Albany, Calif., the nation's most widely publicized laetrile doctor; Ernst T. Krebs Jr. of San Francisco, who has frequently been identified as the "guru" of the laetrile movement, and Robert Bradford of Los Altos, Calif., president of the largest group seeking legalization of laetrile, the Committee for Freedom of Choice in Cancer Therapy Inc.

Conspiracy Is Charged

Each of the three has been convicted on charges relating to the use and sale of the drug.
Laetrile and the politics of therapeutic choice

Action is Considered Because a Growing Number of States Are Legalizing Use of the Drug

By JANE E. BRODY

The National Cancer Institute is considering the first human tests of the highly controversial drug laetrile, the institute's acting director said yesterday.

Although there is still no scientific evidence that laetrile is effective against cancer in animals or in test tubes, the director, Dr. Guy Newell, said that the possibility of a clinical trial was being "seriously considered" because a growing number of states were legalizing use of the drug.

"More and more people are being exposed to it, and we need data one way or the other to give to responsible physicians and state health departments," he said. He added, however, that there had been no change in the institute's "position" on laetrile; the drug is still considered ineffective as a cancer treatment.

If the laetrile trials are done, it would not be the first time the institute had tested in patients drugs that provided no evidence of anticancer activity in animals. Several such drugs that physicians in other countries have said are effective in cancer patients have been tested in patients here, Dr. Newell said. However, none of them proved to have any effect in American cancer patients.

An epidemiologic study made in which perhaps 10,000 of the patients who have been treated with laetrile are traced and a study made of the kinds of cancers they had, what other treatments they received and their survival rate.

The data derived from the various studies be reviewed by a committee of scientists and lay people to counter claims of possible bias.

If the results of the studies show no effect of laetrile, Dr. Thomas said, that "wouldn't change the minds of the zealots running the laetrile market, but it would be very important to get good hard facts for the benefit of practicing physicians and cancer patients."

Recognized Therapies Retained

Dr. Newell said that the studies, if done, would not jeopardize the well-being of participating cancer patients. Rather than deprive some patients of cancer therapies recognized as effective, the patients would receive accepted treatment and laetrile or a placebo in addition.
Laetrile as an ideological divide that spanned conventional political divides
persistence of popular appeal and political press
in spite of official denials of efficacy

WHY
LAETRILE
WON'T GO
AWAY

Is the Laetrile controversy an American tragicomedy in the theater of the absurd, or is it opening up new ways of coping with patients' needs?

By Lee Edson

Donald S. Fredrickson, head of the National Institutes of Health, spoke first. He was followed by Dr. Donald Kennedy, Commissioner of the Federal Food and Drug Administration, who rules over the approval of cancer drugs; Dr. Lewis Thomas, poet-president of Memorial Sloan-Kettering Cancer Center, and Dr. Joseph Ross of the University of California at Los Angeles, a veteran fighter against cancer quackery. Each witness came with a prepared speech, which, in effect, declared that there was no evidence that Laetrile has any leg to cancer surgery, was by turns compassionate and stern, puzzled and authoritative, critical and firm. Finally, he looked hard at the representatives of both sides and said he'd make them a proposition. “Let us do human tests,” he urged. “If it turns out that the results are affirmative, you will find no finer defender of Laetrile than myself.” Then, turning to the pro-Laetrilists, he added: “If they prove to be negative, will you agree to desist telling the public about the prevention and control of cancer through Laetrile?”
laetrile (1977) and ivermectin (2021)

common features of trust and distrust

- profound skepticism of science-based regulation of a popular drug
- unbridgeable divide between scientific, regulatory, and expert knowledge on the one hand, and popular testimonials on the other
- widespread denial of the role of clinical trials in demonstrating efficacy
- critique of mainstream media as complicit in a medical-industrial system
- conspiracy theory in which the FDA, the AMA, and the NIH are colluding in order to protect a higher-priced approved agent
- heroic figures of iconoclastic physicians penalized for prescribing cheaper, putatively effective therapeutic agent
- substantial political controversy involving executive, legislative, and judicial branches of both state and federal governments
what’s new about new social media?

media content is user generated rather than professional

velocity and scale of media circulation is unprecedented

polarization of issues is directly incentivized by media platforms, and has become a driver of revenue

ability to fact-check, and to monitor fact-checking process, compromised by sprawling nature of the media itself

increased linking of media sources with pre-existing political ideology creates “echo chambers” in which the framing of factual knowledge is radically different and non-overlapping
In Poland’s politics, a ‘social civil war’ brewed as Facebook rewarded online anger

An independent data analysis of major political parties in Poland that was conducted for The Post showed that after 2018, negative messages were more likely to receive a high number of shares.
Whistle-Blower Unites Democrats and Republicans in Calling for Regulation of Facebook

Frances Haugen spent hours detailing to lawmakers how the social network harms young people. Facebook disagreed with her testimony but said new rules for the internet were long overdue: ‘It is time for Congress to act.’

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SOCIAL MEDIA

Covid-19: Who fact checks health and science on Facebook?

Overwhelming pressure from governments and the public has compelled social media platforms to take unprecedented action on what users share online in the pandemic. But who fact checks the fact checkers? Laurie Clarke reports

Laurie Clarke freelance journalist

In a move likened to the way governments have assumed emergency powers in response to the covid pandemic, Facebook has removed 16 million pieces of its content and added warnings to around 67 million. YouTube has removed more than 850,000 videos related to “dangerous or misleading covid-19 medical information.”

While a portion of that content is likely to be wilfully wrongheaded or vindictively misleading, the pandemic is littered with examples of scientific opinion that have been caught in the dragnet—resulting in their removal or de-prioritisation, depending on the platform and context. This underscores the difficulty of defining scientific truth, prompting the bigger question of whether social media platforms such as Facebook, Twitter, Instagram, and YouTube should be tasked with this at all.

“I think it’s quite dangerous for scientific content to be labelled as misinformation, just because of the way people might perceive that,” says Sander van der Linden, professor of social psychology in society at Cambridge University, UK. “Even though it might fit under a definition of misinformation in a very technical sense, I’m not sure if that’s the right way to describe it more generally because it could lead to greater politicisation of science, which is

But the pandemic has seen a shifting patchwork of criteria employed by these companies to define the boundaries of misinformation. This has led to some striking U-turns: at the beginning of the pandemic, posts saying that masks helped to prevent the spread of covid-19 were labelled “false”; now it’s the opposite, reflecting the changing nature of the academic debate and official recommendations.

Twitter manages its fact checking internally. But Facebook and YouTube rely on partnerships with third party fact checkers, convened under the umbrella of the International Fact-Checking Network—a non-partisan body that certifies other fact checkers, run by the Poynter Institute for Media Studies, a non-profit journalism school in St Petersburg, Florida. Poynter’s top donors include the Charles Koch Institute (a public policy research organisation), the National Endowment for Democracy (a US government agency), and the Omidyar Network (a “philanthropic investment firm”), as well as Google and Facebook. Poynter also owns the Tampa Bay Times newspaper and the high profile fact checker PolitiFact. The Poynter Institute declined The BMJ’s invitation to comment for this article.

For scientific and medical content the International Fact-Checking Network involves little known outfits
Is the proliferation and politicization of “fake news” in the 21st century truly unprecedented?
19th c. partisan papers & 21st c. echo chambers
what’s new about new social media?

- Media content is user generated rather than professional.
- Velocity and scale of media circulation is unprecedented.
- Polarization of issues is directly incentivized by media platforms, and has become a driver of revenue.
- Ability to fact-check, and to monitor fact-checking process, is compromised by the sprawling nature of the media itself.
- Increased linking of media sources with pre-existing political ideology creates “echo chambers” in which the framing of factual knowledge is radically different and non-overlapping.
MEDICAL KNOWLEDGE and the CHALLENGE OF NEW MEDIA

Jeremy Greene, MD, PhD, FACP
Johns Hopkins University School of Medicine
Strategies & Solutions for Closing the Trust Gap
Evidence Mobilization Action Collaborative

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