Improving health through effective communication: Lessons from research on misinformation

Wen-Ying Sylvia Chou, PhD, MPH
National Cancer Institute

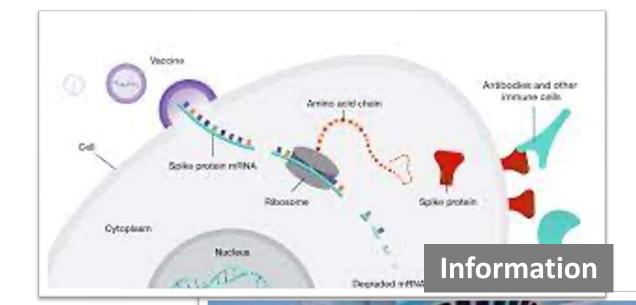
AAHB

Savannah, GA, April, 2024



Agenda

- Health communication challenges in an evolving media ecosystem
- Current research on health/science misinformation
- Lessons learned for communication practice and health behavior science





Challenges: Trust in science

- Measuring trust
- Causes of mistrust/distrust
- Trustworthiness: Building and sustaining trust
- Changes due to social polarization

JOURNAL ARTICLE

Citizen attitudes toward science and technology, 1957–2020: measurement, stability, and the Trump challenge

Jon D Miller ™, Belén Laspra, Carmelo Polino, Glenn Branch, Mark S Ackerman, Robert T Pennock

Trust in Scientific Expertise				
Trust Index	2016	2020	Change	
Very Low	1%	6%	+5	
Low	2	9	+7	
Moderate/DK/NA	74	42	-32	
High	16	30	+14	
Very High	7	13	+6	
N =	2,108	2,736	-	

The evolving social media landscape

- Regulatory efforts
 - Access (e.g., for minors)
 - Restrictions or bans on certain platforms
 - EU Digital Services Act (DSA) on content moderation, user privacy, and transparency
- Platforms practices
 - Content moderation rules and enforcements;
 algorithmic manipulation; account verification
 - Data access for researchers
- Ongoing litigation
- Use of AI tools
 - LLMs (e.g., ChatGPT)
 - Deep fake images/videos

JAMA Oncology

Use of Artificial Intelligence Chatbots for Cancer Treatment Information

Shan Chen, MS¹; Benjamin H. Kann, MD¹; Michael B. Foote, MD²; et al

WORLD

Fake photos of Pope Francis in a puffer jacket go viral, highlighting the power and peril of AI



Generative AI Tools for health communication

- Unclear impact on information environment
- LLMs: not ready for prime time
 - Generally accurate cancer information but inconsistent output and cannot handle complex questions
 - A promising tool for patient education
- Text-to-image tools:
 - Concerns related to bias, stereotypes, misinformation, and fraud
 - Current NCI study

JOURNAL ARTICLE

Using ChatGPT to evaluate cancer myths and misconceptions: artificial intelligence and cancer information 3

Skyler B Johnson, MD , Andy J King, PhD, Echo L Warner, PhD, Sanjay Aneja, MD, Benjamin H Kann, MD, Carma L Bylund, PhD

JNCI Cancer Spectrum, Volume 7, Issue 2, April 2023, pkad015, https://doi.org/10.1093/jncics/pkad015

MEDPAGETODAY°

Perspectives > Second Opinions

What Does AI Say About the Claims on Ivermectin for COVID?

— We put the technology to the test

by Daniel Teres, MD, Jane Oppenlander, PhD, and Martin A. Strosberg, MPH, PhD February 4, 2024



"A cancer patient", generated by Stable Diffusion

"Misinfodemics": A perfect storm in health communication?

- Health and science content is ubiquitous
- Information silos and echo chambers on social media
- Falsehoods spread faster than truths and garner more engagement and emotional reactions
- Credible information is often complex, nuanced, evolving, conflicting and uncertain
- Disinformation campaigns erode a sense of consensus and drive divisions
- Emotions, politics, and ideologies all at play

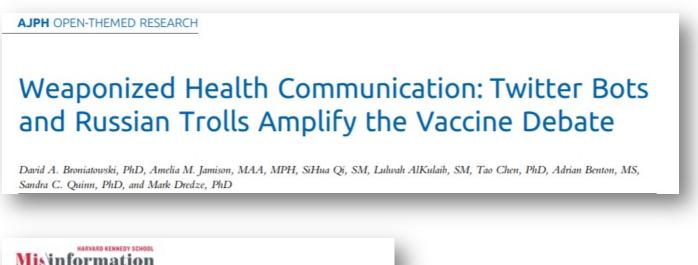
What to measure, and how to do it?

- Hype and trends vs. reality across different information silos
- Methodological limitations of web panels, survey, focus groups, and interviews
- Perceptions and awareness vs. actual exposure
- Dynamic measures/information lifecycle/overtime
- What information do people say/think they need vs. what they actually need to make informed health decisions
- Impacts of health communication

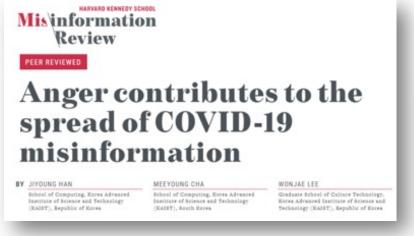
Potential impact of misinformation

- Prevention, screening, treatment and follow-up (e.g., delays in care, unproven treatment)
- Patient-provider relationship (e.g., exposure to conspiracy theories reduces trust in medical system)
- Frayed social fabric/damaged social cohesion
- Psychological and emotional effects (e.g., anxiety, confusion)
- Financial loss (e.g., "miracle" products)
- Distrust and shifting public discourse
- Exacerbation of health disparities
 - Levels of susceptibility
 - Non-English media and content

Observational research on misinformation







Home » American Journal of Public Health (AJPH) » May 2021

Association of "#covid19" Versus "#chinesevirus" With Anti-Asian Sentiments on Twitter: March 9–23, 2020

Yulin Hswen ScD, MPH, Xiang Xu MS, Anna Hing MPH, Jared B. Hawkins PhD, John S. Brownstein PhD, and Gilbert C. Gee PhD

- Science denialism
- Politicized topics and chilling effects on researchers and health care workforce

Debunking

- Correcting/debunking is generally effective, but less so when there is a prolonged "debate"
- Empathetic refutations in patientprovider encounters:
 - Elicit concerns -> affirm values -> refute -> provide facts
- When/how to correct—context matters

JOURNAL OF MEDICAL INTERNET RESEARCH

Mourali & Drake

Original Paper

The Challenge of Debunking Health Misinformation in Dynamic Social Media Conversations: Online Randomized Study of Public Masking During COVID-19

The Empathetic Refutational Interview to Tackle Vaccine Misconceptions: Four Randomized **Experiments**

Dawn Holford M. Philipp Schmid, Angelo Fasce, Stephan Lewandowsky

Perspective



The COVID-19 Misinfodemic: **Moving Beyond Fact-Checking**

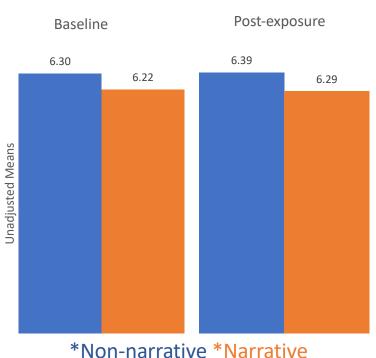
© 2020 Society for Public Health Education sagepub.com/journals-permissions DOI: 10.1177/1090198120980675 journals.sagepub.com/home/heb SSAGE

Health Education & Behavior

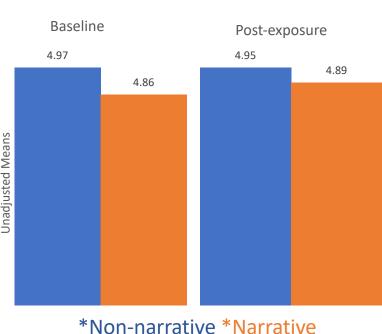
Wen-Ying Sylvia Chou, PhD 10, Anna Gaysynsky, MPH20, and Robin C. Vanderpool, DrPH

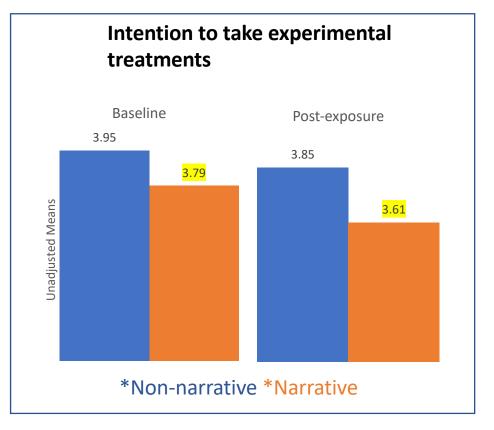
Can narratives change minds in the midst of a public health emergency?

Intention to social distance



Intention to receive COVID-19 vaccination





> Am J Health Promot. 2022 Jan 27;8901171221075612. doi: 10.1177/08901171221075612. Online ahead of print.

Effects of narrative messages on key COVID-19 protective responses: Findings from a randomized online experiment

Irina A Iles ¹, Anna Gaysynsky ¹, Wen-Ying Sylvia Chou ²

Inoculation ("Prebunking")

- Informing people about how they might be misled or manipulated may reduce susceptibility
 - Warning of attack -> preemptive refutation -> micro-dose of misinformation
- While promising, most studies are online experiments.
 How to deliver inoculation interventions in real world settings, at scale?
 - A field study of short prebunking videos as YouTube ads improve people's ability to identify manipulation techniques under realworld conditions
 - In 2022 Google showed prebunking video ads against false claims about Ukrainian refugees. Videos were seen 38 million times across platforms. Ad viewers were more able to identify misinformation techniques and less likely to spread false claims
- From text-based to visual and multimodal misinformation





Google to expand misinformation 'prebunking' in Europe

By DAVID KLEPPER February 13, 2023

*Ads shown in: Poland, the Czech Republic and Slovakia

Research priorities in health misinformation

Improve Surveillance



- Information poverty/communities most at risk
- Real-time monitoring of rumors and motivations behind their spread
- Understudied platforms; visual content; implied misinformation
- Dynamics (misinformation lifecycle and cross-platform movement)

Focus on Consequences



- Linking exposure to outcomes, including:
 - Attitudes (e.g., apathy, confusion, mistrust)
 - Behaviors
 - Relationships (e.g., patient-provider)
 - Decision-making
 - Cognitive biases
 - Emotions (e.g., anger, fear)
 - Values, ideology, and identity
 - Trust

Understand and respond to psychological drivers



Innovative Intervention Development



- Corrections and prebunking at scale
- Health/science/media literacy initiatives
- Multi-sector policies on content moderation
- Targeting the most vulnerable

Research Article

Mitigating Health and Science Misinformation: A Scoping Review of Literature from 2017 to 2022

Kathryn Heley, Wen-Ying Sylvia Chou 🔀 📵, Heather D'Angelo, Nicole Senft Everson, Abigail Muro, Jacob A. Rohde & ...show all

Published online: 27 Mar 2024

Methods	
Search	Keyword search in 4 databases for English articles
Inclusion criteria	a) Empirical datab) Health- or science-related misinformationc) Tests a mitigation strategyd) Measures misinformation-related outcomes or effects
Final Sample	115 publications representing 148 studies

A scoping review on mitigation strategies: Results

Codes	Results
Common Topics	COVID-19 (k=48), vaccines (k=45), and climate change (k=25)
Study location	United States (k=71), Australia (k=9), United Kingdom (k=7), and Germany (k=7); few studies were focused on LMICs
Samples	Online panels or crowdsourcing platforms (k=91)
Populations of focus	Very few on susceptible populations [older adults ($k=3$), politically conservative ($k=1$), or individuals with low educational attainment ($k=1$)]
Strategies tested	 Correction (k=97/148; 65.5%) Education/health literacy (k=39/148; 26.4%) Prebunking (k=24/148; 16.2%) Others
Outcomes	 76 positive results 17 null results 68 reported mixed results

Takeaways for communication practice

Key Findings	Implications/Future Directions
Interventions promising for emerging health topics; "backfire effects" are minimal	 Scaling "low touch" interventions (e.g., brief videos, fact-checks) in limited resource settings Disseminating tested intervention strategies through established infrastructure (hospitals, clinics, payors)
No panacea exists to mitigate misinformation and generate sustained change	 Exploring the impact of multilevel interventions (e.g., a combination of individual, interpersonal, organizational, community, societal level interventions) Using multiprong strategies that address the individual and their information environment

Lessons learned from misinformation research

- Relationships matter (good messages are not enough)
 - Sources, messengers, echo chambers
- Research needs to be more useful for communication practice
 - Value of translational science
 - Collaboration outside silos and sustainable infrastructure
 - Ready-made practical tips

Establish/build relationships

Commentary

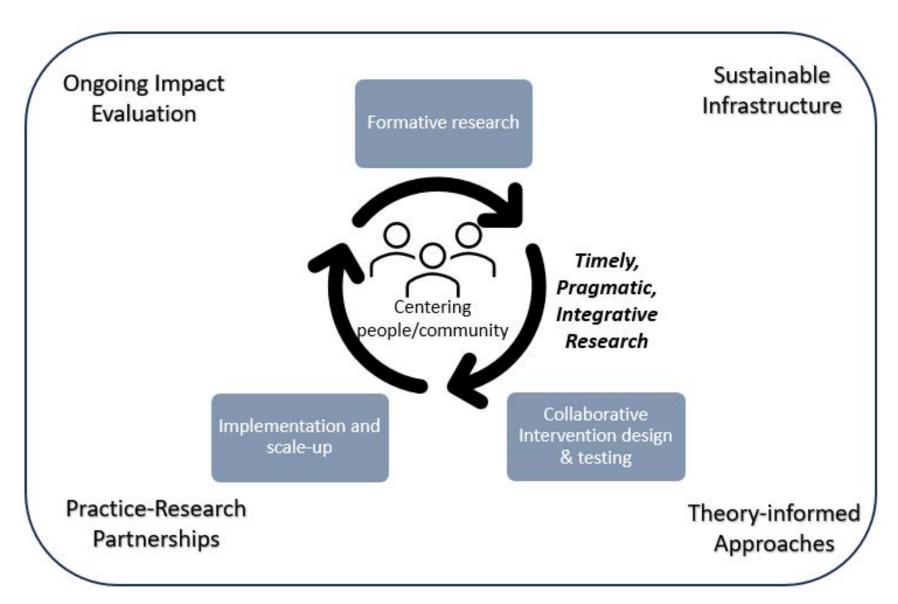
A relationship-centered approach to addressing mistrust

Wen-Ying Sylvia Chou **■** & Anna Gaysynsky

Published online: 21 Sep 2023

- Better messaging alone is insufficient when challenged by polarization and 'outrage politics'
- Strategies to consider:
 - Make personal connections (e.g. being vulnerable, personal disclosure)
 - Recognize and value lived experiences
 - Acknowledge power dynamics and historical injustices
 - Hire staff from community
 - Facilitate the formation of supportive relationships
 - Leverage existing trusted social relationships
 - Support healthcare professionals in improving relationships with patients and increasing interpersonal trust (e.g., trauma-informed care)
- Assess relationship-related factors (e.g., trust, social capital) over time

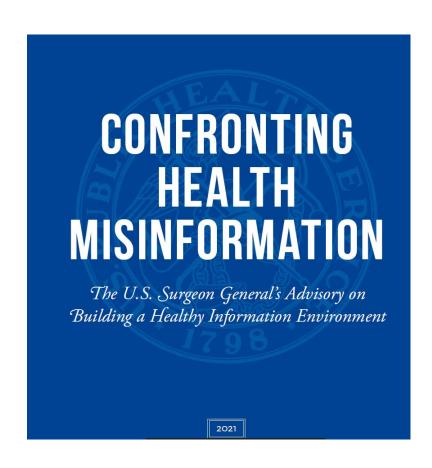
A translational health communication research framework



Chou, Gaysynsky, and Tan (2024)

Working together

- Individuals
- Communities (e.g., faith leaders, community-based organizations, libraries)
- Educators
- Health professionals and organizations
- Journalists and media organizations
- Researchers
- Technology platforms
- Governments (local, state, federal)
- Policy makers
- Foundations / non-profits
- Influencers / opinion leaders



Health communication research to meet the current moment



Communication Science

Viewpoin

September 7, 2023

Health Information in 2023 (and Beyond)
Confronting Emergent Realities With Health

William M. P. Klein, PhD1; Wen-Ying Sylvia Chou, PhD1; Robin C. Vanderpool, DrPH1

Science Communication informs the public about scientific findings (may or may not have direct application to their lives)

 E.g., Cancer genetics experts share research results in an engaging way

VS.

Health communication advances the health and well-being of individuals/populations (may or may not explain the research)

• E.g., campaign to educate parents about risk of SIDS and promote safe sleep practices

- 1. Involve HC science early on in design and program planning
- 2. Include communication practitioners
- 3. Assess how and where people share and receive health information
- 4. Address information people encounter in daily lives and manage uncertainty
- 5. Attend to disparities in ability to access, process, and act on information
- 6. Overcome challenges in social and technologic environment (e.g., social media data access)

Practical tips

- Leverage a broad range of credible and trusted sources
- Clear and accurate topline message
 - Public's tendency to focus on the headline or visuals
- Target techniques and motivations of manipulation instead of content
- Plan to deal with unintended consequences
 - Cherry-picking, findings being called into question, lost nuances and caveats
- Healthy skepticism vs. cynicism
 - Among science deniers
- Avoid leaving an information vacuum or ceding the information environment to others
- Discuss the scientific process: context, source and meaning of data
- Avoid false balance and avoid giving falsehoods more oxygen
- More information is <u>not</u> the solution
- Counter themes & tropes, rather than fact-checking individual anecdotes
- Science and health literacy initiatives
- Uncertainty communication

Extra: Definitions, boundaries

Health misinformation: any health-related claim of fact that is false, inaccurate, or misleading according to the best available evidence at the time (Chou et al. 2020, OSG 2021, Kington et al. 2021)

Disinformation: a coordinated or deliberate effort to spread misinformation in order to gain money, power, or reputation.

Additional considerations:

- Intent of sharing
- Impact of exposure
- **Medium** & **format** of communication
- A business model for financial and political gains

"Trust and Misinformation in the Age of Social Media"

An invitation-only working group meeting on August 23-24, 2018, at the NCI Shady Grove Campus leveraged scientific expertise from diverse disciplines and sectors (e.g., journalism, computer science, and health communication) to develop a research agenda for **understanding and addressing cancer-related misinformation on social media**

This Issue Views 14,873 | Citations

Viewpoint

December 18, 2018

JAMA Network™

Addressing Health-Related Misinformation on Social Media

Wen-Ying Sylvia Chou, PhD, MPH¹; April Oh, PhD¹; William M. P. Klein, PhD²

JAMA. 2018;320(23):2417-2418. doi:10.1001/jama.2018.16865

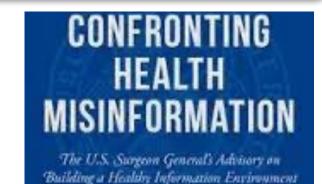
American Journal of Preventive Medicine

CURRENT ISSUES

Misinformation as a Misunderstood Challenge to Public Health

Brian G. Southwell, PhD, ^{1,2,3} Jeff Niederdeppe, PhD, ⁴ Joseph N. Cappella, PhD, ⁵ Anna Gaysynsky, MPH, ⁶ Dannielle E. Kelley, PhD, ⁶ April Oh, PhD, ⁶ Emily B. Peterson, PhD, ⁶ Wen-Ying Sylvia Chou, PhD





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Identifying Credible Sources of Health Information in Social Media: Principles and Attributes

Raynard S. Kington, MD, PhD, MBA, Phillips Academy in Andover; Stacey Arnesen, MS, National Library of Medicine; Wen-Ying Sylvia Chou, PhD, MPH, National Cancer Institute; Susan J. Curry, PhD, The University of Iowa; David Lazer, PhD, Northeastern University; and Antonia M. Villarruel, PhD, RN, FAAN, University of Pennsylvania