

Overcoming the challenge of online health misinformation in cancer communication

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National Cancer Policy Forum Workshop on
Health Literacy and Communication Strategies in Oncology
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False and inaccurate information about cancer on social media

The Washington Post
Democracy Dies in Darkness

Key Drivers:

- Viral and siloed nature of SM
- A sense of vulnerability and desire for hope/optimism
- Low trust in providers
- Limited health literacy

Style

They turn to Facebook and YouTube to find a cure for cancer — and get sucked into a world of bogus medicine

THE WALL STREET JOURNAL.



TECH

Facebook, YouTube Overrun With Bogus Cancer-Treatment Claims

Tech platforms are tweaking their algorithms and cutting off advertising for pages, videos promoting scientifically dubious information

Major Challenges to cancer communication

- Oncology/cancer control efforts are increasingly challenged by:
 - Growing amount of inaccurate or false information
 - Online/social media as primary source of information, including health related information
 - Declining trust in social institutions (e.g., medical system and scientific expertise)
- Disseminating evidence-based information AND addressing misinformation
- Role of health communication science in developing optimal approaches
 - Timing
 - Channels
 - Targeting/tailoring
 - Health/science literacy considerations
 - Building and leveraging trust
 - Multi-level and multi-sector approaches: government (Federal, state and local), journalists, clinical systems, clinicians, technology platforms, other industry, and social scientists....

Working definition of health misinformation

“A health-related claim of fact that is currently false due to a lack of scientific evidence” (Chou 2018 JAMA)

- This definition focuses on the claim itself and not the intent, effect, or context
- Some claims of fact that are NOT false may equally have negative impact
- Consider images/visuals, videos, memes, etc.

Social media proliferation: What's the bottom line for health?



Benefits

- Social support
- Targeted & tailored information sharing
- Equitable health information access
- Real-time outreach & engagement
- Peer-to-peer interactions
- Low-cost interventions



Risks

- Cyber-aggression
- Information silos and echo chambers
- Risks in limited health literacy communities
- Rapid spread of anecdotes and falsehoods
- Lack of expert gatekeeping
- Low-cost for “bad” information

Misinformation on social media

POLICY FORUM | SOCIAL SCIENCE

The science of fake news

David M. J. Lazer, Matthew A. Baum, Yochai Benkler, Adam J. Berinsky, Kelly M. Greenhill, Filippo Menczer,

AJPH OPEN-THEMED RESEARCH

Weaponized Health Communication: Twitter Bots and Russian Trolls Amplify the Vaccine Debate

David A. Broniatowski, PhD, Amelia M. Jamison, MAA, MPH, SiHua Qi, SM, Luhvah AlKulaib, SM, Tao Chen, PhD, Adrian Benton, MS, Sandra C. Quinn, PhD, and Mark Dredze, PhD

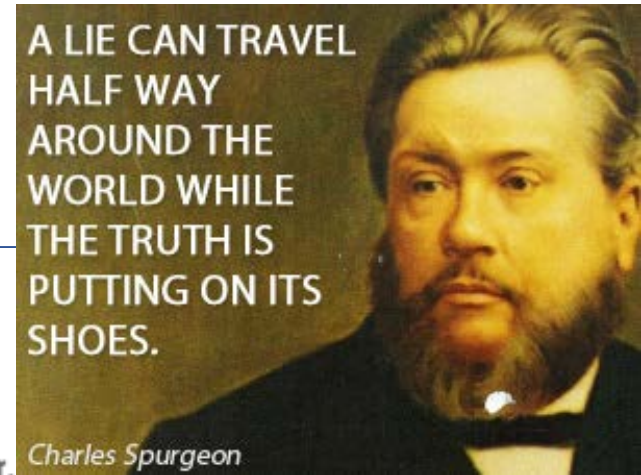
HEALTH MISINFORMATION VIA SOCIAL MEDIA

The Case of Vaccine Safety on Pinterest

Jeanine Guidry and Marcus Messner

The spread of fake news by social bots

Chengcheng Shao, Giovanni Luca Ciampaglia, Onur Varol, Alessandro Flammini, and Filippo Menczer



REPORT

The spread of true and false news online

Soroush Vosoughi¹, Deb Roy¹, Sinan Aral^{2,*}

RESEARCH

POLITICAL SCIENCE

Fake news on Twitter during the 2016 U.S. presidential election

Nir Grinberg^{1,2*}, Kenneth Joseph^{3*}, Lisa Friedland^{1*}, Briony Swire-Thompson^{1,2}, David Lazer^{1,2,†}

Cancer-related misinformation

 11  Like 3  Visit site  Send  Share



Found on [healthimpactnews.com](#)

 **Health Impact News** • 2 years ago
Inventor of Rotavirus Vaccine Wants To End Parental Exemptions For School Vaccinations



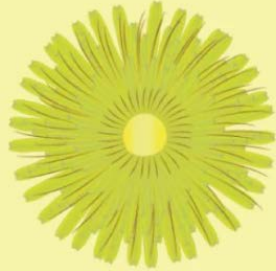
Ditch the Toxic Sunscreen; Use Coconut Oil Instead

[See More](#)

by haveeseen

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).



Jim Carrey 
@JimCarrey

 Follow

They say mercury in fish is dangerous but forcing all of our children to be injected with mercury in thimerosal is no risk. Make sense?

9:13 PM - 30 Jun 2015



NaturalNews.com
about a year ago



If you pay attention to the mainstream narrative, you'll begin to see a pattern...



The mainstream media lies about vaccines just like the...

One of the "mainstream" media's narratives since President-elect Donald J. Trump...

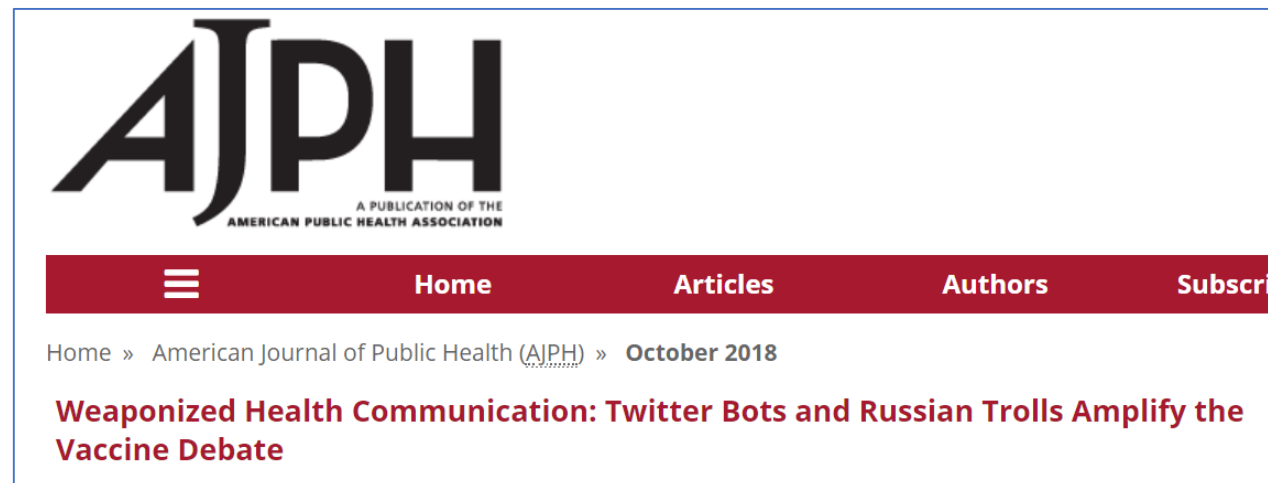
[WWW.NATURALNEWS.COM](#)

**RETIRED PHARMACY CHIEF SAID:
THE WORLD NEEDS TO KNOW,
ALKALINE WATER KILLS CANCER
THIS IS HOW TO PREPARE IT!**



Case Study: Vaccination “debate” on Twitter (Broniatowski 2018)

- Pervasive anti-vaccine sentiment, perpetuated by the emergence of bots, trolls, and divisive disinformation campaigns
- “Accounts masquerading as legitimate users create false equivalency, **eroding public consensus** on vaccination.”
- “Vaccine-hesitant parents are more likely to turn to the Internet for information and **less likely to trust health care providers and public health experts** on the subject. Exposure to the vaccine debate may suggest that there is **no scientific consensus**, shaking confidence in vaccination.”



Developing A Pragmatic Research Agenda

Focus on Consequences



- Does misinformation exposure matter to behavior change/health outcomes?
- What's the threshold of exposure?

Improve Surveillance Efforts



- Information poverty/communities most at risk?
- Bubbles and information silos?
- Longitudinal and spatial distributions of misinformation
- Implied vs. explicit forms of misinformation

Raise Awareness and Education



- How to create and sustain trust?
- How to leverage trusted influencers?
- How to foster science literacy generally?

Intervention Development



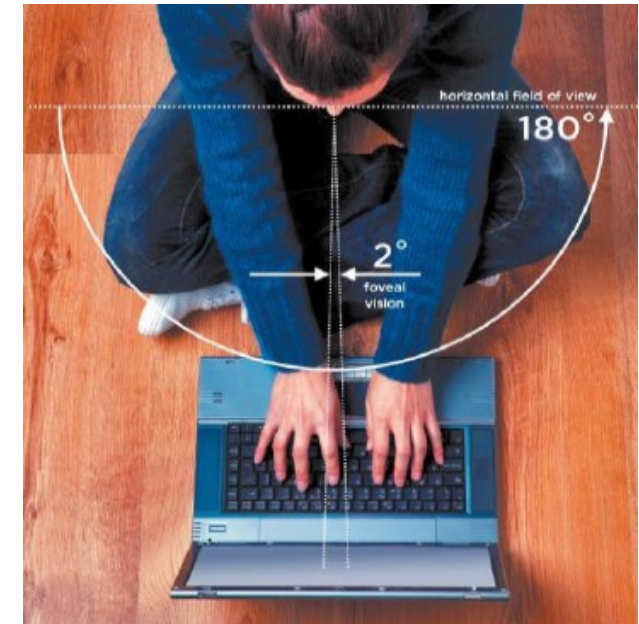
- Interventions to address/mitigate misinformation
- Correction interventions – backfire effect?
- Role of identity, values, and emotions

Chou et al. Addressing health-related misinformation on social media. *JAMA*. 2018;320(23):2417-8.

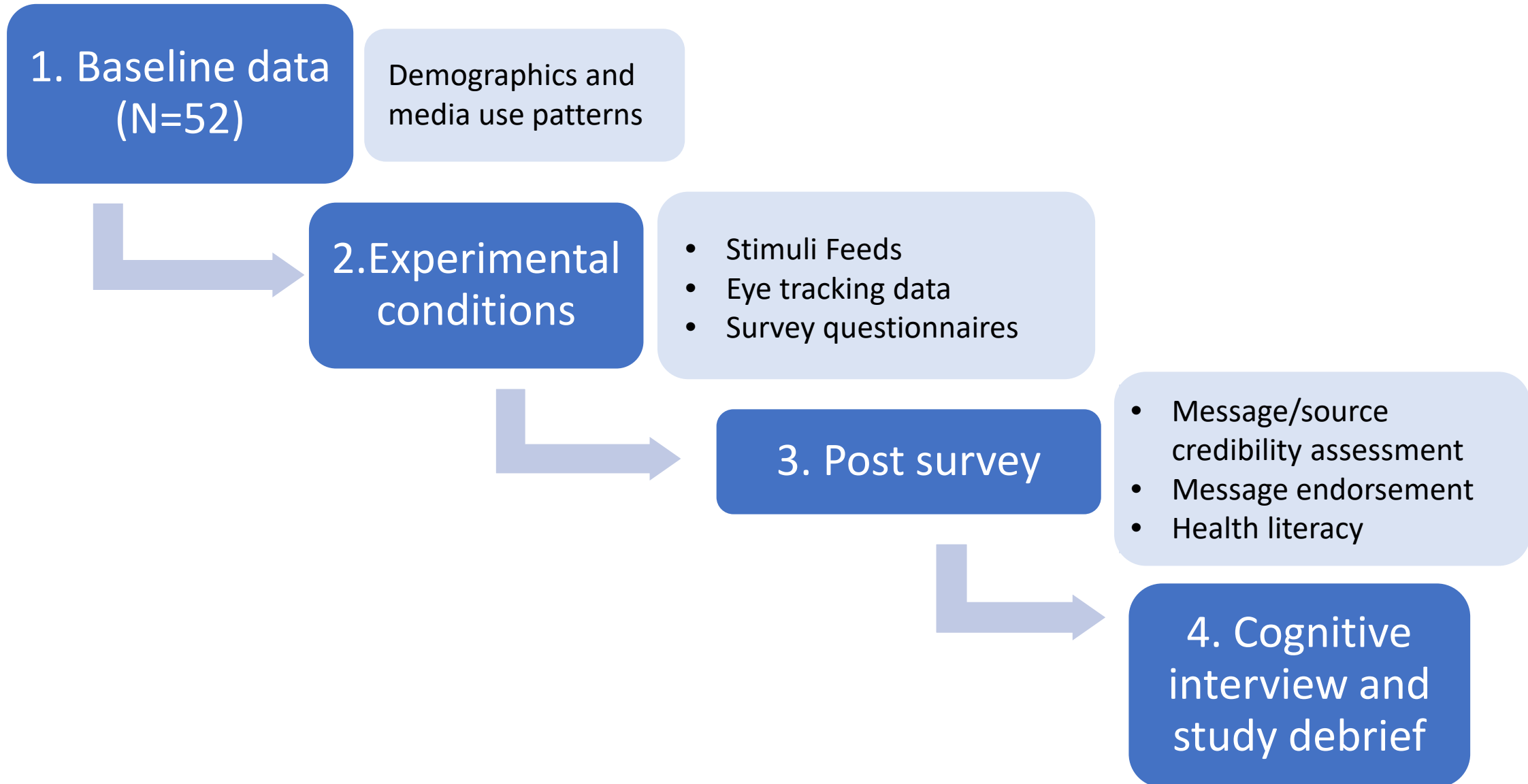
Southwell et al. Misinformation as a Misunderstood Challenge to Public Health. *AJPM*. 2019 ePub ahead of print.

A case study: A mixed methods eye tracking study of cancer messages on social media

- Understand the **context and process** of message credibility assessment
- Identify and address information needs of populations most at risk of acting upon misinformation
- **Research question: How do users process cancer prevention messages on Facebook?**
 - What factors influence attention?
 - What factors impact the perceived source and message credibility?



Study Design

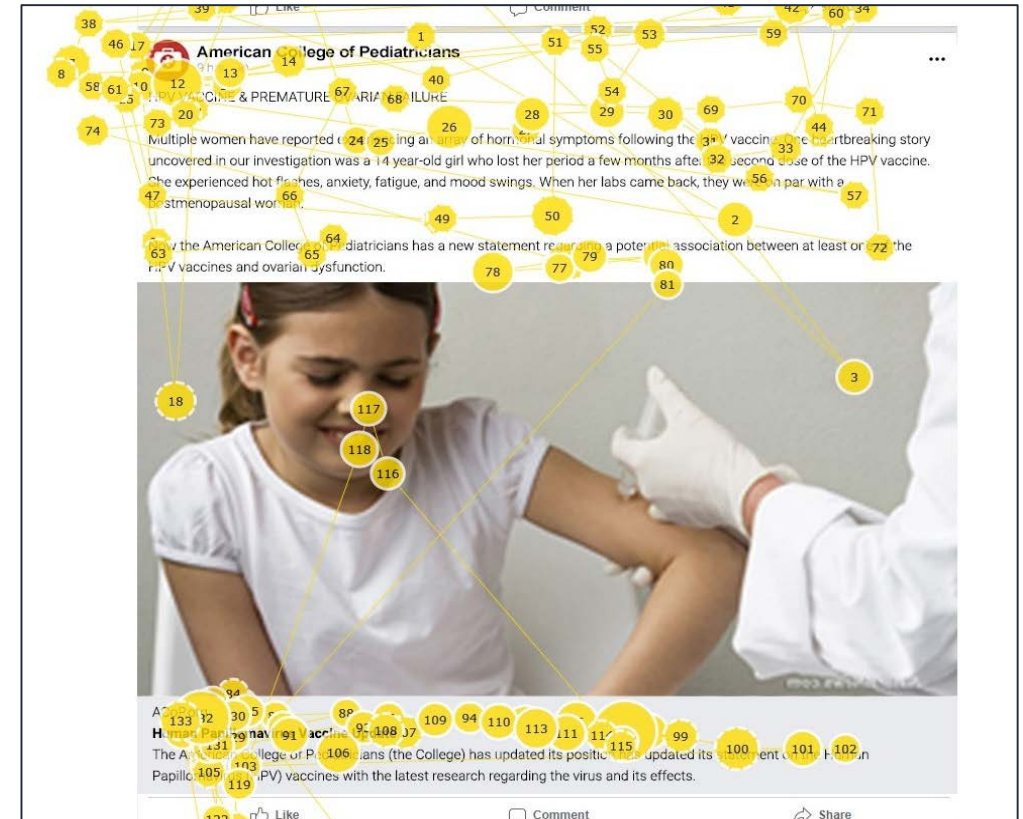


Stimuli conditions

1. Structure: Narrative vs. Non-narrative
2. Message Source: Government vs. health organizations vs. Individual source
3. Veracity: Evidence-based vs. Non-evidence-based
4. Topics: HPV vaccination vs. Sun Safety

Areas of Interest in target posts:

1. Source
2. Text
3. Image
4. Full Post

[illegible]

Select preliminary findings

- **Source** of a post matters and gets attention
- **Source trust**: higher for government agencies than individuals
- **Message credibility**: No difference found among government organizations, health (including “bogus”) organizations, and individuals; when viewing non-credible messages, higher trust was placed on health organizations than individuals
 - Risk of illegitimate organizations masquerading as credible health information sources
 - Importance of branding-->developing trust
- The role of **health literacy** in message processing and message believability

Current NCI initiatives



NCI funding opportunities:

PAR-16-248/249 (original)

PAR-18-638/639 (renewed)

*Innovative Approaches to
Studying Cancer*

*Communication in the New
Media Environment*

Call for Proposals:

Special issue about Health Misinformation on Social Media

The American Journal of Public Health, in collaboration with the National Cancer Institute, intends to publish a special issue on health misinformation on social media.

The special issue will focus on four main content areas:

1. health misinformation surveillance
2. the context of health misinformation
3. the impact of health misinformation
4. responses/interventions to address health misinformation

Extended proposals are due to Anna Gaysynsky, Assistant Guest Editor, at Anna.Gaysynsky@nih.gov by **11:59 PM EDT on Friday, August 30, 2019.**

The full Call for Proposals is available at https://ajph.aphapublications.org/pb-assets/downloads/CFP_HealthMisinformation_Full.pdf.

For specific questions on proposal content or orientation, please contact Guest Editor Wen-Ying Sylvia Chou at chouws@mail.nih.gov.

Other tangible opportunities for change

- **Health care organizations**

- Resources for debunking myths and misinformation (e.g. [NCI Common Cancer Myths and Misconceptions](#))
- Best practices for frequently encountered topics (e.g. vaccine hesitancy, alternative cancer therapies, pro-anorexia videos)?
- Partnering with SM industry in curation and management of online forums

- **Communication practitioners**

- Monitoring bots, trolls, disinformation campaigns, medical conspiracy theories in order to proactively mitigate risks of divisive discourse
- Leveraging trusted networks and brands
- Campaigns to counteract promotion of unsubstantiated viewpoints
- Media literacy training



Thank you!

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