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NYU Langone Health

Caveat Emptor/ Let the Buyer Beware: Pitfalls of the Internet in Prostate Cancer

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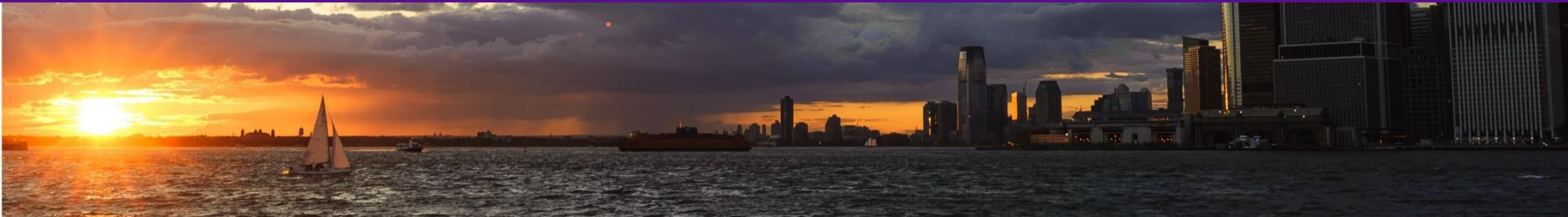
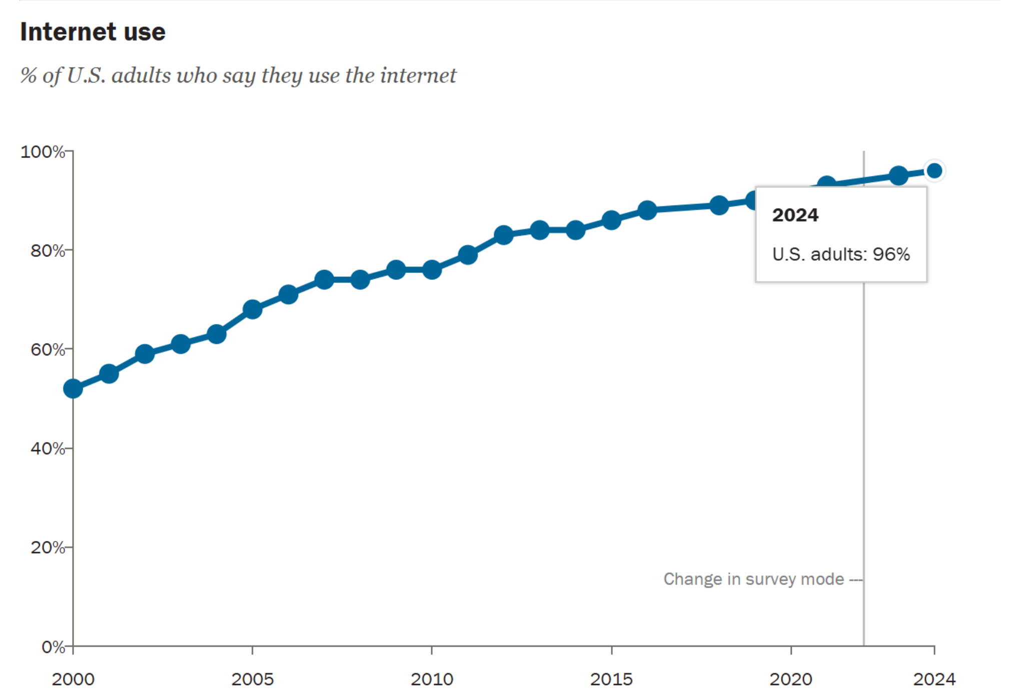
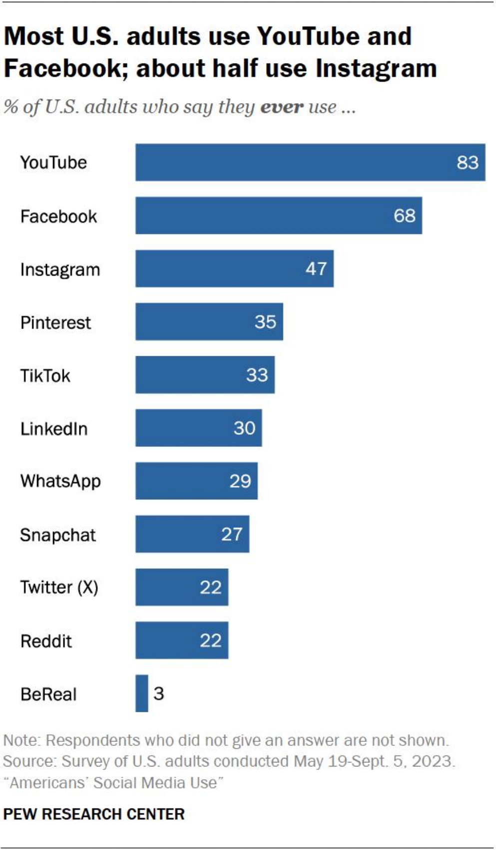


96% of U.S. Adults Use the Internet



Most U.S. Adults Use Social Media Especially YouTube



Most U.S. adults use YouTube and Facebook; about half use Instagram

*% of U.S. adults who say they **ever** use ...*

Note: Respondents who did not give an answer are not shown.
Source: Survey of U.S. adults conducted May 19-Sept. 5, 2023.
"Americans' Social Media Use"

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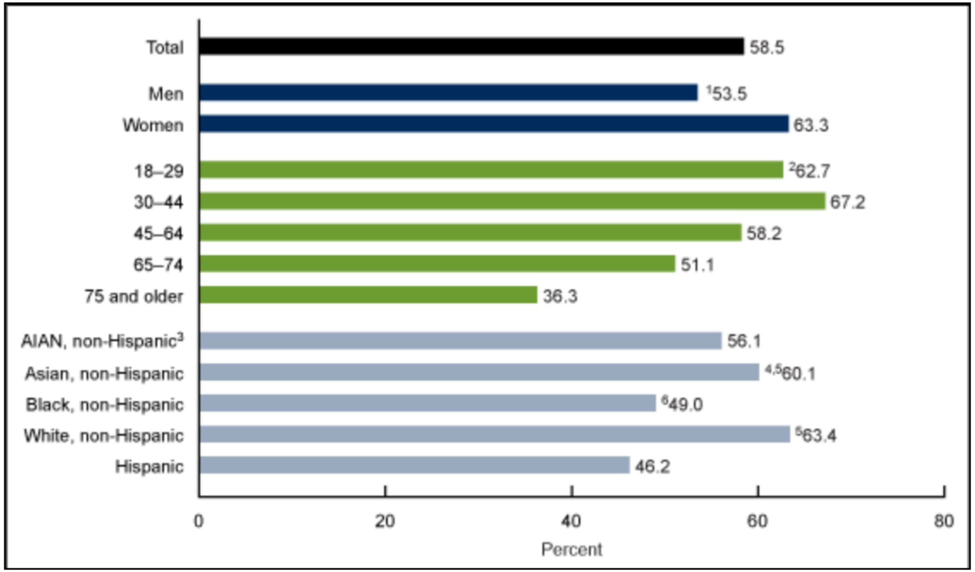
Most U.S. Adults Use Internet for Health Information

Figure 1. Percentage of adults who used the Internet in the past 12 months to look for health or medical information, by sex, age, and race and Hispanic origin: United States, July–December 2022



Source: CDC

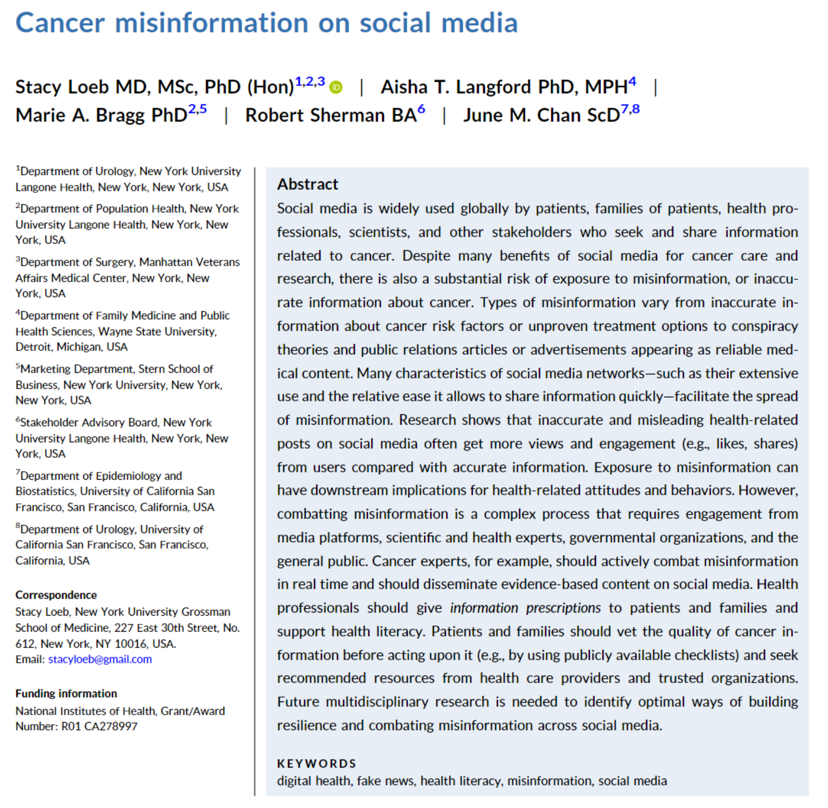
“Caveat Emptor”- Beware the Quality of Online Information

Misinformation: Incorrect or misleading information

Distinct from “disinformation” which is deliberately deceptive

Cancer Misinformation is Widespread on Social Media

Review Paper in *CA: A Cancer Journal for Clinicians*



Cancer misinformation on social media

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Funding information

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Abstract

Social media is widely used globally by patients, families of patients, health professionals, scientists, and other stakeholders who seek and share information related to cancer. Despite many benefits of social media for cancer care and research, there is also a substantial risk of exposure to misinformation, or inaccurate information about cancer. Types of misinformation vary from inaccurate information about cancer risk factors or unproven treatment options to conspiracy theories and public relations articles or advertisements appearing as reliable medical content. Many characteristics of social media networks—such as their extensive use and the relative ease it allows to share information quickly—facilitate the spread of misinformation. Research shows that inaccurate and misleading health-related posts on social media often get more views and engagement (e.g., likes, shares) from users compared with accurate information. Exposure to misinformation can have downstream implications for health-related attitudes and behaviors. However, combatting misinformation is a complex process that requires engagement from media platforms, scientific and health experts, governmental organizations, and the general public. Cancer experts, for example, should actively combat misinformation in real time and should disseminate evidence-based content on social media. Health professionals should give *information prescriptions* to patients and families and support health literacy. Patients and families should vet the quality of cancer information before acting upon it (e.g., by using publicly available checklists) and seek recommended resources from health care providers and trusted organizations. Future multidisciplinary research is needed to identify optimal ways of building resilience and combating misinformation across social media.

KEYWORDS

digital health, fake news, health literacy, misinformation, social media

Prostate Cancer Misinformation is Widespread

YouTube

42% of top 150 videos had some misinformation

Instagram

41% of posts with objective information was misinformative

TikTok

41% of posts with objective information was misinformative

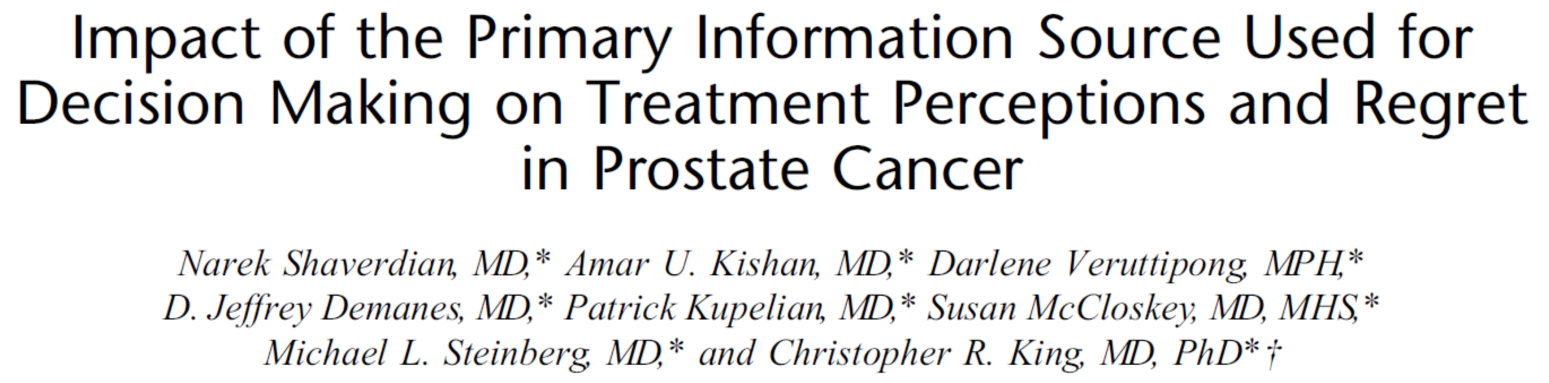
Pinterest

15% of pins in search for prostate cancer have misinformation

Podcasts

13% contained moderate to high misinformation

Loeb et al. *Eur Urol Focus* 2020, 15; 6(3): 437.
Herbert et al. JMIR Cancer 2022; 8: e36244
Xu et al. Prostate Cancer Prostateic Dis 2022: 25: 791.
Xu et al. *BJU Int* 2021; 128: 435.
Scott et al. Prostate Cancer Prostatic Disease 2024

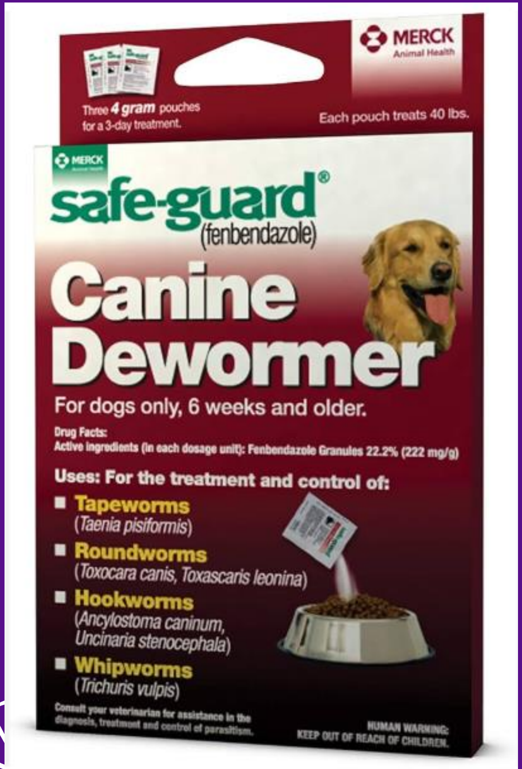


Impact of the Primary Information Source Used for Decision Making on Treatment Perceptions and Regret in Prostate Cancer

Narek Shaverdian, MD, Amar U. Kishan, MD,* Darlene Veruttipong, MPH,**
D. Jeffrey Demanes, MD, Patrick Kupelian, MD,* Susan McCloskey, MD, MHS,**
Michael L. Steinberg, MD, and Christopher R. King, MD, PhD*†*

- Survey of n=276 patients with prostate cancer treated with radiation therapy
- 44 (16%) reported internet as their primary information source
- On multivariate analysis, Internet as the primary information source (vs a radiation oncologist) associated with 46x odds of treatment regret (OR 46.47, 95% CI 9.3-231, *P*< 0.001)

Animal drugs (e.g., Fenbendazole = canine dewormer) commonly recommended for prostate cancer on social media



ACG CASE REPORTS JOURNAL

CASE REPORT | LIVER

Severe Drug-Induced Liver Injury Due to Self-administration of the Veterinary Anthelmintic Medication, Fenbendazole

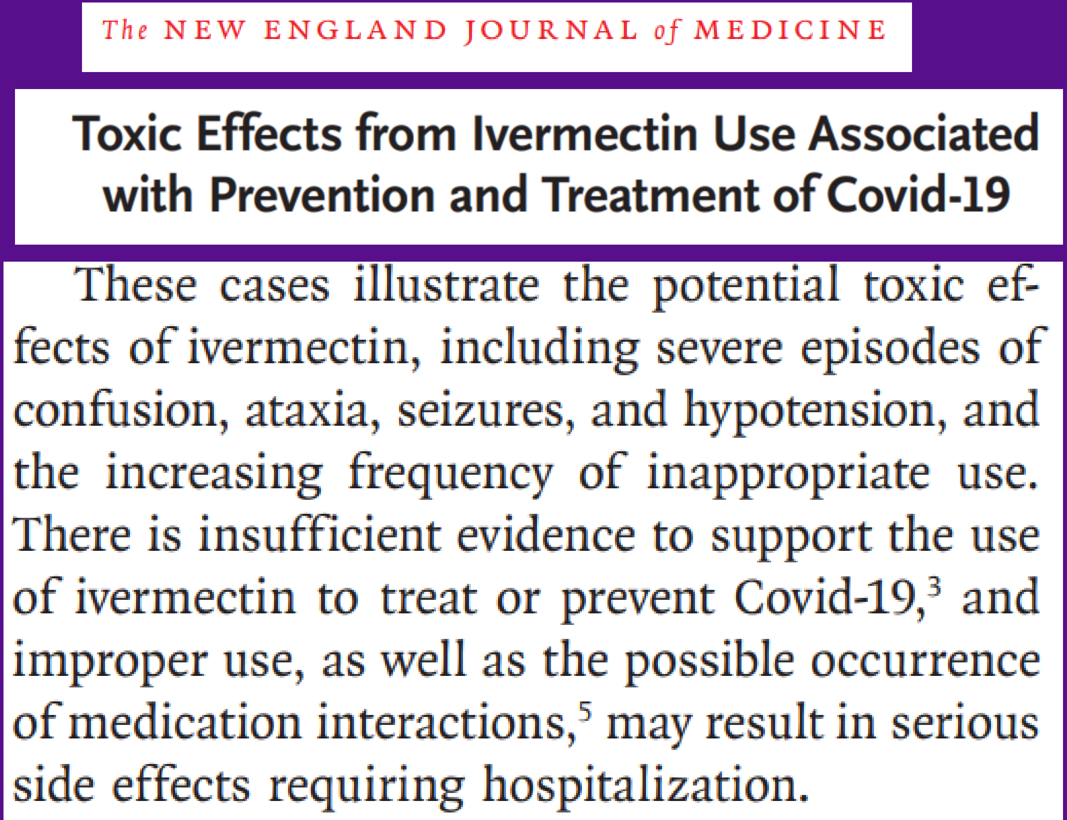
Aishwarya Thakurdesai, MBBS[1], Lucia Rivera-Matos, MD[1,2], Navroop Nagra, MBBS[1,2], Brandon Busch, MD[1,2], Daniel D. Mais, MD[3], and Matthew C. Cave, MD[1,2]

[1] *Department of Internal Medicine, University of Louisville, Louisville, KY*
[2] *Division of Gastroenterology, Hepatology and Nutrition, University of Louisville, Louisville, KY*
[3] *Department of Pathology and Laboratory Medicine, University of Louisville, Louisville, KY*

ABSTRACT

Fenbendazole is an anthelmintic agent approved for veterinary applications. Even though it is not approved by the US Food and Drug Administration for human use, such use appears to be increasing due to the popularization of fenbendazole's potential anticancer effects by social media. We describe the first case of histologically confirmed severe drug-induced liver injury, hepatocellular pattern, associated with the self-administration of fenbendazole in a 67-year-old woman who presented with 2 weeks of jaundice. Liver function tests normalized in 3 months after the cessation of fenbendazole.

Ivermectin (anti-parasitic) commonly recommended for prostate cancer on social media → Risk of serious side effects



The NEW ENGLAND JOURNAL of MEDICINE

Toxic Effects from Ivermectin Use Associated with Prevention and Treatment of Covid-19

These cases illustrate the potential toxic effects of ivermectin, including severe episodes of confusion, ataxia, seizures, and hypotension, and the increasing frequency of inappropriate use. There is insufficient evidence to support the use of ivermectin to treat or prevent Covid-19,[3] and improper use, as well as the possible occurrence of medication interactions,[5] may result in serious side effects requiring hospitalization.

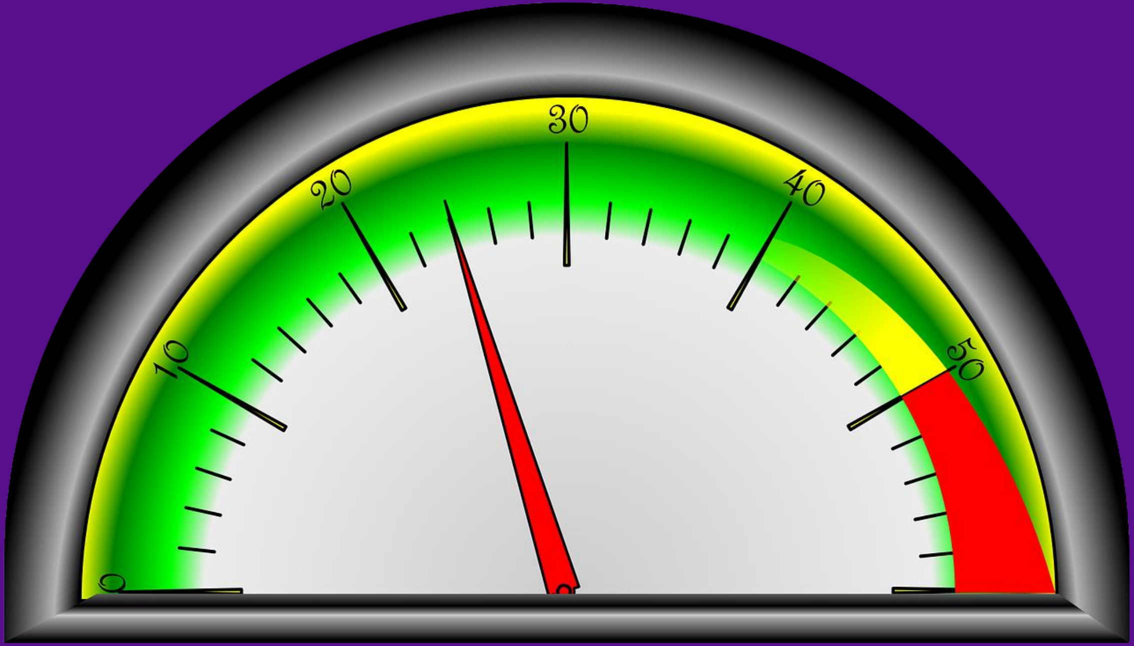
The Misinformation Problem

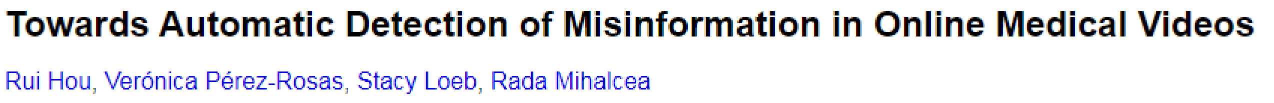
Millions of online posts about prostate cancer

New content is continuously added

Logistically infeasible for experts to manually review all content

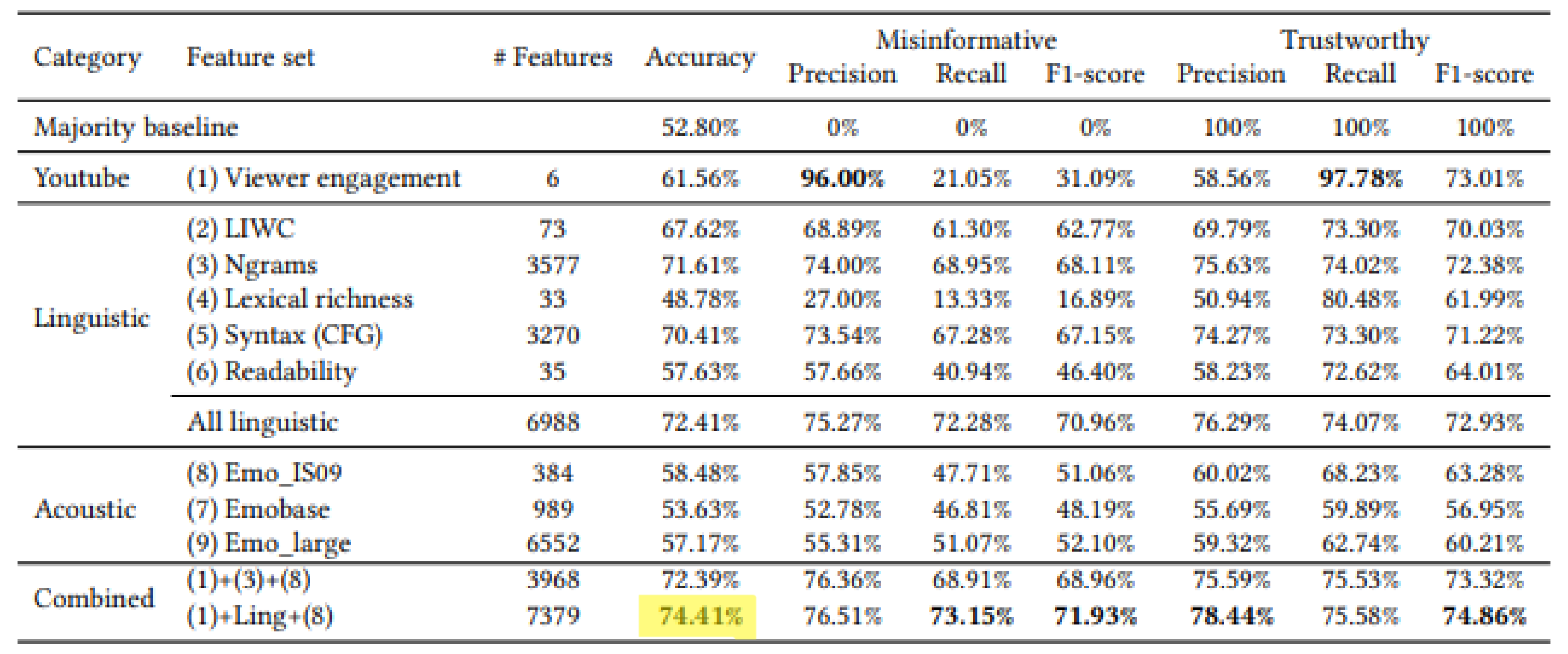
Possible Solution: Misinformation Detector?





Towards Automatic Detection of Misinformation in Online Medical Videos

Rui Hou, Verónica Pérez-Rosas, Stacy Loeb, Rada Mihalcea



Category	Feature set	# Features	Accuracy	Misinformative Precision	Misinformative Recall	Misinformative F1-score	Trustworthy Precision	Trustworthy Recall	Trustworthy F1-score
Majority baseline			52.80%	0%	0%	0%	100%	100%	100%
Youtube	(1) Viewer engagement	6	61.56%	**96.00%**	21.05%	31.09%	58.56%	**97.78%**	73.01%
Linguistic	(2) LIWC	73	67.62%	68.89%	61.30%	62.77%	69.79%	73.30%	70.03%
	(3) Ngrams	3577	71.61%	74.00%	68.95%	68.11%	75.63%	74.02%	72.38%
	(4) Lexical richness	33	48.78%	27.00%	13.33%	16.89%	50.94%	80.48%	61.99%
	(5) Syntax (CFG)	3270	70.41%	73.54%	67.28%	67.15%	74.27%	73.30%	71.22%
	(6) Readability	35	57.63%	57.66%	40.94%	46.40%	58.23%	72.62%	64.01%
	All linguistic	6988	72.41%	75.27%	72.28%	70.96%	76.29%	74.07%	72.93%
Acoustic	(8) Emo_IS09	384	58.48%	57.85%	47.71%	51.06%	60.02%	68.23%	63.28%
	(7) Emobase	989	53.63%	52.78%	46.81%	48.19%	55.69%	59.89%	56.95%
	(9) Emo_large	6552	57.17%	55.31%	51.07%	52.10%	59.32%	62.74%	60.21%
Combined	(1)+(3)+(8)	3968	72.39%	76.36%	68.91%	68.96%	75.59%	75.53%	73.32%
	(1)+Ling+(8)	7379	74.41%	76.51%	**73.15%**	**71.93%**	**78.44%**	75.58%	**74.86%**

- 74% accuracy for combined model including meta-data, linguistic and acoustic variables to identify misinformative prostate cancer videos

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A Multifaceted Approach is Needed To Combat Misinformation

Healthcare providers and community health workers (e.g., promote health literacy)

Healthcare systems (e.g., community outreach)

Community groups (e.g., awareness campaigns)

Professional societies (e.g., disciplinary action)

Social networks (e.g., censoring accounts)

Government (e.g., legislation)

Schools (e.g., curriculum on health literacy)

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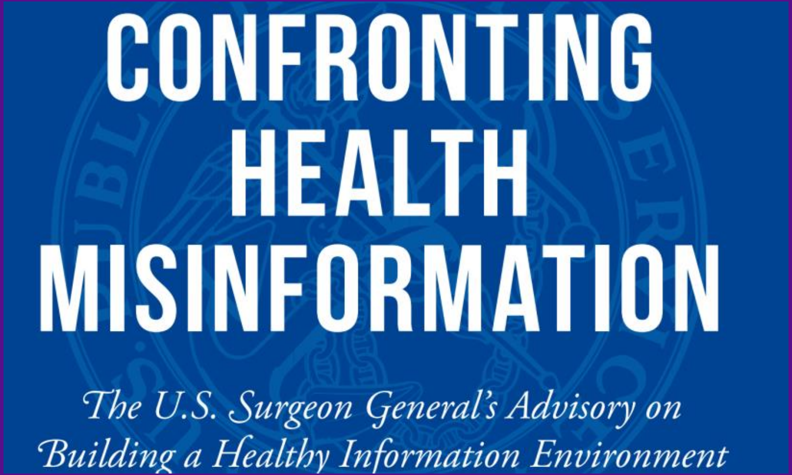
Combating Misinformation

CONFRONTING HEALTH MISINFORMATION

The U.S. Surgeon General's Advisory on Building a Healthy Information Environment

2021

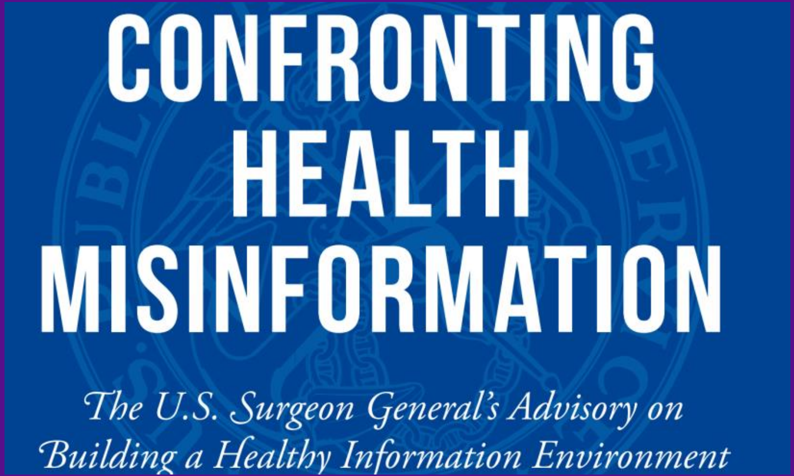


CONFRONTING HEALTH MISINFORMATION

The U.S. Surgeon General's Advisory on Building a Healthy Information Environment

What Healthcare Providers Can Do:

- Proactively engage with patients and the public on health misinformation
- Partner with community groups and other local organizations to prevent and address health misinformation
- Use technology and media platforms to share accurate health information with the public



CONFRONTING HEALTH MISINFORMATION

The U.S. Surgeon General's Advisory on Building a Healthy Information Environment

What Individuals and Families Can Do:

- Learn how to identify and avoid sharing health misinformation (“If you’re not sure, don’t share”)
- Engage with your friends and family on the problem of health misinformation
- Address health misinformation in your community

NAM Perspect. 2021; 2021: 10.31478/202107a.
PMCID: PMC8486420
Published online 2021 Jul 16. doi: 10.31478/202107a
PMID: 34611600

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

Raynard S. Kington, MD, PhD, MBA, Stacey Arnesen, MS, Wen-Ying Sylvia Chou, PhD, MPH, Susan J. Curry, PhD, David Lazer, PhD, and Antonia M. Villarruel, PhD, RN, FAAN

Useful paper summarizing methods for identifying credible health content

For example, the CRAP Test

Currency: How recent is the info? Is it current/updated?
Reliability: What kind of information? Is it opinion? Balanced? Are there references?
Authority: Who is the creator? Credentials? Sponsor? Reputable? Any COI?
Purpose: Fact or opinion? Biased? Pushing an agenda? Selling something?

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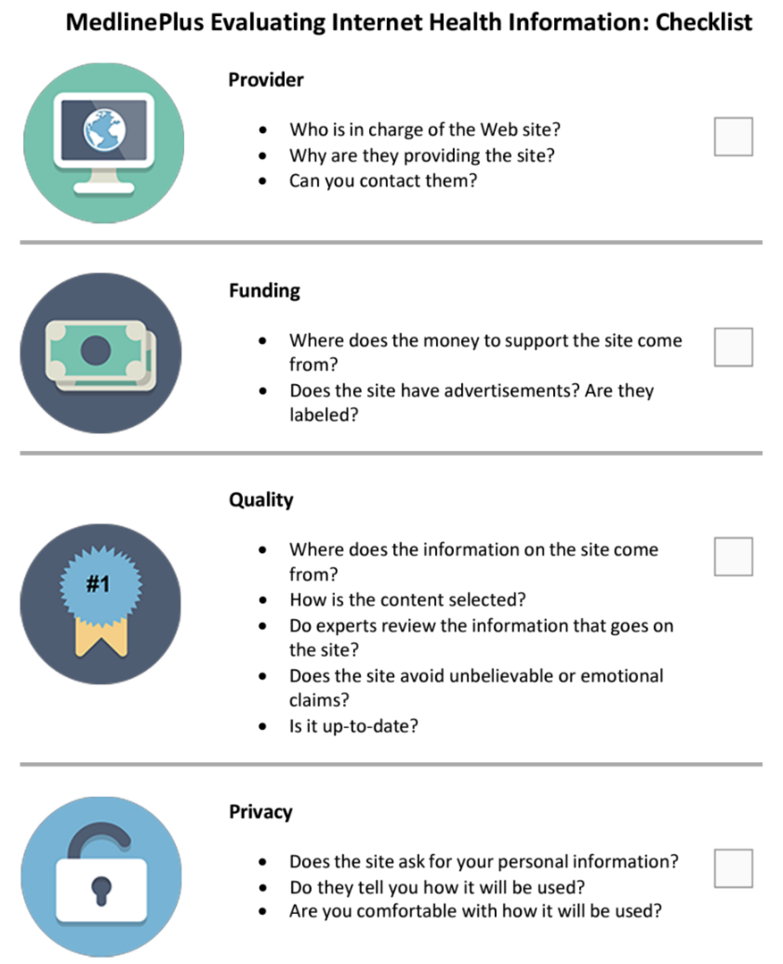

MedlinePlus Evaluating Internet Health Information: Checklist

Provider

- Who is in charge of the Web site?
- Why are they providing the site?
- Can you contact them?

☐

Funding

- Where does the money to support the site come from?
- Does the site have advertisements? Are they labeled?

☐

Quality

- Where does the information on the site come from?
- How is the content selected?
- Do experts review the information that goes on the site?
- Does the site avoid unbelievable or emotional claims?
- Is it up-to-date?

☐

Privacy

- Does the site ask for your personal information?
- Do they tell you how it will be used?
- Are you comfortable with how it will be used?

☐

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Other Problems with Online Prostate Cancer Information

- Accuracy of information
- Poor understandability and actionability
- Limited representation of diversity
- Scarcity of relevant content for non English-preferring patients

1) Understandability – Can it be easily understood?

- CONTENT: Purpose is evident
- LANGUAGE: Common, everyday language. Any medical terms are explained. Uses active voice
- ORGANIZATION: Organized into chunks /sections. Informative headers. Logical sequence. Provides a summary.
- LAYOUT & DESIGN: Visual cues. Easy to read/hear.
- VISUAL AIDS: Clear illustrations/photos. Simple tables with clear headings.

Measured by “PEMAT” on a scale from 0 to 100%

2) Actionability- Can it be easily acted on?

- Identifies at least 1 action the user can take (e.g., get screened)
- Addresses the user directly when describing actions
- Breaks down any action into manageable, explicit steps
- Explains how to use charts, graphics, tables or diagrams to take actions

Measured by "PEMAT" on a scale from 0 to 100%

Problems with Understandability & Actionability-
Comparing Prostate Cancer Information Across Platforms

- Median Understandability: 67%
- Median Actionability: 75%

- Median Understandability: 75%
- Median Actionability: 0%

- Median Understandability: 60-88%
- Median Actionability: 0%

- Poor Understandability: 55%
- Poor Actionability: 100%

- Poor Understandability: 35%
- Poor Actionability: 65%

Loeb et al. *Eur Urol Focus* 2020, 15; 6(3): 437.
Herbert et al. JMIR Cancer 2022; 8: e36244
Xu et al. Prostate Cancer Prostateic Dis 2022: 25: 791.
Xu et al. *BJU Int* 2021; 128: 435.

JAMA Oncology | **Brief Report**

Assessment of Artificial Intelligence Chatbot Responses to Top Searched Queries About Cancer

Alexander Pan, BS; David Musheyev, BA; Daniel Bockelman, BS; Stacy Loeb, MD, MSc, PhD; Abdo E. Kabarriti, MD

4 AI chatbots
- ChatGPT v3.5
- Perplexity
- Chatsonic
- Bing AI

Inputs: Top 5 search queries about top 5 cancers

Skin

Lung

Breast

Colorectal

Prostate

- Quality was generally good *(median DISCERN 5/5)*
- No misinformation
- Poor actionability *(median 20% on PEMAT)*
- College reading level

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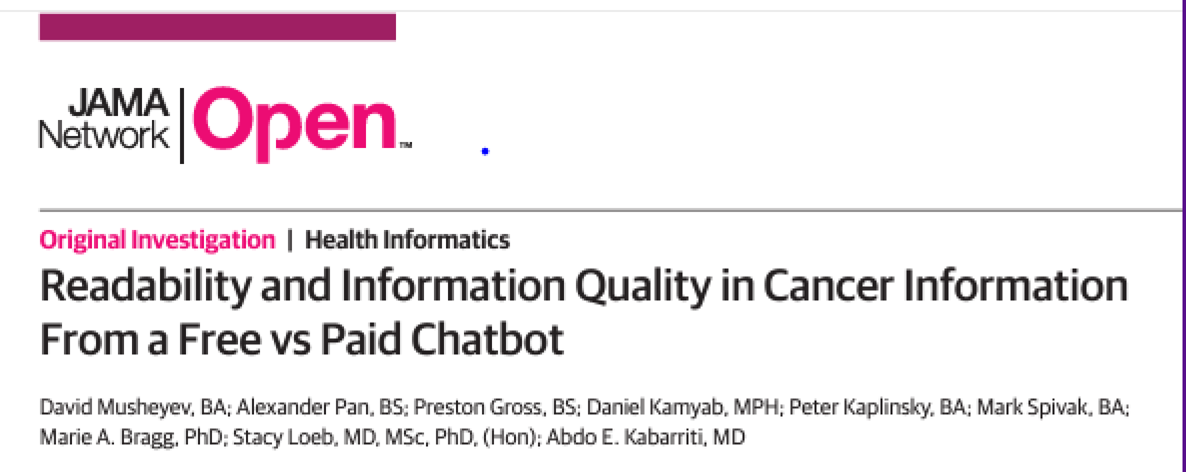


JAMA Network | Open

Original Investigation | Health Informatics

Readability and Information Quality in Cancer Information From a Free vs Paid Chatbot

David Musheyev, BA; Alexander Pan, BS; Preston Gross, BS; Daniel Kamyab, MPH; Peter Kaplinsky, BA; Mark Spivak, BA; Marie A. Bragg, PhD; Stacy Loeb, MD, MSc, PhD, (Hon); Abdo E. Kabarriti, MD

- Significantly better readability with the paywalled versus the free chatGPT
- Need to prompt the free chatbot to improve readability

Other Problems with Online Prostate Cancer Information

- Accuracy of information
- Poor understandability and actionability
- Limited representation of diversity
- Scarcity of relevant content for non English-preferring patients

Research Correspondence

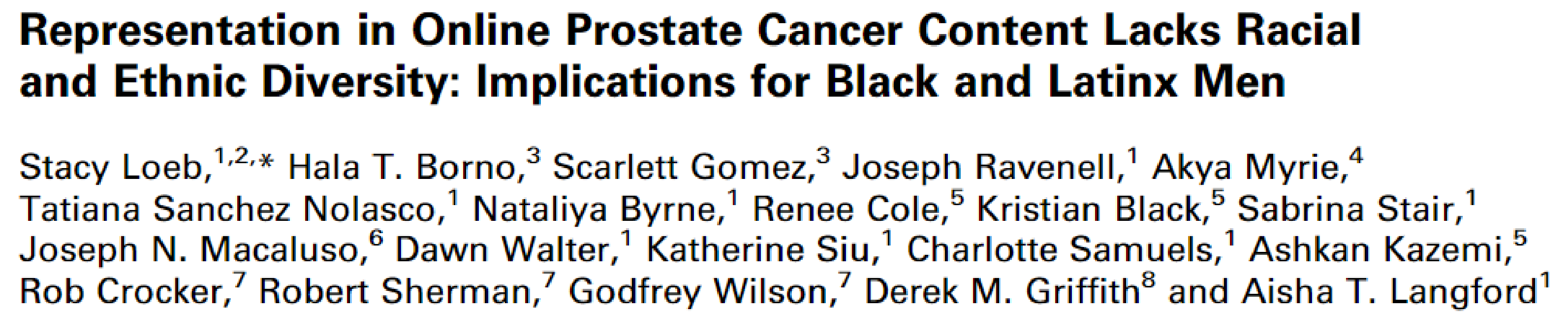
BJUI
BJU International

Racial disparities and online health information: YouTube and prostate cancer clinical trials

- Black males are disproportionately affected by prostate cancer and are under-represented in clinical trials
- 150 videos about prostate cancer clinical trials
- Among 292 people in the videos, 4% were perceived as Black

Borno et a. BJUI 2020; 126: 11-13.

Supported by Department of Defense, Prostate Cancer Foundation, and Blank Family Foundation



Representation in Online Prostate Cancer Content Lacks Racial and Ethnic Diversity: Implications for Black and Latinx Men

Stacy Loeb,[1,2,*] Hala T. Borno,[3] Scarlett Gomez,[3] Joseph Ravenell,[1] Akya Myrie,[4]
Tatiana Sanchez Nolasco,[1] Nataliya Byrne,[1] Renee Cole,[5] Kristian Black,[5] Sabrina Stair,[1]
Joseph N. Macaluso,[6] Dawn Walter,[1] Katherine Siu,[1] Charlotte Samuels,[1] Ashkan Kazemi,[5]
Rob Crocker,[7] Robert Sherman,[7] Godfrey Wilson,[7] Derek M. Griffith[8] and Aisha T. Langford[1]

Examined 1st 150 websites (Google search) and 1st 150 videos (YouTube) about "prostate cancer"

Online People

- 1526 total people featured
- 9% perceived as Black, 1% Latinx

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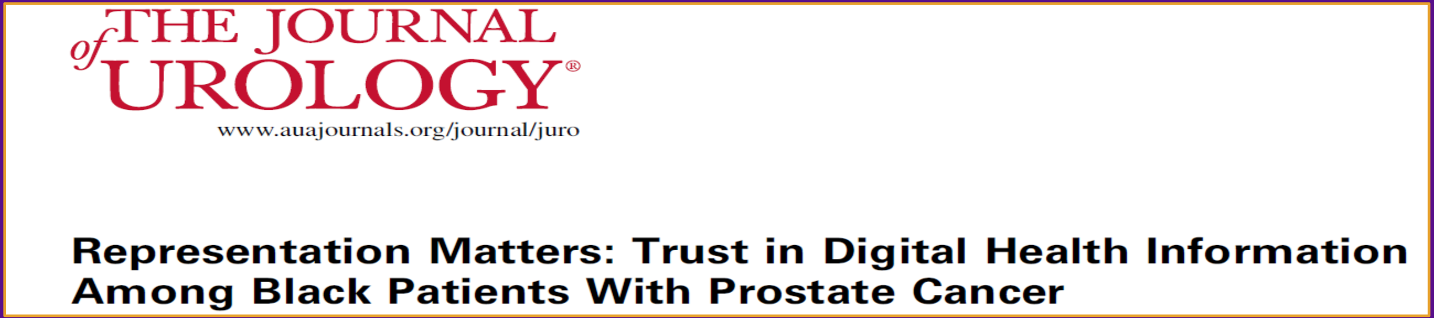
Loeb et al. J Urol 2022; 207: 559-564.
Supported by Department of Defense, Prostate Cancer Foundation and Blank Family Foundation



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Representation Matters: Trust in Digital Health Information Among Black Patients With Prostate Cancer

Focus groups with Black patients with prostate cancer identify negative consequences from underrepresentation

- *“To the majority of African Americans, you think you're less likely to get it [prostate cancer] because you see less African Americans on the internet and on the websites, when it's absolutely the other way around.”*

Other Problems with Online Prostate Cancer Information

- Accuracy of information
- Poor understandability and actionability
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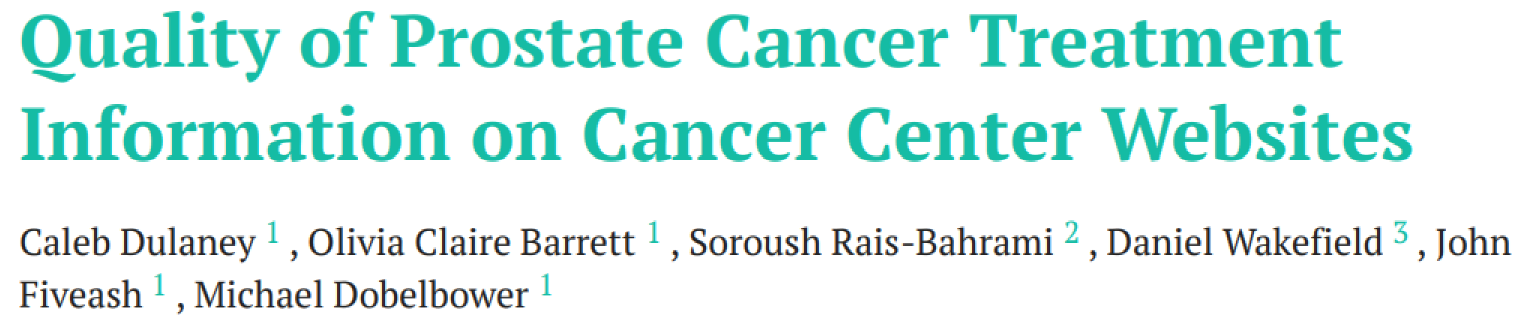
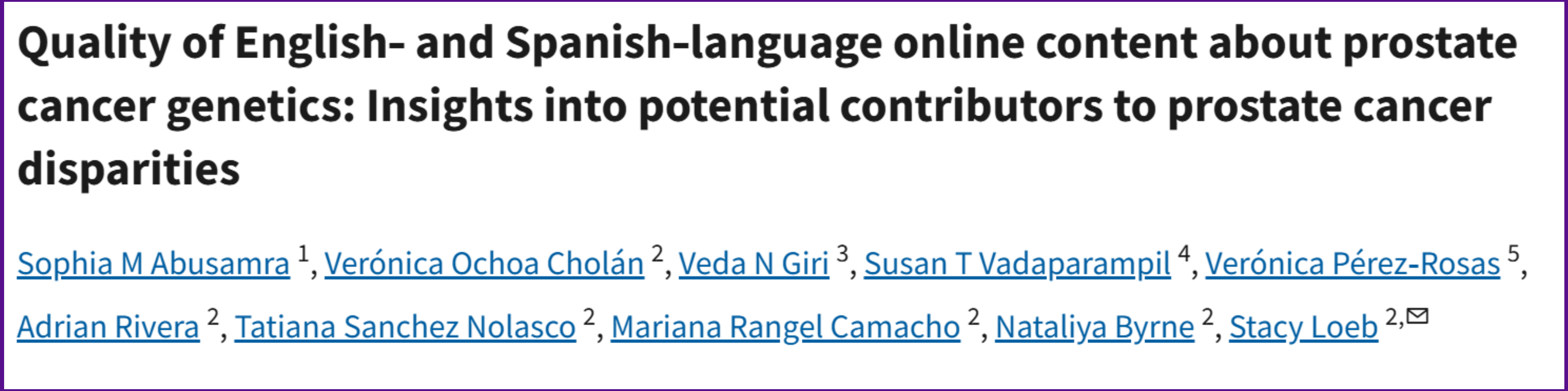


Quality of Prostate Cancer Treatment Information on Cancer Center Websites

Caleb Dulaney[1], Olivia Claire Barrett[1], Soroush Rais-Bahrami[2], Daniel Wakefield[3], John Fiveash[1], Michael Dobelbower[1]

- Only 24% have information available in Spanish

Dulaney et al. Cureus 2016; 8 (4): e580.



Quality of English- and Spanish-language online content about prostate cancer genetics: Insights into potential contributors to prostate cancer disparities

Sophia M Abusamra[1], Verónica Ochoa Cholán[2], Veda N Giri[3], Susan T Vadaparampil[4], Verónica Pérez-Rosas[5], Adrian Rivera[2], Tatiana Sanchez Nolasco[2], Mariana Rangel Camacho[2], Nataliya Byrne[2], Stacy Loeb[2,✉]

- Lower uptake of genetic evaluation among Hispanic patients with prostate cancer in the U.S. as well as those who are non-English preferring
- Examined the top websites and YouTube videos in searches for “BRCA and prostate cancer” and “genetic testing and prostate cancer” in English and Spanish
- Significantly less relevant content in Spanish vs English (51% vs 69%, p=0.02)

BJUI Compass 2025 Mar 23; 6(3): e70011.

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Conclusion

- Misinformation about prostate cancer is widespread in online networks
- Misinformation exposure can have a negative impact for health and the patient-provider relationship
- Other problems with online information include poor readability, insufficient representation of diversity and limited non-English content
- A multi-stakeholder approach is needed to address misinformation

Acknowledgement

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Movember

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