Misinformation and Other Pitfalls of Online Information About Prostate Cancer

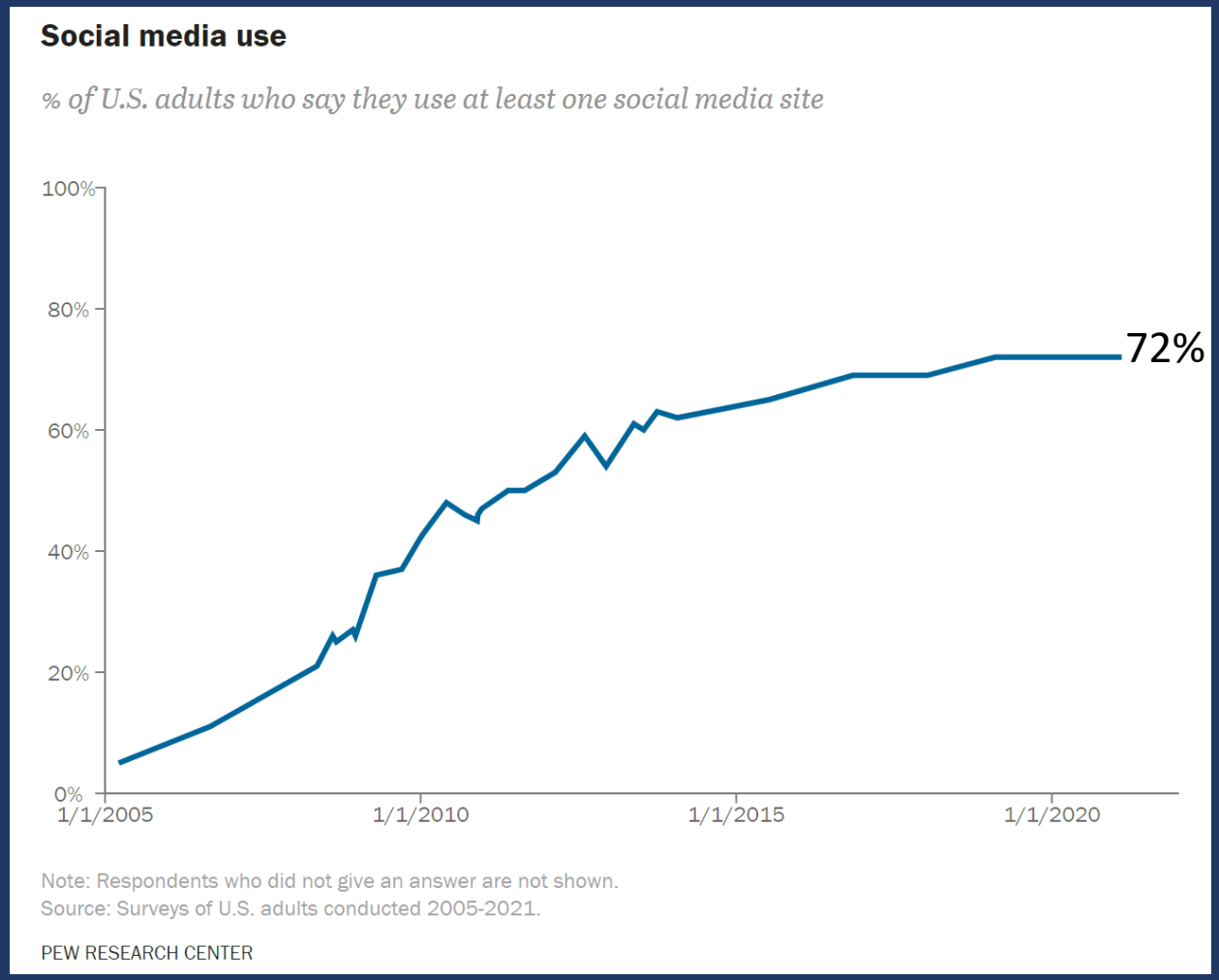
Stacy Loeb MD MSc PhD (hon)

Professor of Urology and Population Health, New York University and Manhattan Veterans Affairs

Host of Men's Health Show on SiriusXM Radio

ZERO Health Equity Task Force and Medical Advisory Board

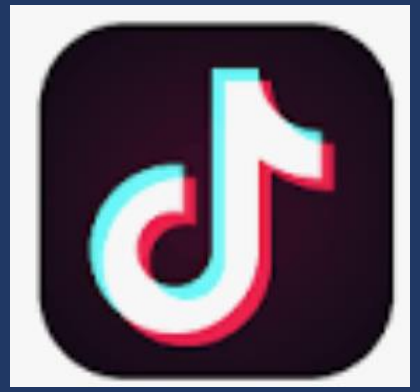
Increasing Social Media Use Among US Adults



“Caveat Emptor”- Beware the Quality of Online Information

- Misinformation: Incorrect or misleading information
- Distinct from “disinformation” which is deliberately deceptive

Prostate Cancer Misinformation is Widespread



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. Unpublished Data

available at www.sciencedirect.com
journal homepage: www.europeanurology.com

European Association of Urology

Platinum Priority – Brief Correspondence
Editorial by XXX on pp. x–y of this issue

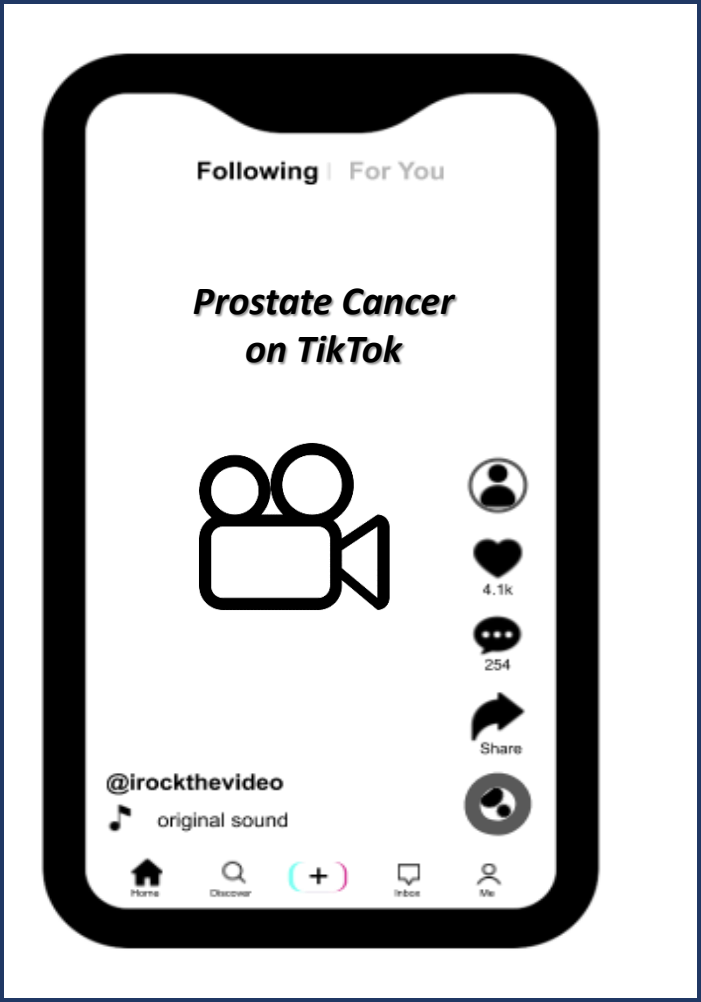
Dissemination of Misinformative and Biased Information about Prostate Cancer on YouTube

Stacy Loeb [a,b,c,], Shomik Sengupta [d], Mohit Butaney [e], Joseph N. Macaluso Jr. [f], Stefan W. Czarniecki [g], Rebecca Robbins [b], R. Scott Braithwaite [b], Lingshan Gao [a], Nataliya Byrne [a,b,c], Dawn Walter [a,b,c], Aisha Langford [b]*

- 77% of videos contained poor quality, potentially misinformative and/or biased content
  - 6.3 million views of these videos

- Worse quality → significantly more views and thumbs up

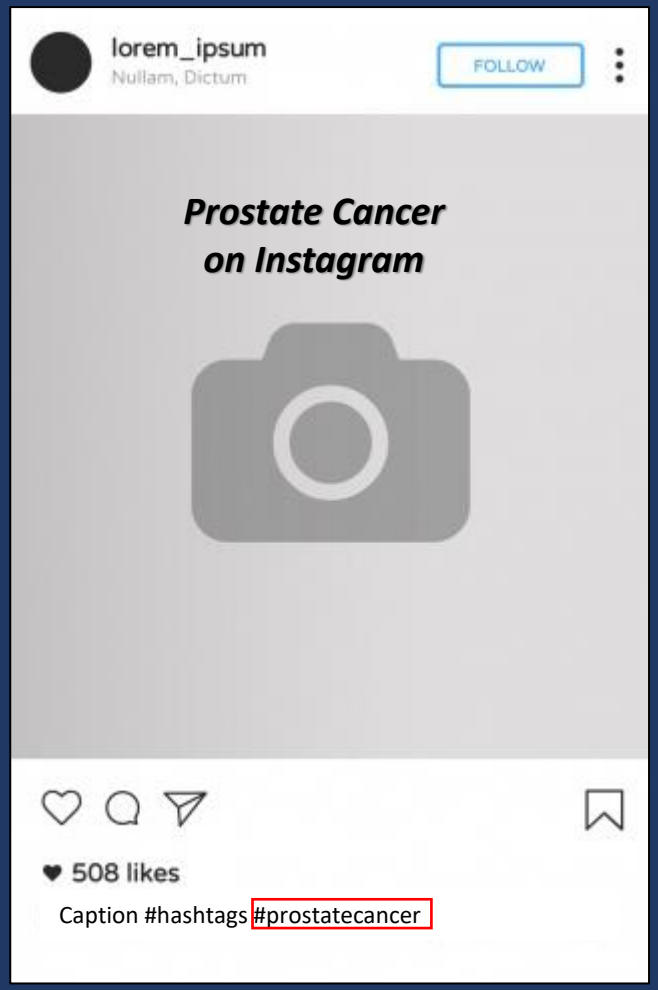
Prostate Cancer on TikTok



- Low to moderate quality: 98%
- Contains objective information: 31%
  - Misinformation: 41%

Xu et al. *BJU Int* 2021, epub.

Prostate Cancer on Instagram



- Low to moderate quality: 90%
- Contains objective information: 30%
  - Misinformation: 40%

Xu et al. *Prostate Cancer Prostatic Disease* 2021 epub.

Exploring Urological Malignancies on Pinterest: Content Analysis

Amber S Herbert [1]; Naeemul Hassan [2]; Rena D Malik [3]; Stacy Loeb [4]; Akya Myrie [5]

- Examined 357 pins on genitourinary cancer
- 75% moderate to poor quality information
- Misinformation ranged from 4% of testicular cancer pins to 26% of bladder cancer pins

JMIR Cancer 2022

Prostate Cancer Podcasts

- Scored 100 podcasts about prostate cancer
- 52% were low to moderate quality
- 13% contained moderate to high misinformation

Scott et al. In Press

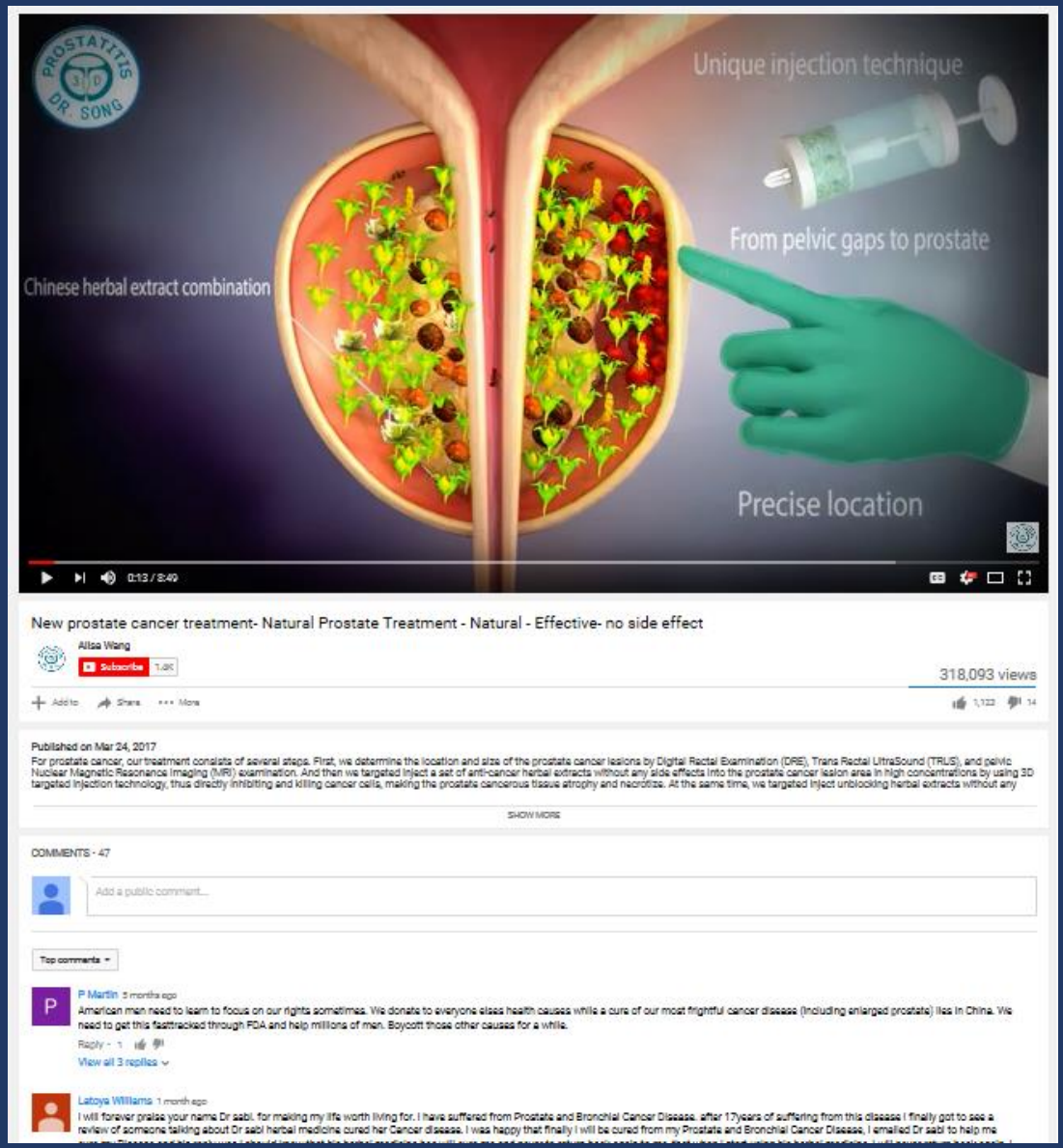
Quality of Prostate Cancer Treatment Information on Cancer Center Websites

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

- Checked for information on 11 key questions for prostate cancer decision-making → on average, sufficient information to answer only 19%

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

YouTube Video Promoting Herbal Injections into Prostate for Treatment for Prostate Cancer (Not evidence based but >300,000 views)



Instagram Post with Misleading Information about Early Signs of Prostate Cancer

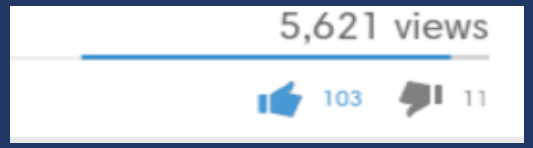
The Misinformation Problem

- Millions of online posts about prostate cancer
  - New content is continuously added
- Logistically infeasible for experts to manually review all content

Automated Detection of Misinformation Using Multimodal Features (74% accuracy)

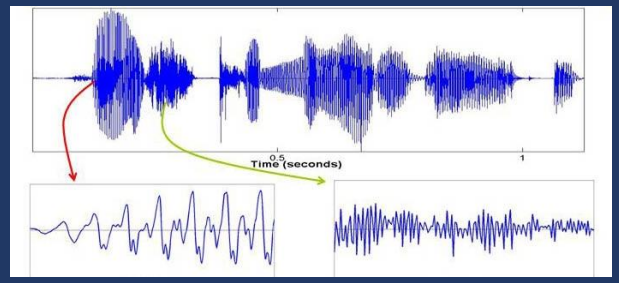
Prostate cancer video

YouTube API



Video data and viewer engagement metrics

FFMPEG



Acoustic features

Speech Recognition

Auto-punctuation

Stanford CoreNLP

Linguistic features (e.g. n-grams)

Other Pitfalls of Online Information

- Poorly understandable and actionable
- Underrepresentation of racial/ethnic diversity
- Limited information in other languages

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%

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

Scale from 0 (lowest) to 100 (highest)

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

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

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

Poor Understandability Defined as <75%

- 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.

Research Correspondence

BJUI
BJU International

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

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

Borno et a. BJUI 2020

Top Prostate Cancer Websites & YouTube Videos Lack Racial/Ethnic Diversity

Online
People

Limited Racial/Ethnic Diversity in Prostate Cancer Content

- 7.5% Black
- 0% Hispanic

- 3% Black
- 0.5% Hispanic

- 12.6% Black
- 0% Hispanic

Supported by a Department of Defense PCRP Health Disparity Research Award

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.

Ongoing Qualitative Study on the Impact of Underrepresentation for Black Men with Prostate Cancer

- "Even when you YouTube and you Google different things, you don't really see many African American males saying that they have it. I would imagine to the majority of African Americans, which we're more likely to get it, you think you're less likely to get it because you see less African Americans on the internet and on the websites, you know, when it's absolutely the other way around. So, the websites could be set up more -- they could be set up better."

Loeb et al. USAV Abstract 2023

Supported by Department of Defense PCRP

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
- 59% mobile-friendly

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

The Upside: Benefits of Online Networks for Prostate Cancer Care

←Connect with each other→

- Get health information
- Give & receive support
- Find providers
- Fundraising
- Advocacy

- Stay up to date
- Clinical Care
- Education
- Research
- Networking
- Advocacy

Recommendations for Patients and Families

- Ask your healthcare provider for high-quality sources of information
- Check the date of online information
- Check trusted sources first (e.g., ZERO website, PCF, Urology Care Foundation)

- Hosted by Drs. Veda Giri and Stacy Loeb
- Topics include key genes involved in prostate cancer, genetic counseling, genetic testing, and precision medicine
- Guests include physicians, genetic counselors, patients and family members
- Prospective study found the podcast series to be useful for lay audiences

Funded by a Department of Defense PCRP 2019 Idea Development Award (W81XWH2010310)

ENGAGEMENT STUDY

How to Vet Online Information: Medline Plus 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?

Conclusions

- Caution: misinformation about prostate cancer is widespread across social networks
- Other drawbacks to online information include poor understandability and limited representation of diversity
- Despite these drawbacks, online networks also hold great promise for education, support and ultimately improving the quality of care

Acknowledgement

- Department of Defense
- National Cancer Institute
- Prostate Cancer Foundation