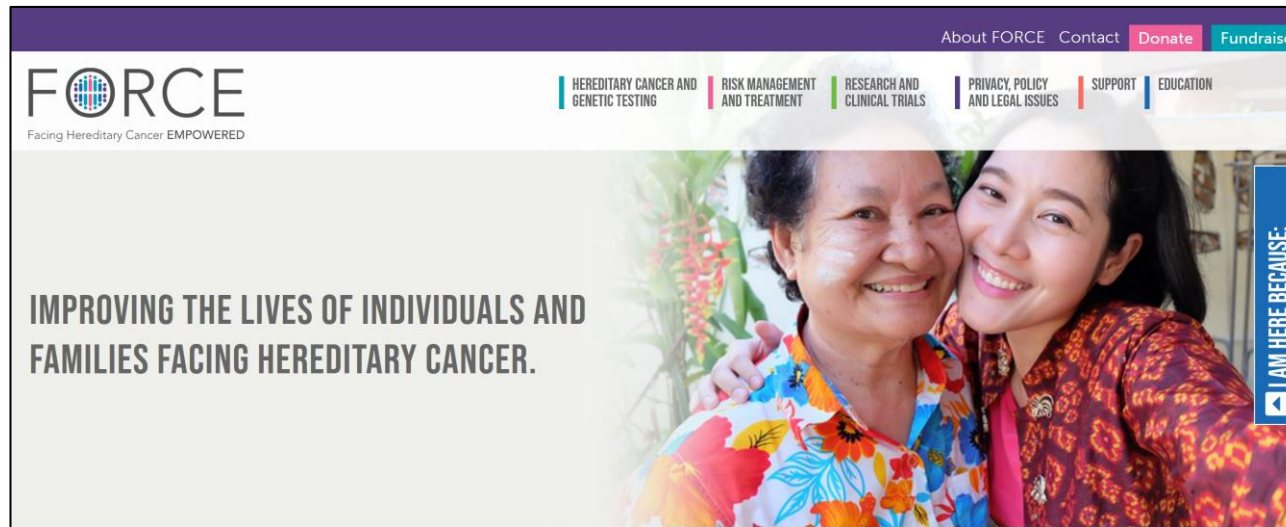# Digital Health Information: Media Coverage and Impact on Patients - Resources

FORCE
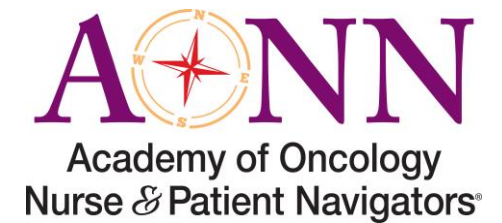Facing Hereditary Cancer EMPOWERED

Facing Our Risk of Cancer Empowered (FORCE)

In partnership with:

Objectives

By the end of this module, you will be able to:

1. Define health literacy and digital health literacy.

2. Discuss how health literacy affects patient understanding of health information.

3. List the challenges faced by patients in evaluating digital health information.

4. Outline how using plain language can help patients understand health information.

5. Describe how social determinants of health, culture, and personal beliefs may influence how patients interpret health information.

6. Outline how media coverage affects patient understanding of cancer and medical decision-making.

7. Discuss tips and resources for communicating with patients about health media reports.

Health Literacy

- **Personal health literacy:** the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.[1]

- **Organizational health literacy:** the degree to which organizations <u>equitably</u> enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others. [1]

1. What is Health Literacy? CDC

Digital Health Literacy or eHealth Literacy

- An individual's ability to seek, understand and assess electronic health information and apply the knowledge gained to address a health issue or problem.[6,7]

Find

Understand

Assess

Apply
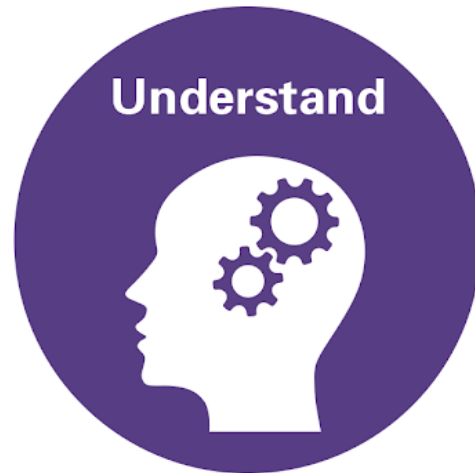
6. Novillo Ortiz, D. 2017. Digital Health Literacy. WHO.

7. Norman, C.D. & Skinner, H.A. 2006. eHealth Literacy: Essential Skills for Consumer Health in a Networked World. J Med Internet Res, 8(2), e-9.

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Social Determinants of Health & Digital Health Literacy[8]

Social Determinants of Health

- Education Access & Quality
- Healthcare Access & Quality
- Economic Stability
- Neighborhood and Built Environment
- Social and Community Context

Social Determinants of Health
Copyright-free

Healthy People 2030

Find

Understand

Assess

Apply

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8. Healthy People 2030, U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. Retrieved 11/11/2020, from https://health.gov/healthypeople/objectives-and-data/social-determinants-health

Traps of Online Information

- Majority of patients use online resources to access information about cancer.[9] Challenges exist for those who do.[10-12]
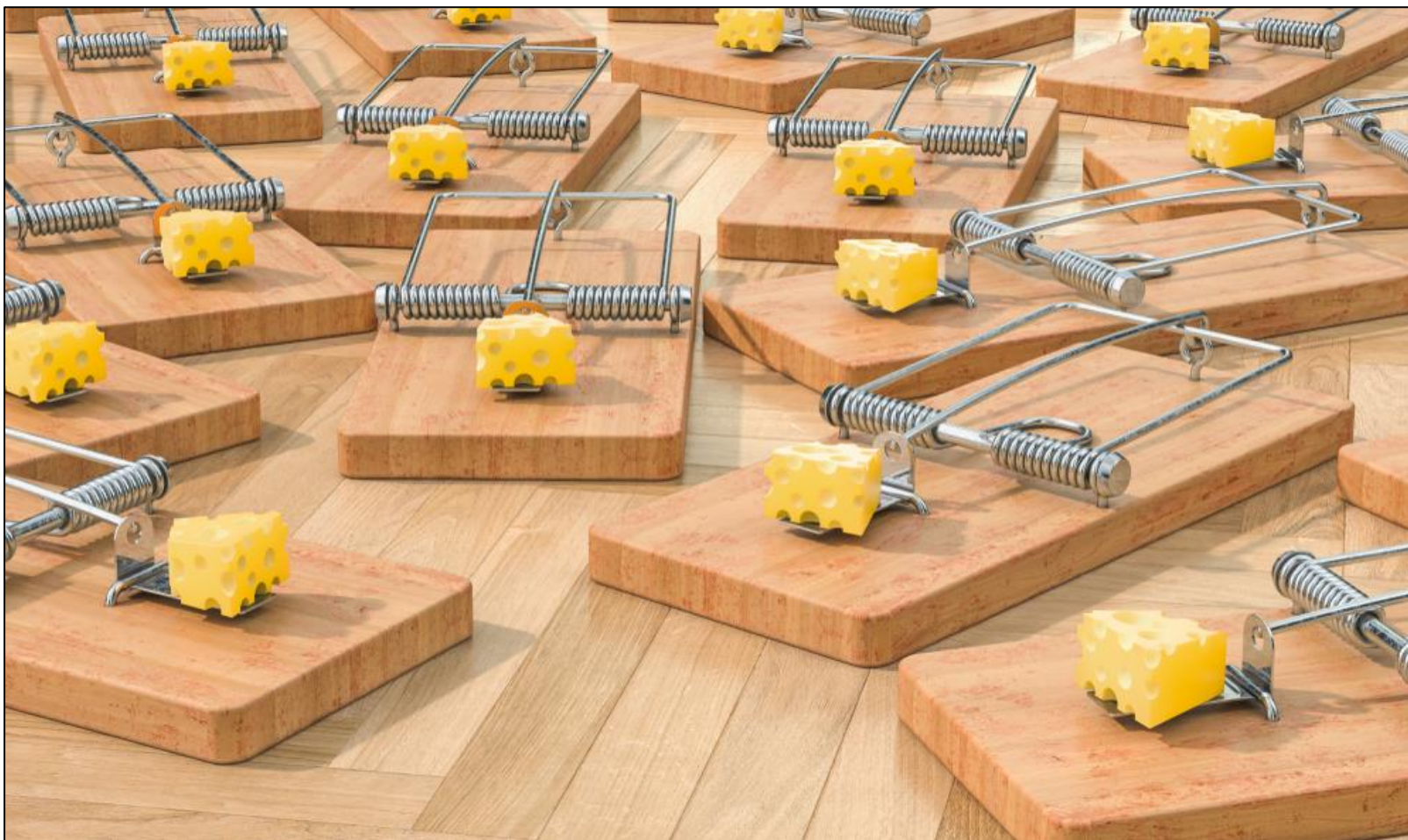
Digital health information may be:
- contradictory
- extensive
- sensationalized
- inaccurate
- lacking expert review
- lacking context
- jargon-filled
- locked behind a paywall
- retargeted

9.Tennant et al. J Med Internet Res 2015;17(3):e70.
10.Sommerhalder et al. Pat Edu & Counsel 2009; 77(2): 266.
11. Jiang S, Liu PL *Psycho-Oncology*. 2020;29(1):61-67
12. Lee K, Hoti K, Hughes JD, Emmerton L. *J Med Internet Res*. 2014;16(12):e262

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XRAY Program

FacingOurRisk.org/XRAY

XRAY was supported by the Cooperative Agreement Number: 5NU01DP005404-04-00, funded by the Centers for Disease Control and Prevention.

Strategies & Techniques to Improve Health Literacy

- Create awareness about health literacy

- Use plain language[14]

- Apply concepts of "Teach-back"[15]

- Apply the concept of "Ask Me 3"[16]

14. Source: PlainLanguage.gov
15. Source: Agency for Health Research and Quality. https://www.ahrq.gov/sites/default/files/wysiwyg/professionals/quality-patient-safety/patient-family-engagement/pfeprimarycare/PatientsGuideToTeachBack.pdf
16. Source: Institute for Healthcare Improvement. http://www.ihi.org/resources/Pages/Tools/Ask-Me-3-Good-Questions-for-Your-Good-Health.aspx

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Plain Language[14]

- Communication with people in a way they can understand the first time they read or hear it.

14. Plainlanguage.gov

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Teach-back[15]

- Ask patients to repeat back essential information in their own words.

  - Provides opportunity to reteach if needed.

- Educate patients about proactively using teach-back with their providers.

15. Source: Agency for Health Research and Quality. https://www.ahrq.gov/sites/default/files/wysiwyg/professionals/quality-patient-safety/patient-family-engagement/pfeprimarycare/PatientsGuideToTeachBack.pdf

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Ask Me 3[16]

- Encourages patients to make sure that they have the answer to three questions before leaving their doctors office:
  - What is my main problem?
  - What do I need to do now?
  - Why is it important for me to do this?

16. Source: Institute for Healthcare Improvement. http://www.ihi.org/resources/Pages/Tools/Ask-Me-3-Good-Questions-for-Your-Good-Health.aspx

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"XRAY Vision"

CHECK information before passing on to others!

Source

Content

Context & Relevance

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Check the Source

- **.**gov are government agencies
  - Very reliable
  - CDC, NIH, NCI

- **.**edu are academic institutions and universities
  - Reliable
  - Watch for press releases

- NewsGuard is a browser extension that provides a "nutritional label" on news websites (requires a subscription)

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Check the Source

- **.**org are non-profit organizations
  - What is their mission?
  - Who are their advisors and board members?

- **.**com are commercial, for-profit companies
  - What is their business?
  - Who are the owners or governing bodies?
  - Are they selling products?

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Check the Content

- Is it current?
- Is it neutral?
  - Look for terms like "miraculous," and "cure."
  - Look for conspiracy theories
- Are the statistics clear?
- Does the content make sense?

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Check the Content Before Sharing

- Was an expert cited?

- Is the cited authority a real person?

- What are their credentials?

- What is their affiliation?

- Check fact-checker websites like Snopes.com.

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Check the Context and Relevance

- Was this human research?

- How many people were studied?

- What phase/how large was the study?

- Were participants representative of the patient population?

- Were the results peer reviewed?

- Do the results affect clinical care or outcomes?

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Take Home Messages

1. Health literacy is an important component of health communication. We can all play a role in improving health literacy.

2. There are features unique to digital health information that makes it particularly challenging for patients to navigate. These features facilitate the wide and rapid spreading of misinformation.

3. There are tools and resources available to help empower patients to improve their health literacy.
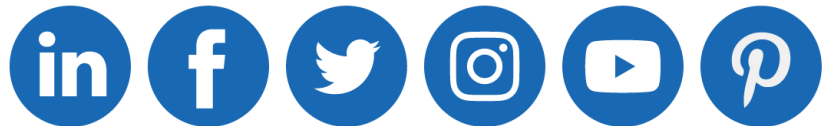
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Connect with FORCE

Website: FacingOurRisk.org

Helpline: 866-288-RISK

Email: suefriedman@FacingOurRisk.org

Get Social: FacingOurRisk

Thank You to Our Partners

- Academy of Oncology Nurse & Patient Navigators
- Alejandra de Mendoza, PhD
- Allison Kurian, MD
- Asian Pacific Partners for Empowerment; Advocacy, & Leadership
- Barbara Segarra-Vasquez, DHSc/Univ. PR
- Beautiful Gate
- Breast Cancer Resource Center
- CURE/Oncology Nursing News
- Deb Duquette, CGC
- Debbie Setuain
- Eileen Kastura
- Florida Breast Cancer Foundation
- For The Breast of Us
- Geographic Health Equity Alliance

- Ghecemy Lopez, MAEd
- Gulf State YBCS Network
- Jennifer Klemp, PhD
- Johns Hopkins
- LatinaSHARE
- Laura Guyer, PhD
- Lisa Rezende, PhD
- Living Beyond Breast Cancer
- Louisiana Public Health Institute
- Lourdes Baezconde-Garbanati, PhD, MPH
- Metastatic Breast Cancer Alliance
- Metastatic Breast Cancer Network
- METAvivor
- Michigan Department HHS

- National African American Tobacco Prevention Network
- National Alliance for Hispanic Health
- National LGBT Cancer Network
- Nat'l Society of Genetic Counselors
- Sanford Health
- SelfMade Health Network
- Sharsheret
- Susan G. Komen
- Susan Vadaparampil, PhD
- Tigerlily Foundation
- Thomas Jefferson University
- Touch: The Black Breast Cancer Alliance
- University of Illinois, Chicago
- Utah Department of Health
- Young Survival Coalition

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References

1. CDC website: What is health literacy: https://www.cdc.gov/healthliteracy/learn/index.html.
2. FORCE needs assessment for PROJECT EXTRA (Cooperative agreement: NU58DP2019010210 supported by the CDC). Unpublished.
3. Safeer et. al. Health Literacy: The Gap Between Physicians and Patients. *American Family Physician*. 2005. 72(3)
4. Scott, et. al. Health Literacy and Preventive Health Care Use Among Medicare Enrollees in a Managed Care Organization. *Medical Care*. May 2002 - Volume 40 - Issue 5 - p 395-404.
5. Novillo Ortiz D, (WHO) 2017. Digital health literacy.
6. 7. Norman, C.D. & Skinner, H.A. 2006. eHealth Literacy: Essential Skills for Consumer Health in a Networked World. J Med Internet Res, 8(2), e-9.
7. Jacobs W, Amuta AO, Jeon KC. Health information seeking in the digital age: An analysis of health information seeking behavior among US adults. *Cogent Social Sciences*. 2017;3(1):1302785. doi:10.1080/23311886.2017.1302785
8. Healthy People 2030, U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. Retrieved 11/11/2020, from https://health.gov/healthypeople/objectives-and-data/social-determinants-health
9. Tennant et al. J Med Internet Res 2015;17(3):e70).
10. Sommerhalder et al. Pat Edu & Counsel 2009; 77(2): 266.
11. Jiang S, Liu PL *Psycho-Oncology*. 2020;29(1):61-67
12. Lee K, Hoti K, Hughes JD, Emmerton L. *J Med Internet Res*. 2014;16(12):e262
13. FORCE XRAY microsite. https://www.facingourrisk.org/XRAY
14. PlainLanguage.gov
15. Agency for Health Research and Quality. https://www.ahrq.gov/sites/default/files/wysiwyg/professionals/quality-patient-safety/patient-family-engagement/pfeprimarycare/PatientsGuideToTeachBack.pdf
16. Institute for Healthcare Improvement. http://www.ihi.org/resources/Pages/Tools/Ask-Me-3-Good-Questions-for-Your-Good-Health.aspx.

Resources

1. Centers for Disease Control and Prevention: Attributes of a Health Literate Organization: https://www.cdc.gov/healthliteracy/planact/steps/index.html

2. Agency for Health Research and Quality (AHRQ): Ten Attributes of Health Literate Health Care Organizations: https://www.ahrq.gov/health-literacy/publications/ten-attributes.html

3. Institute for Healthcare Advancement: https://iha4health.org/

4. Centers for Disease Control and Prevention: Clear Communication User Guide: https://www.cdc.gov/ccindex/pdf/clear-communication-user-guide.pdf

5. HealthGuard by NewsGuard is a browser extension that provides a "nutritional label" on news websites (requires a subscription): https://www.newsguardtech.com/healthguard-overview/

6. Snopes.com is a media fact-checking/myth debunking website: https://www.snopes.com/

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