Health Literacy in the Digital Age: Applications to Genomics

Marleah Dean Kruzel, PhD and Sue Friedman, DVM
Disclosures

This work is supported by the Center for Disease Control and Prevention (CDC-RFA-DP19-1906). Opinions expressed by presenters are their own.
Objectives

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

1. Define health literacy and digital health literacy.
2. Discuss the impact of online health information on healthcare.
3. Describe how social determinants of health, culture, and personal beliefs may influence how patients interpret and act on genomic health information.
4. List the challenges faced by patients in evaluating digital health information on genomics.
5. Outline how media coverage affects patient understanding of cancer genetics and medical decision-making.
6. Discuss tips and resources for communicating about online health information and media reports.
“I did not understand any of my test results, despite asking my doctor to explain on more than one occasion.” – Patient Survey Respondent

Health Literacy & Digital Health Literacy
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 equitably 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.\(^2,3\)


Health Information Is Filtered Through Personal Lens

Perception of digital health information may be affected by:
- age
- gender
- diagnosis & stage
- personal experiences
- belief system
- cultural perspective
- source of information
- social determinants of health


Identity and Experiences

A satisfying romantic relationship may improve breast cancer survivors’ health


Breast cancer survivors in romantic relationships who feel happy and satisfied with their partners may be at lower risk for a host of health problems, new research suggests.

Diagnosis and Stage

Medical Daily

Metastatic Cancer Negatively Affects Employment, But Treating Symptoms Can Help


Dis/Trust in Medicine

Dis/Trust in Medicine


Breast cancer survivors in romantic relationships who feel happy and satisfied with their partners may be at lower risk for a host of health problems, new research suggests.
Social Determinants of Health & Digital Health Literacy

“The COVID 19 pandemic demonstrates that lack of Broadband Internet Access influences each of the... social determinants of health.” – Benda et al. (2020, p. 1123)
Social Determinants of Health

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

Digital Health Literacy

- Find
- Understand
- Assess
- Apply

“COVID-19 dramatically illustrated the nation’s vulnerability. Of the approximately 50 million students sent home by school closings, over 9 million lack home internet access.”

“Genetics may hold special allure and generate new groups of health information seekers.” – McBride et al., 2009, p. 585.
The Internet and Health

• The Internet and social media provide a unique opportunity for individuals to access health information, enhancing health-promoting behaviors.\textsuperscript{11}

Patients report online health information to be\textsuperscript{12}:

• Inaccurate/false
• Misleading information

Clinicians are concerned about the online information’s\textsuperscript{12-13}:

• Quality
• Credibility

• The Internet is creating inequalities for accessing health information.\textsuperscript{13-15}
Example: Genetics and Cancer

- Individuals use the Internet and social media to learn about and discuss information about genetics and genomics.\(^7\)
- Up to 90% of individuals with cancer use online resources to access information about cancer,\(^{16}\) particularly breast cancer patients.\(^{17}\)
- For example, in one study, 46.5% of patients look \textbf{first} to the \textit{Internet} for information about cancer genetics, disease, and genetic testing.\(^{18}\)
- Yet, patients have concerns about credibility, accuracy, trust, and privacy.\(^{19}\)
Challenges of Online Health Information

“As a student with good health literacy, it’s easy to forget how people may perceive misinformation on the Internet.” – Genetic counseling student.
Traps of Online Information

• Majority of patients use online resources to access information about cancer.¹⁶ Challenges exist for those who do.²⁰⁻²²

Digital health information may be:
• contradictory
• extensive
• sensationalized
• inaccurate
• lacking expert review
• lacking context
• jargon-filled
• locked behind a paywall
• retargeted

²². Lee K, Hoti K, Hughes JD, Emmerton L. J Med Internet Res. 2014;16(12):e262
1) Contradictory

**Scary headlines aside, drinking milk probably does not cause breast cancer**


**Dairy milk consumption linked to 80 percent spike in breast cancer risk**

2) Extensive

Google

breast cancer

All News Images V Settings Tools

About 478,000,000 results (0.76 seconds)

Google

prostate cancer

All News Images V Settings Tools

About 106,000,000 results (0.90 seconds)
3) Sensationalized

https://www.jpost.com/health-science/a-cure-for-cancer-israeli-scientists-say-they-think-they-found-one-578939

https://www.barrons.com/articles/these-companies-are-racing-to-develop-a-blood-test-that-detects-cancer-what-investors-should-know-51617878700
4) Inaccurate

5) Lacking Expert Review

https://facebook.com/learntherisk

Unlicensed medical 'cures' are flourishing in closed Facebook groups, where cancer treatments — and even surgery — are sold beyond the reach of the law


Gwyneth Paltrow's 'The Goop Lab' treats fake science like the real thing. Here's why that's dangerous.

6) Lacking Context


https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4674776/
7) Jargon Filled and Locked Behind a Paywall


https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5507740/

https://www.nature.com/articles/s41436-021-01151-8#access-options

https://www.gynecologiconcology-online.net/action/showCart?backUri=%2Farticle%2FS0090-8258%2820%2933947-0%2Ffulltext&addToCart=true
8) Targeted and Retargeted

Biases in Algorithms Hurt Those Looking for Information on Health

Just because YouTube recommends a video doesn't mean it has medically valid information.

July 14, 2020 • Ariane Soueidi, Michigan State University


https://www.youtube.com/watch?v=QusYH-wk-f0
FORCE eXamining the Relevance of Articles for You (XRAY) Program

“There is so much toxic disinformation in the world of hereditary cancer. FORCE’s XRAY program is an antidote.” – FORCE volunteer
XRAY was supported by the Cooperative Agreement Number: 5NU01DP005404-04-00, funded by the Centers for Disease Control and Prevention.
Asparagine bioavailability governs metastasis in a model of breast cancer

Using a functional model of breast cancer heterogeneity, we previously showed that clonal sub-populations proficient at generating circulating tumour cells were not all equally capable of forming metastases at secondary sites\(^1\). A combination of differential expression and focused in vitro and in vivo RNA interference screens revealed candidate drivers of metastasis that discriminated metastatic clones. Among these, asparagine synthetase expression in a patient’s primary tumour was most strongly correlated with later metastatic relapse. Here we show...
Key components of XRAY reviews include:
• plain language summary
• clinical relevance scores
• expert guidelines
• question prompts
• links to related clinical trials
• ratings of the accuracy of the media coverage
• links to related resources and references
• printer-friendly versions

Study: Is asparagus linked to breast cancer metastasis?

Most relevant for: People diagnosed with breast cancer

A new study published in the journal *Nature* shows that asparagine, a protein building block that takes its name from asparagus, promotes the spread of breast cancer in mice. The study by cancer experts from Britain, Canada and the U.S. investigated whether limiting the levels of asparagine in mice could reduce tumor metastasis. (3/2/18)

https://www.facingourrisk.org/XRAY/asparagus-and-metastasis
I had a mastectomy to lessen my risk of breast cancer. Does new science say that was a mistake?

A new study used CRISPR to reconstruct all of the possible BRCA gene mutations, and the odds that they all lead to cancer may be lower than the company that created the BRCA test would like us to believe.
Study: A new method for determining whether genetic variants in BRCA1 increase cancer risk

Most relevant for: People who have a Variant of Uncertain Significance in a gene associated with cancer risk.

Ever since BRCA1 was discovered, researchers have been trying to understand which of the thousands of possible DNA changes in this gene increase cancer risk and which are harmless changes. A new study in Nature reports how a cutting-edge technology called "genome editing" may be used to classify changes—known as variants of uncertain significance—in BRCA1 as harmful or harmless. Once validated, this same technology may be used to classify variants in other genes. (9/29/18)

https://www.facingourrisk.org/XRAY/classifying-uncertain-variants
Germline BRCA mutation and outcome in young-onset breast cancer (POSH): a prospective cohort study

Eline R Copson, PhD - Tom C Maldman, MSc - William J Tapper, PhD - Ramsey J Cattrell, PhD - Stephanie Greiville Hoystge, MB - Prof Douglas G Altman, PhD - et al.

Summary

Background

Retropective studies provide conflicting interpretations of the effect of inherited genetic factors on the prognosis of patients with breast cancer. The primary aim of this study was to determine the effect of a germline BRCA1 or BRCA2 mutation on breast cancer outcomes in patients with young-onset breast cancer.

https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(17)30891-4/fulltext

"© [1/12/2018] GreenMedinfo LLC. This work is reproduced and distributed with the permission of GreenMedinfo LLC. Want to learn more from GreenMedinfo? Sign up for the newsletter here //www.greenmedinfo.com/greenmed/newsletter."

Facing Hereditary Cancer EMPOWERED
Key components of XRAY reviews include:

- plain language summary
- clinical relevance scores
- expert guidelines
- question prompts
- links to related clinical trials
- ratings of the accuracy of the media coverage
- links to related resources and references
- printer-friendly versions

**XRAY Summary and Relevance Scores**

Study: Survival and mutation status in breast cancer patients under age 40

**Most relevant for:** Young breast cancer patients

Studies have found conflicting rates of survival for BRCA mutation carriers who develop breast cancer, reporting better, worse and similar outcomes compared to patients with sporadic breast cancer. New results of the large Prospective Outcomes in Sporadic versus Hereditary (POSH) breast cancer study found no difference in survival rates between the two groups. The study also concluded that among young triple-negative breast cancer patients during the first 2 years after diagnosis, BRCA mutation carriers had an initial survival advantage compared to women without a BRCA mutation. (02/15/18)

[Read More](https://www.facingourrisk.org/XRAY/survival-mutation-status)
Expert Guidelines, Clinical Trials & Question Prompts

The National Comprehensive Cancer Network (NCCN) has Practice Guidelines on Standards of Palliative Care (2019). These include:

- All cancer patients should be screened for palliative care needs at their initial visit, at appropriate intervals, and as clinically indicated.
- Patients/families/caregivers should be informed that palliative care is an integral part of their comprehensive cancer care.
- Palliative care specialists should be readily available to provide consultation or direct care to patients/families/caregivers and/or health care professionals who request or require their expertise.

The American Society of Clinical Oncologists practice guideline for advanced cancer care (2016) recommend initiation of palliative care within 8 weeks of diagnosis. Other key recommendations include:

- Patients with advanced cancer, inpatients and outpatients, should receive dedicated palliative care services early in the disease course and concurrent with active treatment.
- Referring patients to interdisciplinary palliative care teams is optimal, and services may complement existing programs.
- Providers may refer caregivers of patients with early or advanced cancer to palliative care services.

The full ASCO recommendation can be found [here](#).

Question to Ask Your Doctor

- How do I find a palliative care specialist?
- I’m experiencing the following (e.g. pain, loss of appetite, anxiety, etc.), can a palliative care specialist help me? Does your practice have supportive services available?
- My family member or caregiver is having a difficult time coping with my diagnosis. Can a palliative care expert help them?
- What supportive services would you recommend for me?
Rating the Media Coverage of the Science

WHO COVERED THIS STUDY?

**Medpage Today**
Young-onset breast cancer survival unaffected by BRCA status—but exception seen in triple-negative disease
Rating: 4.0 Stars
- The headline states clearly what the study is about and what the results mean for younger women. It also describes the notable subgroup finding for those with TNBC.
- The article is well written, although somewhat technical and likely difficult for the general public.
- The author describes the study population and findings in detail.
- The author includes perspectives from several outside sources and an interview with the lead researcher.
- The author includes a full paragraph on study limitations.

**Newsweek**
A gene that ‘causes cancer’ probably doesn’t increase your chances of dying from cancer
Rating: 1.0 Stars
- See FORCE Headline Hype
- The headline is incredibly misleading.
- The lede (introductory text) is falsely alarming, using words like “notorious,” and citing one celebrity’s experience.
- The lead study researcher is interviewed, but no outside sources are cited.

**GreenMed Info**
The ‘deadly breast cancer gene’ is a myth, Lancet study confirms
Rating: 0 Stars
- See FORCE Headline Hype
- The title, lede and story are misleading, and dangerously incorrect.
- The author provides no evidence to support his conclusions, providing as references or sources only non-peer-reviewed publications from the GreenMedInfo.com, most of which (6 of 8) were written by him.

How we rated the media

FORCE
Facing Hereditary Cancer EMPOWERED
A new method for determining whether genetic variants in BRCA1 increase cancer risk

https://www.facingourrisk.org/XRAY/classifying-uncertain-variants

Full article: http://www.ncbi.nlm.nih.gov/pubmed/30209999

Ever since BRCA1 was discovered, researchers have been trying to understand which of the thousands of possible DNA changes in this gene increase cancer risk and which are harmless changes. A new study in Nature reports how a cutting-edge technology called "genome editing" may be used to classify changes—known as variants of uncertain significance in BRCA1 as harmful or harmless. Once validated, this same technology may be used to classify variants in other genes. (6/29/18)

Questions To Ask Your Health Care Provider

- Should I see a genetics expert to help me better understand my genetic test results?
- I have a BRCA1 VUS, can this new study help recategorize this change to either harmful or harmless?
- I have a VUS in another gene? Can this test be used to recategorize a VUS in another gene?
- I have a VUS, can I participate in a research study to help scientists learn more about recategorizing variants?

About FORCE

FORCE is a national nonprofit organization, established in 1999. Our mission is to improve the lives of individuals and families affected by adult hereditary cancers.

Is asparagus linked to breast cancer metastasis?

https://www.facingourrisk.org/XRAY/asparagus-and-metastasis

Full article: https://www.nature.com/articles/nature24445

A new study published in the journal Nature shows that asparagus, a protein building block that takes its name from asparagus, promotes the spread of breast cancer in mice. The study by cancer experts from Britain, Canada and the U.S. investigated whether limiting the levels of asparagus in mice could reduce tumor metastasis. (3/21/18)

Expert Guidelines

The National Comprehensive Cancer Network (NCCN) creates guidelines for cancer survivorship. Their survivorship guidelines on nutrition and weight management recommend:

- Assessing dietary intake of fats, vegetables, and unrefined grains, as well as red and processed meats, alcohol, and processed foods or beverages with added fats and/or sugars.
- Assessing eating habits, including portion size, meal timing, and frequency of eating out and use of soda or other sugars in foods or beverages.
- All survivors should be encouraged to:
  - Make informed choices about foods to ensure variety and adequate nutrient intake.
  - Limit refined sugars.
  - Eat a diet that is at least 50% plant-based, with the majority of food being vegetables, fruit and whole grains.
  - Track calorie intake.
  - Set monitoring of caloric intake as an effective strategy for weight management.
  - Minimize alcohol intake.
  - Limit intake to no more than one drink per day for a woman and two drinks per day for a man.

For patients desiring further recommendations on dietary guidelines, the USDA approximate food plate volumes are:

- Vegetables and fruits should comprise half the volume of food on the plate.
- Vegetables: 30% of plate; Fruits 20% of plate.
- Whole grains: 30% of plate.
- Protein: 25% of plate.

Recommended sources of dietary components:

- Fat: Plant sources such as olive or canola oil, avocados, seeds and nuts, and fatty fish.
- Carbohydrates: fruits, vegetables, whole grains and legumes.
- Protein: poultry, fish, legumes, low-fat dairy foods, and nuts.

The American Cancer Society recommendations on nutrition and physical activity include:

- Achieve and maintain a healthy weight throughout life.
- Adopt a physically active lifestyle.
- Consume a healthy diet with an emphasis on plant-based foods.
- Limit the amount of processed and red meats.
- Eat at least 2.5 cups of vegetables and fruits a day.
- Choose whole grains instead of refined grain products.
- Drink no more than 1 alcoholic drink per day (women).

Other experts also provide guidelines for nutrition and health, including:

- The Academy of Nutrition and Dietetics
- The United States Office of Disease Prevention and Health Promotion
- The American Institute for Cancer Research
Hi! In many Facebook groups for people with mutations, there are several people worried that the Covid-19 mRNA vaccine is going to mess with our DNA and make it worse for those of us with cancer mutations. Is there a way FORCE can do some webinars with vaccine doctors to explain mRNA and do some graphics and public health info we can share on these groups from you all to stop this misinformation?
– Request from FORCE member

https://www.youtube.com/watch?v=S69oj8FKGok

https://www.facingourrisk.org/XRAY/COVID-vaccines-for-people-with-cancer

https://www.facingourrisk.org/XRAY/mammography-and-COVID-vaccine
Tips & Resources

“I see how people get scared when research is taken out of context. These tools will help me empower patients to make their own decisions about information they find in the media.” – Genetic counseling student
General Strategies & Techniques to Improve Health Literacy

- Create awareness about health literacy
- Use plain language\(^\text{24}\)
- Apply concepts of “Teach-back”\(^\text{25}\)
- Apply the concept of “Ask Me 3”\(^\text{26}\)

\(^{24}\) Source: PlainLanguage.gov
Ask Me 3

• 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?

“XRAY Vision”

CHECK information before passing on to others!

Source

Content

Context & Relevance
Check the Source

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

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

**.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?

[https://www.cancer.gov/](https://www.cancer.gov/)

[https://cancer.ufl.edu/](https://cancer.ufl.edu/)
Check the Source - NewsGuard

Vaccines are made with the same chemical found to increase
NaturalNews.com website network

Proceed with caution: This website severely violates basic journalistic standards.

A network of sites promoting both medical and non-medical conspiracy theories, particularly the false claim that vaccines are linked to autism.

Score: 5/100

- Does not repeatedly publish false content
- Gathers and presents information responsibly
- Regularly corrects or clarifies errors
- Handles the difference between news and opinion responsibly
- Avoids deceptive headlines

- Website discloses ownership and financing
- Clearly labels advertising
- Reveals who's in charge, including any possible conflicts of interest
- The site provides names of content creators, along with either contact or biographical information

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

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

.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?
Check the Content

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

A cure for cancer? Israeli scientists may have found one

By MARIAN AMITE-HEPPMANN | JANUARY 23, 2019 23:14

https://www.jpost.com/health-science/a-cure-for-cancer-israeli-scientists-say-they-think-they-found-one-578939


The holy grail blood test that checks for FIFTY types of cancer

The holy grail blood test that checks for FIFTY types of cancer:
Groundbreaking technique will be trialled on 165,000 NHS patients next year - The ...

Nov 26, 2020

https://www.dailymail.co.uk/health/article-8991857/The-holy-grail-blood-test-checks-FIFTY-types-cancer.html

https://www.dailymail.co.uk/health/article-7390437/Have-100-000-women-poisoned-breast-implants-Worrying-evidence-new-scam-emerging.html

Confirm Before Sharing!

Check the content:
- Is the cited authority a real person?
- What are their credentials?
- Who began the chain?
- Did this come from an academic institution?
- Is the content on the institution’s website?
- Check fact-checker websites like Snopes.com.
Confirm Before Sharing! Snopes

Check the content:
• Is the cited authority a real person?
• What are their credentials?
• Who began the chain?
• Did this come from an academic institution?
• Is the content on the institution’s website?
• Check fact-checker websites like Snopes.com.
Check the Context

Research clinical 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?


https://www.mirr.co.uk/news/uk-news/chillies-could-help-beat-cancer-9549506


https://www.mirr.co.uk/news/uk-news/chillies-could-help-beat-cancer-9549506
Results: The observed rate of 3 of 5754 cases (0.052%) of head and neck cancers in BRCA-positive probands and likely carriers is significantly higher than the background incidence rate of 3 of 100,000 (0.003%) per year \((P < .001)\).
Take Home Messages
Health literacy is an important component of health communication. We can all play a role in improving health literacy.

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.

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

Website:  www.FacingOurRisk.org
Helpline:  866-288-RISK
Email:    info@FacingOurRisk.org
Twitter:  @FacingOurRisk

Connect with USF

Website:  www.cancercommunication.com
Email:    cancercomm@usf.edu
Twitter:  @marleahdeank