



# Health Literacy in the Digital Age: Applications to Genomics

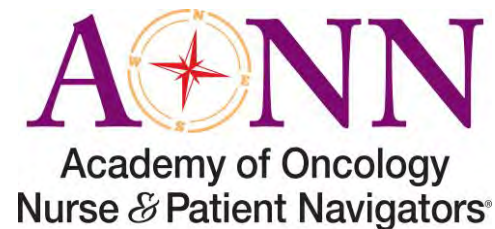
Marleah Dean Kruzel, PhD and Sue Friedman, DVM

**FORCE**

Facing Hereditary Cancer **EMPOWERED**

# 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.

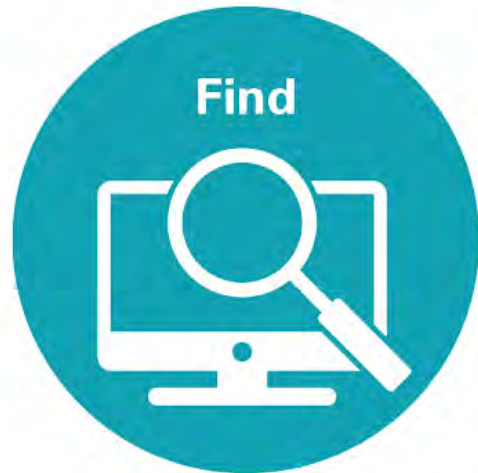
*“I did not understand any of my test results, despite asking my doctor to explain on more than one occasion.” – Patient Survey Respondent*

## Health Literacy & Digital Health Literacy



# 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.<sup>2,3</sup>



2. Novillo Ortiz, D. 2017. Digital Health Literacy. WHO.

3. 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.

# Health Information Is Filtered Through Personal Lens<sup>4</sup>

## Identity and Experiences

🕒 JUNE 3, 2020

### A satisfying romantic relationship may improve breast cancer survivors' health

by Emily Caldwell, The Ohio State University



Credit: CC0 Public Domain

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.

<https://medicalxpress.com/news/2020-06-romantic-relationship-breast-cancer-survivors.html>

## Diagnosis and Stage

Medical Daily Vitality Mental Health Innovation

### THE GRAPEVINE

#### Metastatic Cancer Negatively Affects Employment, But Treating Symptoms Can Help

Dec 21, 2015 10:52 AM By Jaleesa Baukman



New research suggests metastatic cancer symptoms play an important role in whether a patient maintains employment. Pixabay

<https://www.medicaldaily.com/metastatic-cancer-negatively-affects-employment-treating-symptoms-can-help-366216>

## Dis/Trust in Medicine

CNBC

MARKETS BUSINESS INVESTING TECH POLITICS CNBC TV

HEALTH AND SCIENCE

### FDA warns of 14 'fraudulent' cancer cure companies

PUBLISHED WED, APR 26 2017-10:05 AM EDT | UPDATED WED, APR 26 2017-10:23 AM EDT

NBC NEWS Maggie Fox



The Food and Drug Administration warned 14 companies to stop making claims about herbal products and other treatments marketed to treat or prevent cancer.

<https://www.cnn.com/2017/04/26/fda-warns-of-14-fraudulent-cancer-cure-companies.html>

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

4. 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

*“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 & Digital Health Literacy

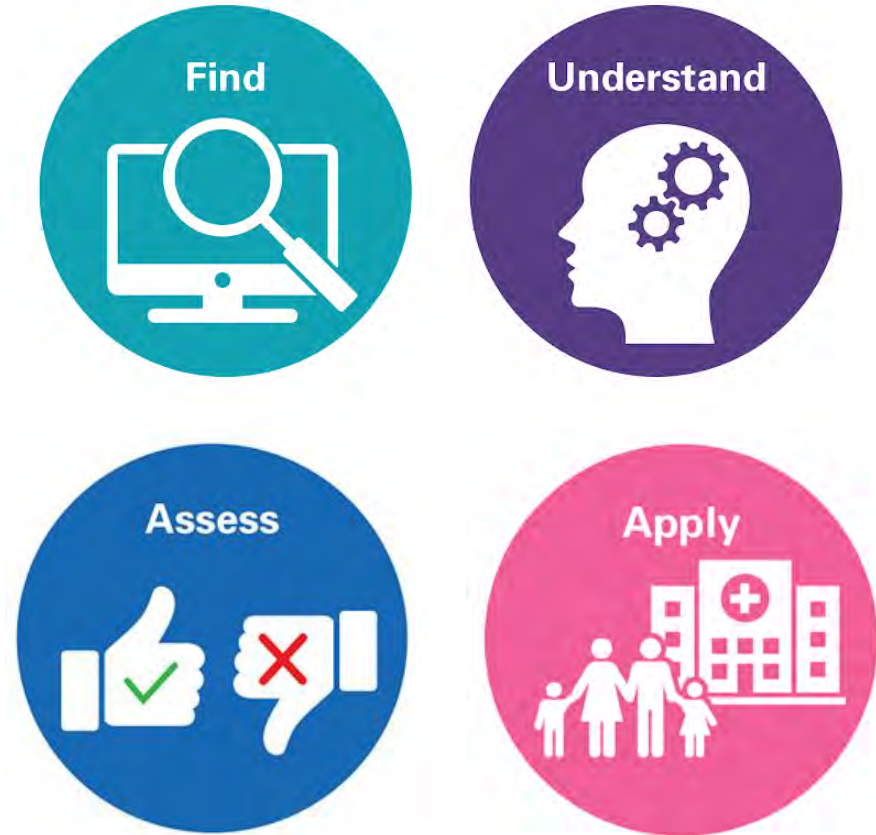


# Social Determinants of Health<sup>5</sup> & Digital Health Literacy<sup>2,3</sup>

## Social Determinants of Health



## Digital Health Literacy



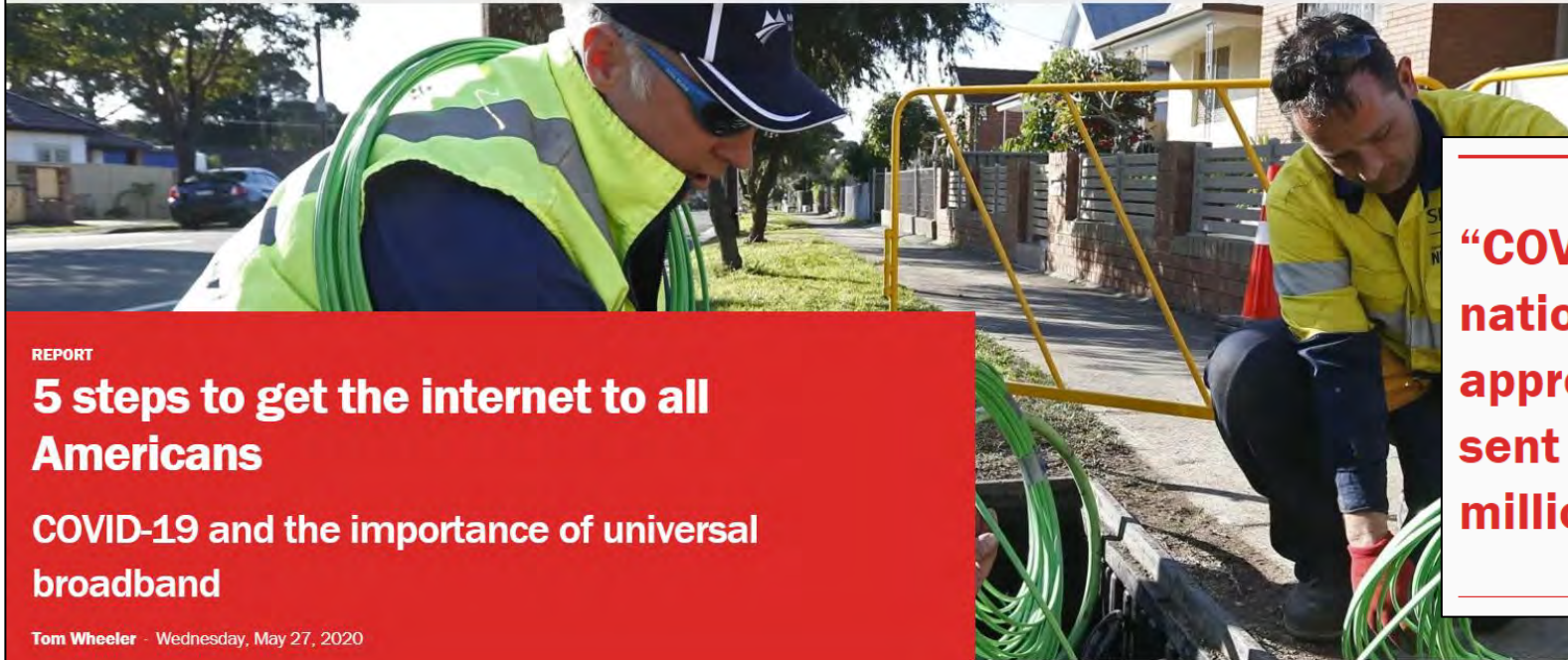
Social Determinants of Health  
Copyright-free

 Healthy People 2030

# Neighborhood and Built Environment

BROOKINGS

AI CITIES & REGIONS GLOBAL DEV INTL AFFAIRS



REPORT

## 5 steps to get the internet to all Americans

COVID-19 and the importance of universal broadband

Tom Wheeler - Wednesday, May 27, 2020

**“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.”**

6. Wheeler T. May 27, 2020. Brookings. <https://www.brookings.edu/research/5-steps-to-get-the-internet-to-all-americans/>

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

# Online Health Information & Genomics

# The Internet and Health



- The Internet and social media provide a unique opportunity for individuals to access health information,<sup>7-10</sup> enhancing health-promoting behaviors.<sup>11</sup>



Patients report online health information to be<sup>12</sup>:

- Inaccurate/false
- Misleading information



Clinicians are concerned about the online information's<sup>12-13</sup>:

- Quality
- Credibility

- The Internet is creating inequalities for accessing health information.<sup>13-15</sup>

# Example: Genetics and Cancer



Image: NHGRI

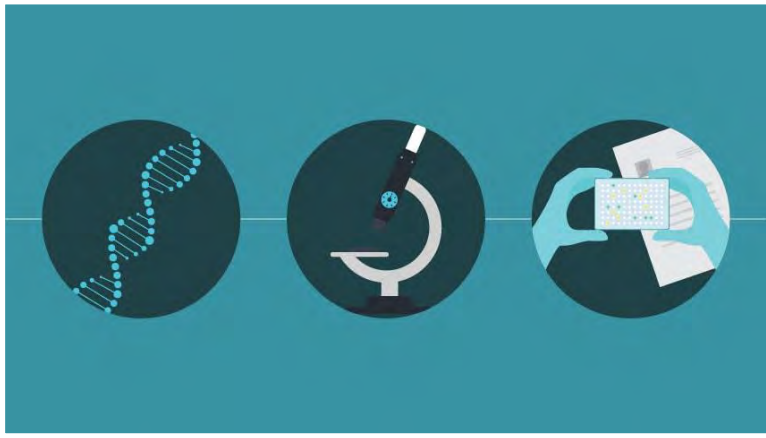


Image: Michigan Health Lab

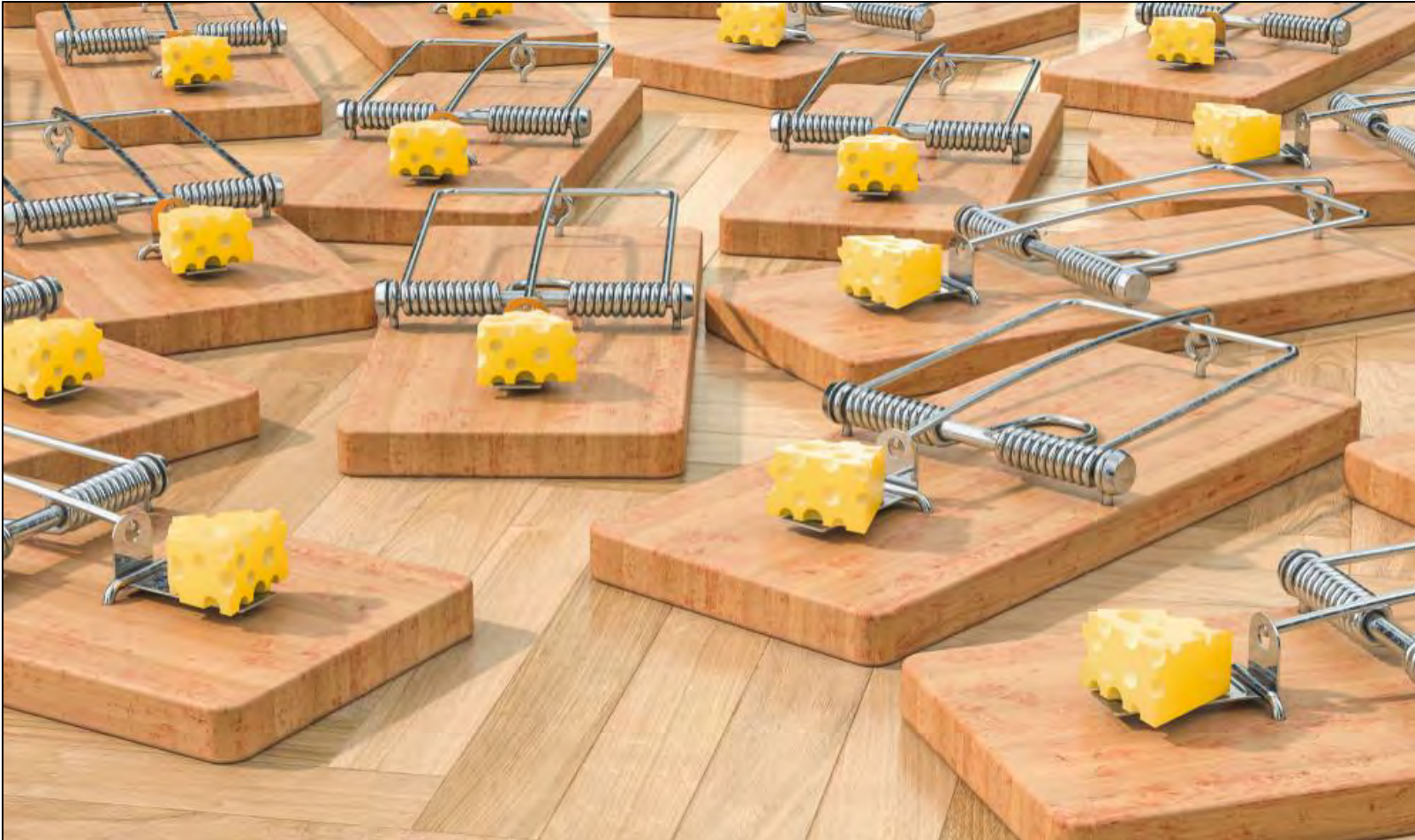
- Individuals use the Internet and social media to learn about and discuss information about genetics and genomics.<sup>7</sup>
- Up to 90% of individuals with cancer use online resources to access information about cancer,<sup>16</sup> particularly breast cancer patients.<sup>17</sup>
- For example, in one study, 46.5% of patients look **first** to the **Internet** for information about cancer genetics, disease, and genetic testing.<sup>18</sup>
- Yet, patients have concerns about credibility, accuracy, trust, and privacy.<sup>19</sup>

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

# Challenges of Online Health Information

# Traps of Online Information

- Majority of patients use online resources to access information about cancer.<sup>16</sup> Challenges exist for those who do.<sup>20-22</sup>



Digital health information may be:

- contradictory
- extensive
- sensationalized
- inaccurate
- lacking expert review
- lacking context
- jargon-filled
- locked behind a paywall
- retargeted

16. Tennant et al. *J Med Internet Res* 2015;17(3):e70).

20. Sommerhalder et al. *Pat Edu & Counsel* 2009; 77(2): 266.

21 Jiang S, Liu PL *Psycho-Oncology*. 2020;29(1):61-67

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

**FORCE**

Facing Hereditary Cancer EMPOWERED

# 1) Contradictory

The Washington Post

*Democracy Dies in Darkness*

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



[https://www.washingtonpost.com/lifestyle/wellness/breast-cancer-milk/2020/03/06/97358168-5e77-11ea-b014-4fafa866bb81\\_story.html](https://www.washingtonpost.com/lifestyle/wellness/breast-cancer-milk/2020/03/06/97358168-5e77-11ea-b014-4fafa866bb81_story.html)

VegNews

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## DAIRY MILK CONSUMPTION LINKED TO 80 PERCENT SPIKE IN BREAST CANCER RISK

<https://vegnews.com/2020/3/dairy-milk-consumption-linked-to-80-percent-spike-in-breast-cancer-risk>



## 2) Extensive



A screenshot of the Google search interface. The search bar contains the text "breast cancer". To the right of the search bar are icons for a microphone and a magnifying glass. Below the search bar, the word "All" is underlined, followed by "News", "Images", "V", "Settings", and "Tools". Below these options, the text "About 478,000,000 results (0.76 seconds)" is displayed.

Google

breast cancer

All News Images V Settings Tools

About 478,000,000 results (0.76 seconds)



A screenshot of the Google search interface. The search bar contains the text "prostate cancer". To the right of the search bar are icons for a microphone and a magnifying glass. Below the search bar, the word "All" is underlined, followed by "News", "Images", "V", "Settings", and "Tools". Below these options, the text "About 106,000,000 results (0.90 seconds)" is displayed.

Google

prostate cancer

All News Images V Settings Tools

About 106,000,000 results (0.90 seconds)

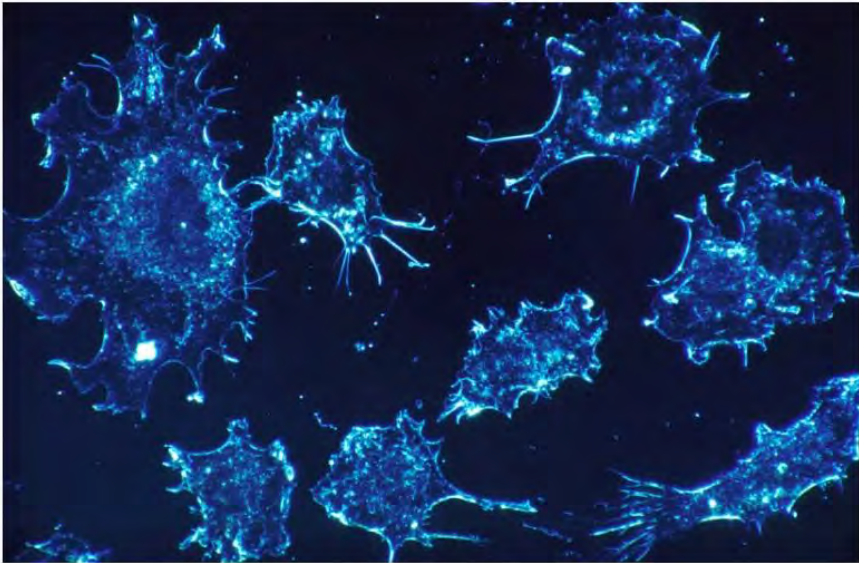
# 3) Sensationalized

THE JERUSALEM POST CORONAVIRUS US ELECTIONS ISRAEL NEWS WORLD NEWS MIDDLE EAST U.S. POLITICS

## A cure for cancer? Israeli scientists may have found one

“Our results are consistent and repeatable.”

By MAAYAN JAFFE-HOFFMAN JANUARY 28, 2019 23:14



Cancer cells [illustrative]  
(photo credit: PIXABAY)

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

BARRON'S  
Topics Magazine Data Advisor Penta 100 Years

BIOTECH AND PHARMA FEATURE

## How a Simple Blood Test Could Reduce Cancer Deaths

By Bill Alpert Updated April 12, 2021 / Original April 8, 2021



READ N

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

# 4) Inaccurate


 **Daily Mail** ✓  
June 21, 2016 · 🌐

'Holy grail' for women with Angelina Jolie breast cancer gene




DAILYM.AI 

Drug that prevents Angelina Jolie breast cancer gene nearly ready

  440 32 Comments 109 Shares

 Like  Comment  Share

<https://www.dailymail.co.uk/health/article-3650551/Scientists-reveal-drug-prevents-Angelina-Jolie-breast-cancer-gene-step-closer.html?ito=social-facebook>



**NEWS** POLITICS PLAN YOUR VACCINE COVID-19 U.S. NEWS OPINION BUSINESS WORLD TECH

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**With Aaron Gilchrist**

Get the latest with NBC News NOW as we cover the most important stories of the day and take deep dives on issues you care about.

**NEW STUDY: U.K. VARIANT MAY HAVE HIGHER MORTALITY RATE, PERHAPS AS HIGH AS 61%**

# 5) Lacking Expert Review

The screenshot shows the Facebook profile for 'Learn The Risk' (@learntherisk). The page features a circular logo with the text 'LEARN THE RISK ORG' and a tagline 'Knowledge • Action • Heredity'. A post from March 31, 2019, contains a text-based warning about vaccine ingredients and a video thumbnail. The video thumbnail shows a woman with a shocked expression next to a list of ingredients: Polysorbate 80 & 20, Aluminum, Latex Rubber, Mercury/Thimerosal, Formaldehyde, and Aborted Fetal Cells. A red arrow points from the text 'Do these sound "healthy" to you?' to the list. The page also displays community statistics: 101,713 likes and 105,189 followers. The 'About' section includes the website 'www.LearnTheRisk.org' and the page creation date of October 30, 2015.

<https://facebook.com/learntherisk>

A screenshot of a Facebook comment from a user whose profile picture is redacted. The comment, posted 1 week ago, reads: "The Vax was Not brought in for Covid-Covid was brought in for the vax. Once you realize that, everything else makes sense" Crimes Against Humanity Lawsuit. Filed 5/21/2021". The comment has 178 likes and a 'REPLY' button.

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

The screenshot shows a closed Facebook group named 'GoMaf Oracle'. The group has 7,647 members and 0 new posts today. A hand is shown holding a small vial, with a yellow circle highlighting it. The background of the group page features a 'DANGER' warning sign with text: 'WARNING: This group contains information that is not intended for general distribution. It is for informational purposes only. Do not use the information in this group to diagnose or treat any medical condition. If you are in need of medical attention, please contact your healthcare provider. NICO, Jawahar, root canals, 10,182 members'. The group was created by 'abc'.

<https://www.businessinsider.nl/in-closed-facebook-groups-pushing-unproven-treatments-2019-8/>

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

by Bethany Ao, Updated: February 4, 2020



<https://www.inquirer.com/health/goop-gwyneth-paltrow-pseudoscience-netflix-jade-egg-20200204.html>

## 6) Lacking Context



★ 20th ANNUAL  
CRITICS' CHOICE  
FILM AWARDS

ANNUAL  
CRITICS'

**'Angelina Jolie gene' may be linked to Alzheimer's, researchers say**

Scientists at the University of California, San Francisco found low levels of BRCA1, the DNA repair gene, in the brains of patients who had died from Alzheimer's.

WWW.DAILYMAIL.CO.UK

<https://www.dailymail.co.uk/health/article-3339670/Could-Angelina-Jolie-gene-increase-risk-dementia-BRCA1-gene-drives-breast-cancer-linked-Alzheimer-s.html>



nature  
COMMUNICATIONS

Home About the journal Authors and referees Browse archive Search

nature.com > journal home > archive by date > november > full text

NATURE COMMUNICATIONS | ARTICLE OPEN

DNA repair factor BRCA1 depletion occurs in Alzheimer brains and impairs cognitive function in mice



<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4674776/>

# 7) Jargon Filled and Locked Behind a Paywall

**WILEY INTERNATIONAL JOURNAL OF CANCER**

This Article For Authors Learn More Submit

*Int J Cancer*. 2020 Oct 15; 147(8): 2150–2158. PMID: PMC7496272  
Published online 2020 Jun 8. doi: [10.1002/ijc.33117](https://doi.org/10.1002/ijc.33117) PMID: [32510614](https://pubmed.ncbi.nlm.nih.gov/32510614/)

**Evaluation of yield and experiences of age-related molecular investigation for heritable and nonheritable causes of mismatch repair deficient colorectal cancer to identify Lynch syndrome**

Janet R. Vos,<sup>1</sup> Ingrid E. Fakkert,<sup>1</sup> Liesbeth Spruijt,<sup>1</sup> Riki W. Willems,<sup>2</sup> Sera Langenveld,<sup>3</sup> Arjen R. Mensenkamp,<sup>1</sup> Edward M. Leter,<sup>3</sup> Iris D. Nagtegaal,<sup>2</sup> Marjolijn J. L. Ligtenberg,<sup>1,2</sup> Nicoline Hoogerbrugge,<sup>1</sup> and FINAL Group †

<https://pubmed.ncbi.nlm.nih.gov/32510614/>

**APPOS BPOS** **Psycho-Oncology** Journal of the Psychological, Social and Behavioral Dimensions of Cancer **WILEY**

PAPER

**Relationship between self-reported and objectively measured physical activity and subjective memory impairment in breast cancer survivors: role of self-efficacy, fatigue and distress**

Siobhan M. Phillips ✉, Gillian R. Lloyd, Elizabeth A. Awick, Edward McAuley

First published: 08 July 2016 | <https://doi.org/10.1002/pon.4156> | Cited by: 3

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

nature > genetics in medicine > acmg practice resource > article

ACMG Practice Resource | Published: 11 May 2021

**Management of individuals with germline variants in *PALB2*: a clinical practice resource of the American College of Medical Genetics and Genomics (ACMG)**

Marc Tischkowitz, Judith Balmaña, William D. Foulkes, Paul James, Joanne Ngeow, Rita Schmutzler, Nicoleta Voian, Myra J. Wick, Douglas R. Stewart, Tuya Pal & ACMG Professional Practice and Guidelines Committee

*Genetics in Medicine* (2021) | Cite this article

516 Accesses | 1 Citations | 30 Altmetric | Metrics

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**ACMG Statements and Guidelines**

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

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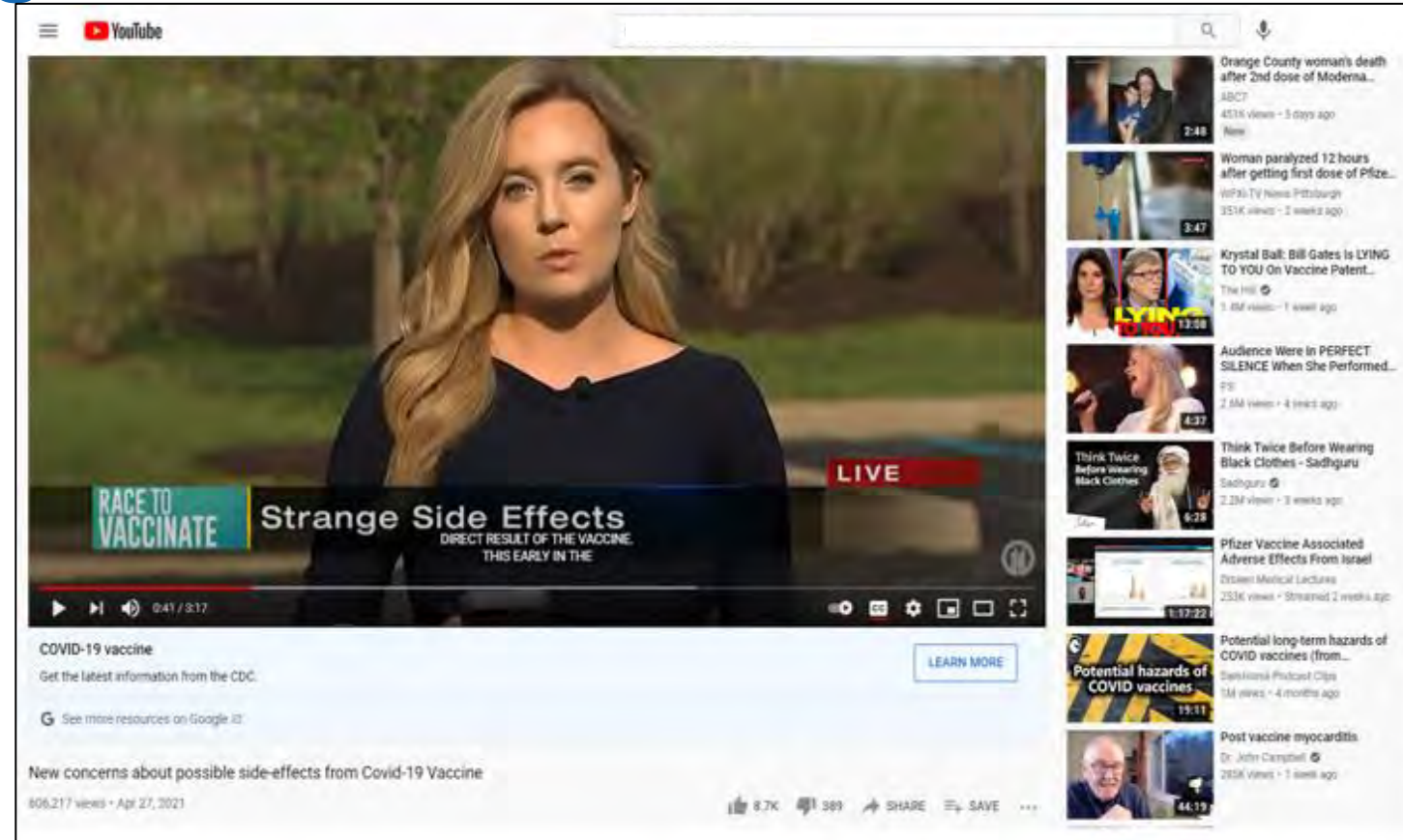
Secure checkout. Personal information is secured with SSL technology.

<https://www.gynecologiconcology-online.net/action/showCart?backUri=%2Farticle%2FS0090-8258%2820%2933947-0%2Ffulltext&addToCart=true>

# 8) Targeted and Retargeted



<https://www.govtech.com/products/biases-in-algorithms-hurt-those-looking-for-information-on-health.html>



<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 Program



[FacingOurRisk.org/XRAY](https://www.facingourrisk.org/XRAY)

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

# Scientific Report



Letter | Published: 07 February 2018

## Asparagine bioavailability governs metastasis in a model of breast cancer

Simon R. V. Knott, Elvin Wagenblast, Showkhin Khan, Sun Y. Kim, Mar Soto, Michel Wagner, Marc-Olivier Turgeon, Lisa Fish, Nicolas Erard, Annika L. Gable, Ashley R. Maceli, Steffen Dickopf, Evangelia K. Papachristou, Clive S. D'Santos, Lisa A. Carey, John E. Wilkinson, J. Chuck Harrell, Charles M. Perou, Hani Goodarzi, George Poulgiannis & Gregory J. Hannon

*Nature* **554**, 378–381 (15 February 2018) | Download Citation

An Erratum to this article was published on 04 April 2018

This article has been updated

### Abstract

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<sup>1</sup>. 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

<https://www.nature.com/articles/nature25465>




# Media Report

## Bunk this veggie: This green is responsible for spreading cancer cells to other organs

- Cambridge researchers state that diet rich in the amino acid asparagine can trigger the spread of cancer cells from their original site to other organs.

By : Sanchalita Mullick | Feb 9, 2018 10:35 IST



Asparagus linked to spread of breast cancer

<https://www.ibtimes.co.in/bunk-this-veggie-this-green-responsible-spreading-cancer-cells-other-organs-759909>

# XRAY Summary and Relevance Scores

**RELEVANCE: LOW**

Low High

**STRENGTH OF SCIENCE: MEDIUM**

Low High

**RESEARCH TIMELINE: ANIMAL STUDIES**

Lab Research Animal Research Human Research Post Approval

[View Related Clinical Trials](#)

[Read More](#)

**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>

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

# Scientific Report

Journal List > HHS Author Manuscripts > PMC6181777

**HHS Public Access**  
Author manuscript  
Peer-reviewed and accepted for publication  
[About author manuscripts](#) [Submit a manuscript](#)

[Nature](#). Author manuscript; available in PMC 2019 Mar 12. PMID: PMC6181777  
Published in final edited form as: NIHMSID: NIHMS1501643  
[Nature](#). 2018 Oct; 562(7726): 217–222. PMID: 30209399  
Published online 2018 Sep 12. doi: 10.1038/s41586-018-0461-z

## Accurate classification of *BRCA1* variants with saturation genome editing

Gregory M. Findlay,<sup>1</sup> Riza M. Daza,<sup>1</sup> Beth Martin,<sup>1</sup> Melissa D. Zhang,<sup>1</sup> Anh P. Leith,<sup>1</sup> Molly Gasperini,<sup>1</sup> Joseph D. Janizek,<sup>1</sup> Xingfan Huang,<sup>1</sup> Lea M. Starita,<sup>1,2,\*</sup> and Jay Shendure<sup>1,2,3,\*</sup>

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The publisher's final edited version of this article is available at [Nature](#)  
See other articles in PMC that [cite](#) the published article.

### Associated Data

- [Supplementary Materials](#)
- [Data Availability Statement](#)

**Abstract** Go to:

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6181777/>

# Media Report

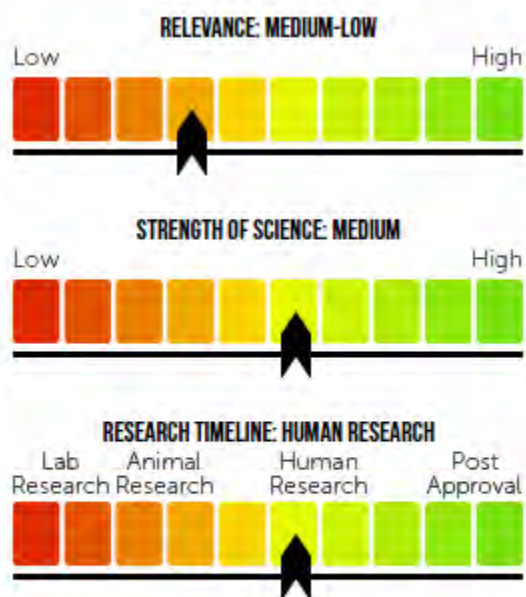
THE FUTURE

## 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.

<https://theoutline.com/post/6257/i-had-a-mastectomy-to-lessen-my-risk-of-breast-cancer-does-new-science-say-that-was-a-mistake>

# XRAY Summary



## 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)

[Read More](#)



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

# Scientific Report

THE LANCET Oncology

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ARTICLES | VOLUME 19, ISSUE 2, P169-180, FEBRUARY 01, 2018

PDF [530 KB] Figures

## Germline *BRCA* mutation and outcome in young-onset breast cancer (POSH): a prospective cohort study

Ellen R Copson, PhD • Tom C Maishman, MSc • Will J Tapper, PhD • Ramsey I Cutress, PhD • Stephanie Greville-Heygate, MB • Prof Douglas G Altman, PhD • et al. Show all authors • Show footnotes

Open Access • Published: January 11, 2018 • DOI: [https://doi.org/10.1016/S1470-2045\(17\)30891-4](https://doi.org/10.1016/S1470-2045(17)30891-4)

Check for updates

Summary

### Summary

Introduction

### Background

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

# Media Report

GreenMedInfo The Science of Natural Healing Research Tools Articles Search 10,000+ Health Topics

## The "Deadly Breast Cancer Gene" Is A Myth, Lancet Study Confirms

Views 40231

Posted on: Friday, January 12th 2018 at 2:30 pm  
Written By: Sayer Ji, Founder

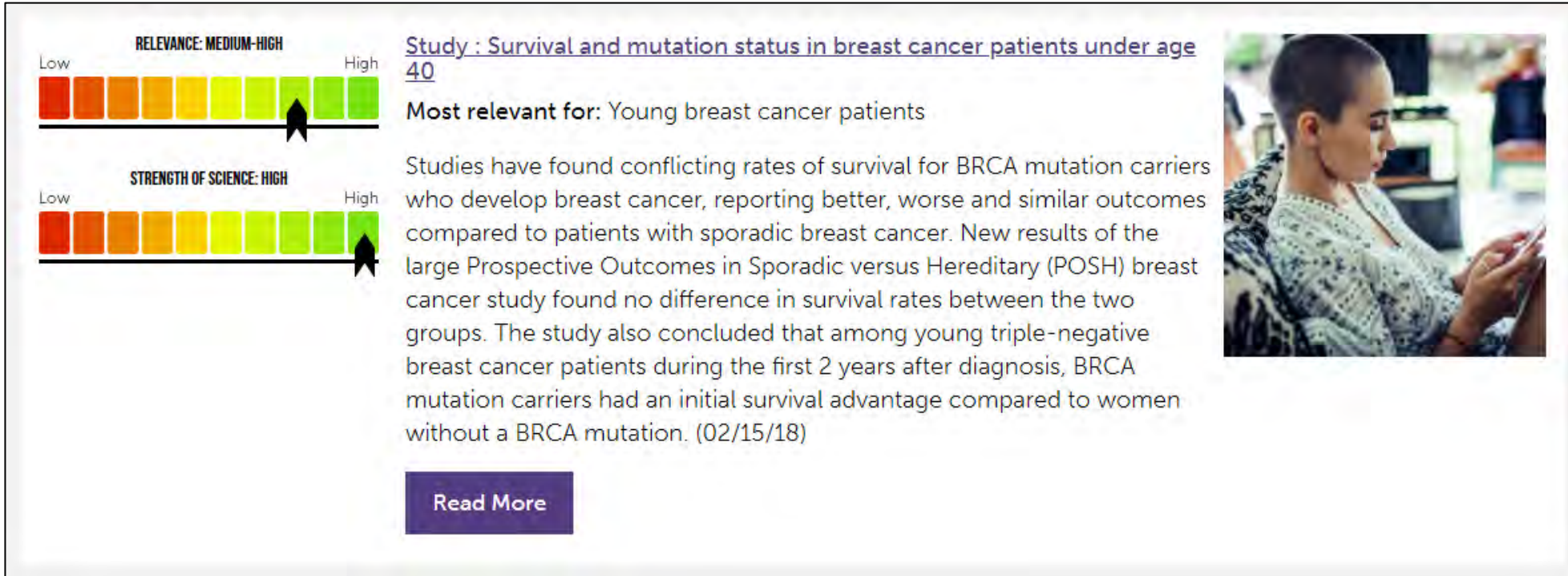
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**A powerful new Lancet study reveals that the so-called breast cancer susceptibility genes -- *BRCA 1* and *BRCA 2* -- do not, in fact, cause breast cancer. Jolie's prophylactic mastectomy, for instance, was for naught.**

"© [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](http://www.greenmedinfo.com/greenmed/newsletter)."

# XRAY Summary and Relevance Scores



**RELEVANCE: MEDIUM-HIGH**

Low High

**STRENGTH OF SCIENCE: HIGH**


Low High

**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>

Key components of XRAY reviews include:

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

# Expert Guidelines, Clinical Trials & Question Prompts



## Expert Guidelines

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](#).



## Open Clinical Trials

- [NCT04009148: Cascade Testing in Families With Newly Diagnosed Hereditary Breast and Ovarian Cancer Syndrome](#). This study offers referral to a genetic counselor and genetic testing for family members of people known to have a mutation in BRCA1 or BRCA2 or mutations in BRIP1, MSH2, MLH1, MSH6, PMS2, EPCAM, RAD51C, and RAD51D.
- [NCT04245176: Genetic Testing for All Breast Cancer Patients \(GET FACTS\)](#). This study aims to determine the impact of a novel genetic counseling method on surgical decisions in individuals with newly diagnosed breast cancer. Open to patients with a new breast cancer diagnosis (invasive or in-situ) who are considering genetic testing and who have not had panel testing for inherited mutations (those with negative test results for BRCA1/2 may still be eligible).
- [NCT02595957: Genomic Services Research Program](#). This study is recruiting people who received unexpected genetic test results about their cancer risk after having genetic testing done for some other reason. This may include people who have results related to the BRCA1, BRCA2, MLH1, MSH2, MSH6, PMS2, PTEN, STK11, TP53 genes.
- [Connect My Variant](#). This study aims to help participants talk to relatives (both immediate and distant) about their family history and genetic test results, to connect them with others who have the same variant and to describe and discuss their family trees together. Eligible people have a known mutation in a gene that increases the risk for disease where there are clear prevention guidelines.
- [NCT04476654: Improving Uptake of Genetic Cancer Risk Assessment in African American Women- Video](#). This study will look at the usefulness of a culturally-tailored video to improve uptake of genetic counseling in Black women with increased risk of [hereditary cancer](#).

[Testing in Ethnically Diverse Women](#). This study will expand genetic testing for hereditary breast and ovarian cancer. Eligible people are women ages 21 to 75 who have a family history, who receive care at the Columbia University Hereditary Cancer Network and can communicate in English.

[Online BRCA Mutations](#). This study measures the cancer risk for BRCA2 genes. The study will also look for other cancer genes during the study. Eligible people include individuals and families at Memorial Hospital in NY/NJ or those with



## Questions 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

## Rating Details

**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.

## WHO COVERED THIS STUDY?

### Medpage Today

[Young-onset breast cancer survival unaffected by BRCA status—but exception seen in triple-negative disease](#) ★★★★★

### Newsweek

[A gene that 'causes cancer' probably doesn't increase your chances of dying from cancer](#) ★☆☆☆☆

### Greenmed Info

[The 'deadly breast cancer gene' is a myth, Lancet study confirms](#) ★☆☆☆☆

[How we rated the media](#)

[How we rated the media](#)

# Printer-Friendly Version



Print

## 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/30209399>

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)

### 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 reclassify this change to either harmful or harmless?
- I have a VUS in another gene? Can this test be used to reclassify a VUS in another gene?
- I have a VUS, can I participate in a research study to help scientists learn more about reclassifying 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.



Print

## Is asparagus linked to breast cancer metastasis?

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

Full article: <https://www.nature.com/articles/nature25465>

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)

### 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 fruits, vegetables and unrefined grains, as well as red and processed meats, alcohol, and processed foods or beverages with added fats and/or sugars.
- Assess eating habits, including portion size, night grazing, snacking habits, frequency of eating out and use of added fats or sugars to foods or beverages
- All survivors should be encouraged to:
  - Make informed choices about food 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
    - Self-monitoring of caloric intake is 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 for 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: 20% 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:

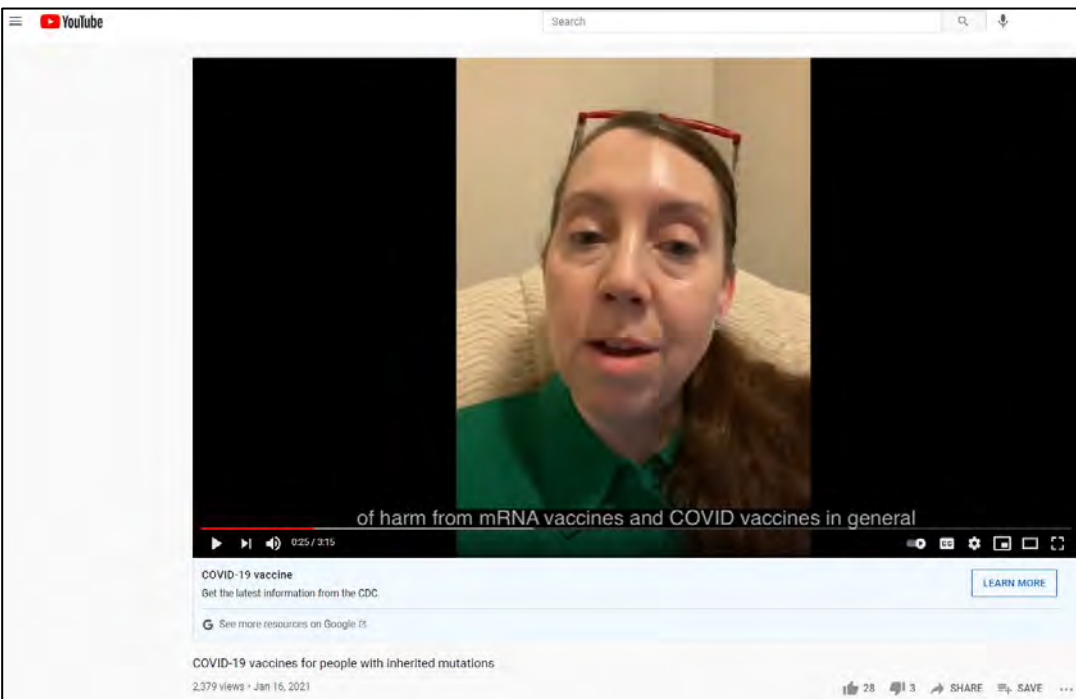
- Achieve and maintain a healthy weight throughout life.
- Adopt a physically active lifestyle.
- Consume a healthy diet with an emphasis on plant-based foods
- Limit the amount of processed and red meats:
  - Eat at least 2.5 cups of vegetables and fruits a day.
  - Choose whole grains instead of refined 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](#)

# XRAY and COVID-19

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>

**RELEVANCE: MEDIUM-HIGH**

Low High

**RESEARCH TIMELINE: POST APPROVAL**

Lab Research Animal Research Human Research Post Approval

[View Related Clinical Trials](#)


**Guideline : COVID vaccines for people with cancer**

**Most relevant for:** Cancer patients, their family and caregivers

Should cancer patients get a COVID vaccine? The National Comprehensive Cancer Network (NCCN) and the American Society of Clinical Oncology (ASCO) provide guidance for people with cancer. These experts recommend that most cancer patients get vaccinated as soon as the vaccine is offered (unless they are allergic to a vaccine component). Cancer patients who have had recent surgery may delay vaccination a few days after surgery. Those with a suppressed immune system are advised to delay getting the vaccine until they're healthy enough to do so. (2/1/21)

*Este artículo está disponible [en español.](#)*

[Read More](#)



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

**RELEVANCE: HIGH**

Low High

**RESEARCH TIMELINE: POST APPROVAL**

Lab Research Animal Research Human Research Post Approval

[View Related Clinical Trials](#)


**Guideline : Expert guidelines on COVID-19 vaccines and timing of breast screening tests**

**Most relevant for:** People considering screening mammography after getting a COVID-19 vaccine.

COVID-19 vaccines work by helping the immune system destroy the virus. Lymph nodes are an important part of the immune system. COVID-19 vaccines may cause temporary swelling in some lymph nodes, which may look suspicious on a mammogram. The Society for Breast Imaging and other professional organizations have released recommendations for the timing of mammograms after COVID-19 vaccines. (3/30/21)

*Este artículo está disponible [en español.](#)*

[Read More](#)



<https://www.facingourrisk.org/XRAY/mammography-and-COVID-vaccine>

*”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*

## Tips & Resources

# General Strategies & Techniques to Improve Health Literacy

- Create awareness about health literacy
- Use plain language<sup>24</sup>
- Apply concepts of “Teach-back”<sup>25</sup>
- Apply the concept of “Ask Me 3”<sup>26</sup>



Institute for Healthcare Advancement: <https://iha4health.org/>

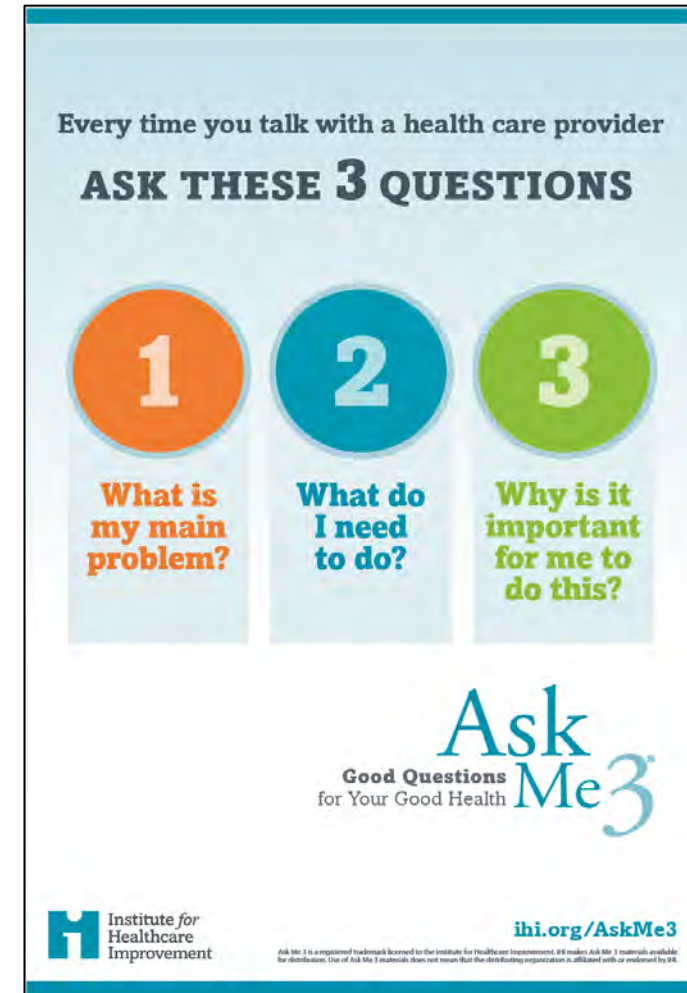
24. Source: PlainLanguage.gov

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

26. Source: Institute for Healthcare Improvement. <http://www.ihl.org/resources/Pages/Tools/Ask-Me-3-Good-Questions-for-Your-Good-Health.aspx>

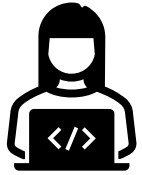
# Ask Me 3<sup>26</sup>

- 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

11-24 Of 16,800 Results Any time ▾

✓ Vaccines are made with the same chemical found to increase

...  
<https://www.naturalnews.com/2017-09-05-vaccines...>

Sep 05, 2017 · Vaccines are made with the same chemical found to increase breast cancer risk among women who have mutations of the BRCA genes. Tuesday, September 05, 2017 by: Tracey Watson Tags: Angelina Jolie, BRCA mutations, BRCA1, BRCA2, breas...



COVID-19 Resources  
• What people with cancer should know • Guidance for cancer researchers • Get the latest public health information from CDC • Get the latest research information from NIH

NIH NATIONAL CANCER INSTITUTE

Español  
1-800-4-CANCER Live Chat Publications Dictionary

ABOUT CANCER CANCER TYPES RESEARCH GRANTS & TRAINING NEWS & EVENTS ABOUT NCI search

NOTHING WILL STOP US 50 YEARS NATIONAL CANCER ACT

Find a Clinical Trial



<https://www.cancer.gov/>


cancer.ufl.edu

University of Florida Health

UFHealth | CANCER CENTER

CONTACT US: (352) 273-8010 → Search

Home About Patient Care Research Members Community Education Giving Events



<https://cancer.ufl.edu/>

.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?



**FORCE**  
Facing Hereditary Cancer EMPOWERED






# Check the Source - NewsGuard




Vaccines are made with the same chemical found to increase


<https://www.naturalnews.com>











 NaturalNews.com website network
 



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



 7


 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
[See the full Nutrition Label →](#)

CREDIBILITY	TRANSPARENCY
 Does not repeatedly publish false content	 Website discloses ownership and financing
 Gathers and presents information responsibly	 Clearly labels advertising
 Regularly corrects or clarifies errors	 Reveals who's in charge, including any possible conflicts of interest
 Handles the difference between news and opinion responsibly	 The site provides names of content creators, along with either contact or biographical information
 Avoids deceptive headlines	



 Free radicals: Definition, cause, and role in cancer

.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?

**FORCE**

Facing Hereditary Cancer EMPOWERED

# Check the Content

THE JERUSALEM POST CORONAVIRUS US ELECTIONS ISRAEL NEWS WORLD NEWS MIDDLE EAST U.S. POLITICS

## A cure for cancer? Israeli scientists may have found one

"Our results are consistent and repeatable."

By MAAVAN JAFFE-HOFFMAN JANUARY 28, 2019 23:14



Cancer cells [illustrative] (photo credit: PIXABAY)


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

Daily Mail

## 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/news/article-8991857/The-holy-grail-blood-test-checks-FIFTY-types-cancer.html>

The New York Times

## Breast Implants Linked to Rare Cancer Are Recalled Worldwide



A textured breast implant. Those made by Allergan have been linked to a higher risk of cancer. imageBROKER, via Alamy

<https://www.nytimes.com/2019/07/24/health/breast-implants-cancer-recall.html>

Daily Mail August 25

## Have 100,000 women been poisoned by their breast implants?



DAILYMAIL.CO.UK  
Worrying evidence of a new scandal regarding breast implants is emerging

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

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?

**FORCE**

Facing Hereditary Cancer EMPOWERED


# Confirm Before Sharing!

FW: John Hopkins Corona Virus Information - Good to Know!

Begin forwarded message:

From: [REDACTED] <[REDACTED]>  
Subject: John Hopkins Corona Virus Information - Good to Know!  
Date: April 4, 2020 at 11:08:40 AM EDT  
To: [REDACTED] <[REDACTED]>

FRIENDS,

The following is from Irene Ken, Asst. Prof in infectious diseases at Johns Hopkins University. 

\* The virus is not a living organism, but a protein molecule (DNA) covered by a protective layer of lipid (fat), which, when absorbed by the cells of the ocular, nasal or buccal mucosa, changes their genetic code (mutation) and convert them into aggressor and multiplier cells.

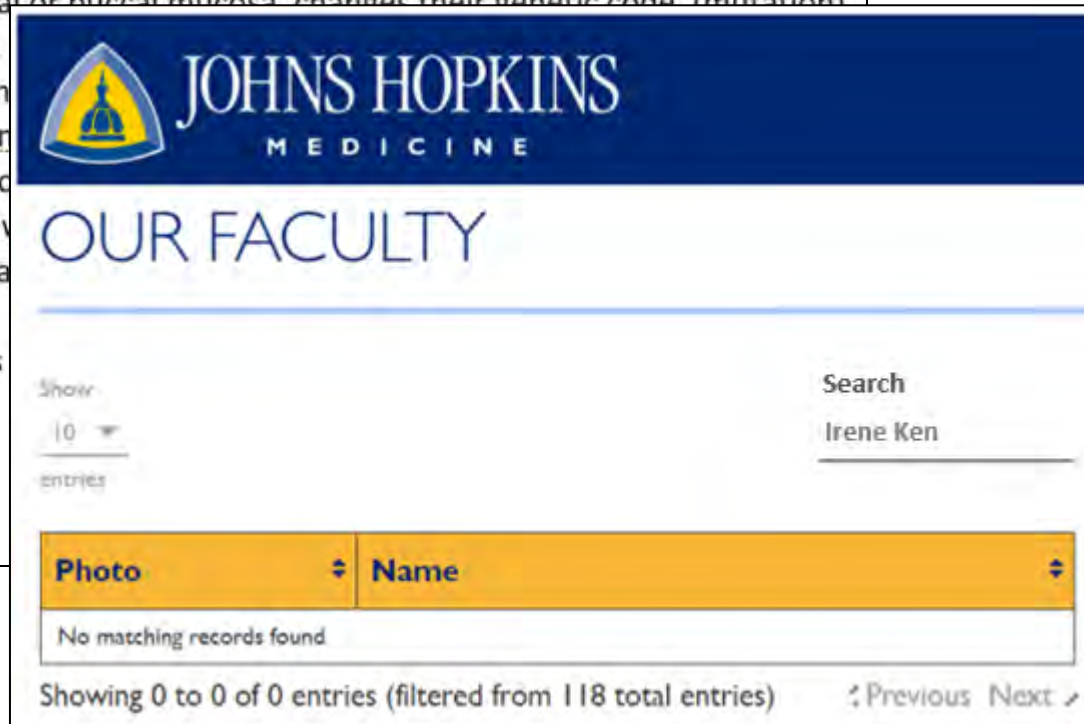
\* Since the virus is not a living organism but a protein, its disintegration time depends on the temperature, humidity, and sunlight.

\* You have to wash your hands before and after touching your face, cell phone, watches, computers, desks, TV, etc. And you have to use hand sanitizer.

\* You have to moisturize dry hands from so much washing. The thicker the moisturizer, the better.

\* Also keep your NAILS SHORT so that the virus does not get under your nails.

-JOHNS HOPKINS HOSPITAL



JOHNS HOPKINS  
MEDICINE

OUR FACULTY

Show 10 entries

Search Irene Ken

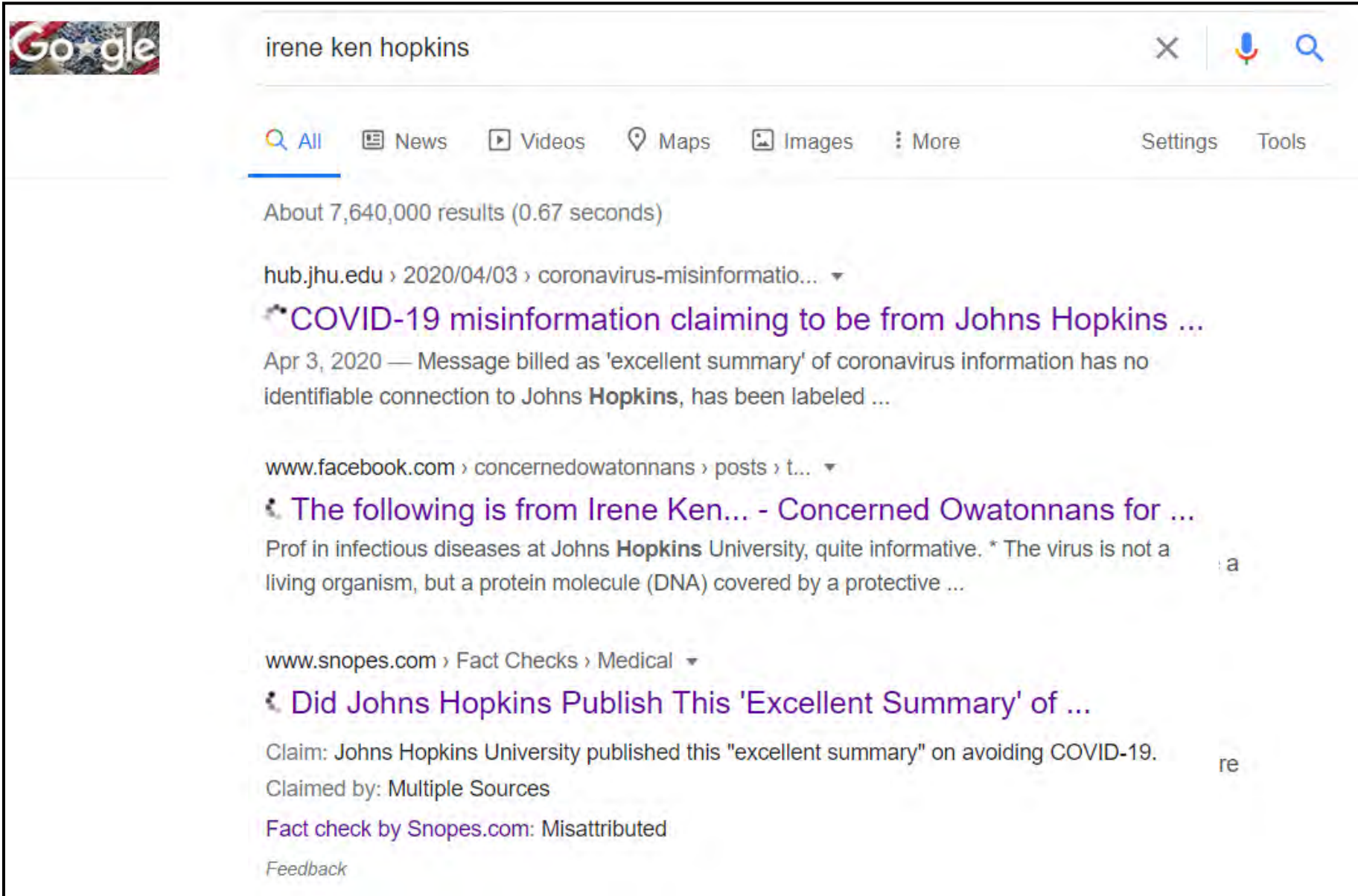
Photo	Name
No matching records found	

Showing 0 to 0 of 0 entries (filtered from 118 total entries) Previous Next

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



The screenshot shows a Google search for "irene ken hopkins". The search results include a link to a message on hub.jhu.edu dated 2020/04/03, titled "COVID-19 misinformation claiming to be from Johns Hopkins ...". The message is dated Apr 3, 2020, and states it is an "excellent summary" of coronavirus information with no identifiable connection to Johns Hopkins. Below this is a Facebook post from "Concerned Owatonnans for ..." dated Apr 3, 2020, which quotes the message and identifies Irene Ken as a prof in infectious diseases at Johns Hopkins University. A Snopes.com fact check is also shown, titled "Did Johns Hopkins Publish This 'Excellent Summary' of ...", which claims that Johns Hopkins University published this "excellent summary" on avoiding COVID-19. The fact check is labeled as "Misattributed".

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



<https://consumer.healthday.com/cancer-information-5/breast-cancer-news-94/soy-safe-even-protective-for-breast-cancer-survivors-720402.html>



<https://www.fda.gov/news-events/press-announcements/fda-approves-first-oral-hormone-therapy-treating-advanced-prostate-cancer>



<https://www.mirror.co.uk/news/uk-news/chillies-could-help-beat-cancer-9549506>



<https://www.mirror.co.uk/news/uk-news/chillies-could-help-beat-cancer-9549506>

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?

# Discerning Media and Health



[https://www.huffpost.com/entry/brca-salivary-gland-cancer\\_n\\_5901542](https://www.huffpost.com/entry/brca-salivary-gland-cancer_n_5901542)

## Original Investigation

December 2014

## Salivary Gland Cancer in *BRCA*-Positive Families

### A Retrospective Review

Tim K. Shen, MS<sup>1</sup>; Theodoros N. Teknos, MD<sup>2</sup>; Amanda E. Toland, PhD<sup>3</sup>; [et al](#)

[» Author Affiliations](#) | [Article Information](#)

*JAMA Otolaryngol Head Neck Surg.* 2014;140(12):1213-1217. doi:10.1001/jamaoto.2014.1998

**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 ( $P < .001$ ).*

<https://jamanetwork.com/journals/jamaotolaryngology/fullarticle/1906230>

# Take Home Messages

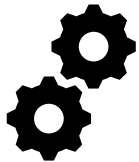
# Take Home Messages



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.



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26. Institute for Healthcare Improvement. <http://www.ihl.org/resources/Pages/Tools/Ask-Me-3-Good-Questions-for-Your-Good-Health.aspx>

# 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?

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