



SESSION 3B: Advancing Progress in Cancer Prevention and Risk Reduction

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FORCE

Facing Hereditary Cancer **EMPOWERED**

Disclosure

- I have no conflicts to disclose

Note: opinions expressed in this presentation are my own.

Barriers to High-Risk People Receiving Preventive Care

Barriers to Preventive Care for High-Risk People

- Confusing patchwork of guidelines, regulations and coverage policies that are hard to navigate and understand
- High out-of-pocket costs for guideline-recommended screening and risk-reduction
- Limited acceptable and affordable risk-management options
- Preventive care delivered piece-meal based on cancer site requiring people to coordinate their own care
- Gaps in knowledge, individual and organizational health literacy

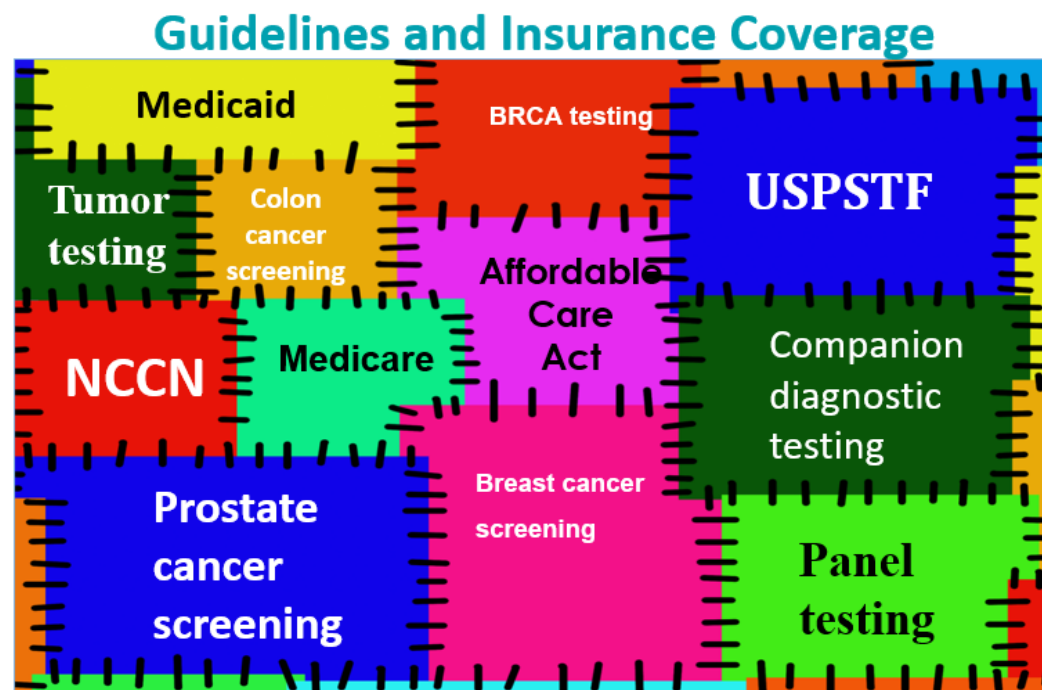
Coverage for Preventive Care is Confusing with Many Gaps



Genomic/Genetic Services: Barriers to Access



Sue Friedman, DVM
National Academies of Science
Roundtable
06/26/18



Gaps in Preventive Care Coverage

- USPSTF guidelines:
 - Germline testing limited to BRCA1/BRCA2 – excludes panel testing for other genes, including Lynch syndrome, even when there is a known mutation in the family
 - Excludes men, people currently in treatment and most risk-management interventions
 - Updated every 5 years
- Medicare
 - Covers germline testing for people diagnosed with cancer for whom results would affect treatment care. Excludes testing for preventive purposes. Excludes previvors
 - Covers the cost for screening colonoscopy every two years for high-risk individuals
 - Covers the cost for annual mammograms for anyone age 45 and older
 - Does not consistently cover breast MRI, risk reducing surgeries or screening for other cancers
- Medicaid
 - Most states cover germline testing for BRCA and Lynch syndrome
 - Screening and prevention varies by state

USPSTF and Insurance

Guideline	Details	Grade
Genetic counseling & testing for BRCA	<ul style="list-style-type: none"> Genetic counseling and BRCA testing for women with family history of breast or ovarian cancer or a known BRCA mutation Excludes women with active disease Excludes men Excludes other genes or syndromes – PALB2, ATM, Lynch Letter grade does not extend to risk-management interventions like MRI or surgery. Out-of-pocket costs can be in the \$1000s of dollars. 	B
Breast screening	<ul style="list-style-type: none"> Breast screening recommendations for women of average risk Biennial mammogram from age 50 - 74 Letter grade C for screening women ages 40-49 – however covered under PALS Act No risk-based breast screening included in guidelines (MRI, mammogram before 50, etc). Guideline expressly exclude high-risk individuals. Out-of-pocket costs can be in the \$1000s of dollars. 	B
Colon cancer screening	<ul style="list-style-type: none"> The USPSTF recommends screening for colorectal cancer starting at age 45– 49 years (letter grade B) and age 50 (letter grade A) continuing until age 75 years. No risk-based recommendation included in letter grade. Guideline expressly exclude high-risk individuals. Out-of-pocket costs can be in the \$1000s of dollars. 	A/B
Prostate cancer screening	<ul style="list-style-type: none"> For men aged 55 to 69 years of average risk, discuss the potential benefits and harms of screening with doctor Letter grade D for men 70 years and older No risk-based recommendation included in guidelines 	C/D

Guidelines with letter grades “A” or “B” require insurance coverage with no out of pocket costs under the ACA

High Out of Pocket Costs and Piecemeal Care



My doctor had to appeal twice before they covered my screening MRI. Even after pre-auth, I still had over \$1000 in out-of-pocket costs.

I just learned about my BRCA2 mutation. Now that I know this, what next step should I take? Do I consult with an internist, or an oncologist or someone else?

Out-of-pocket costs for my annual colonoscopy are about \$1500!

Can someone tell me the protocol for pancreatic cancer screening? My doctor just told me there was none.

Peer Support and Navigation

Peer Navigation Program

Our free Peer Navigation Program connects cancer survivors, people at high risk and caregivers to support and resources personalized for their situation. This program is for individuals who have just learned about their hereditary cancer risk as well as those who have known about it for many years.

Receive free guide



Find
Experts

The organization, Collaborative Group of the Americas- Inherited Gastrointestinal Cancer (CGA-IGC) curates [an updated list of hospitals and programs](#) with expertise in pancreatic cancer screening.

updated: 06/18/2022

Our sample letters help you appeal insurance denials

FORCE has created sample appeal letters for a variety of screening and preventive services as well as treatments needed by members of our community. Simply click on the link to download the letter template in a Microsoft Word file.

It is important that you personalize the letter to include details about your unique circumstances and include supporting documentation such as genetic test results, doctor's notes, etc. to make a solid case for approval. You should also ask your health care provider (surgeon, oncologist, etc.) to submit an insurance appeal on your behalf or to write a letter of medical necessity which you can include with your written appeal.

Need help with an appeal for a service or situation not listed? [Email us](#) for assistance.

Genetic Services

- [BRCA counseling and/or testing](#) - women
- [BRCA counseling and/or testing](#) - men

Cancer Screening

- [Breast screening MRI](#) - women with BRCA mutation
- [Breast screening MRI](#) - women with mutation other than BRCA
- [Breast screening MRI](#) - women with 20% or higher risk (no known mutation)

■ [Colonoscopy](#) - people with Lynch syndrome

Making medical decisions can be confusing. Our volunteers can provide you

Financial Resources and Navigation



Our insurance company is changing their policy based on the information we submitted. They will now cover risk-reducing surgery for women with BRCA mutations. Please know that your hard work is paying off!

My insurance finally approved my risk-reducing mastectomy that they previously denied based on the appeal letter from the FORCE website. I have a PALB2 mutation not BRCA, which I think was part of the problem.

Policy Efforts to Update Guidelines and Coverage

▶ [PRIVACY, POLICY AND LEGAL ISSUES](#) > PUBLIC POLICY INITIATIVES



Reducing Hereditary Cancer Act

EXPAND MEDICARE BENEFICIARY ACCESS TO GENETIC COUNSELING, TESTING, CANCER SCREENING & PREVENTION

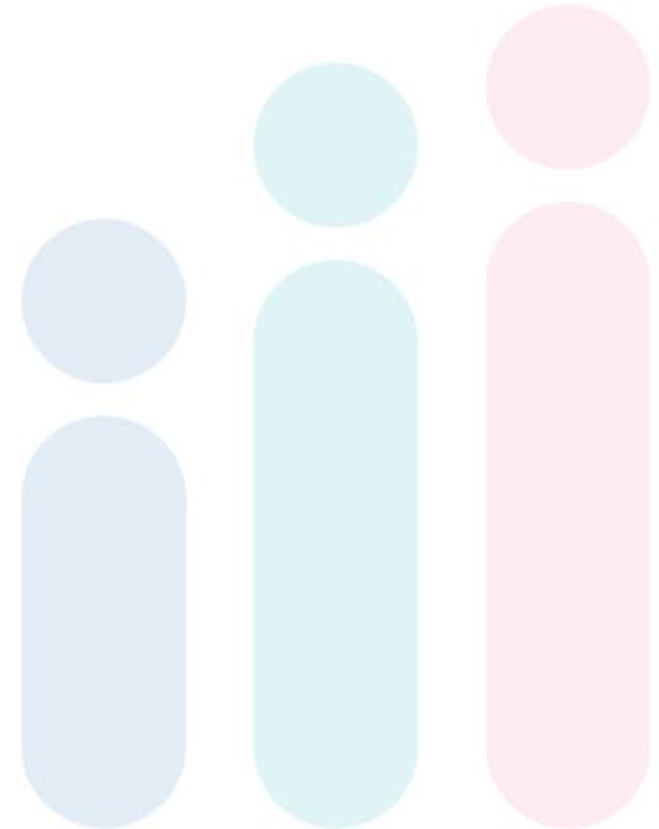
Medicare covers genetic testing only for people already diagnosed with cancer, regardless of family history. For individuals with an inherited mutation causing increased cancer risk, coverage of many screenings and risk-reducing interventions is prohibited by law. This [legislation](#) will modify the Medicare statutes to allow coverage of these potentially life-saving services.

[Read More](#)

FORCE Spearheads Push for High-Risk, Lynch Syndrome Screening Guidelines

USPSTF AGREES TO DEVELOP NATIONAL RECOMMENDATIONS

December 17, 2021 – Today, FORCE was notified that the U.S. Preventive Services Task Force (USPSTF) has agreed to add Lynch syndrome-related cancers to its list of preventive services under consideration. This is a victory for the hereditary cancer community and individuals at increased risk of colorectal and related cancers!

[Read More](#)

Limited Risk-Management Options



I'd do the risk-reducing ovary removal again in a minute, but I wish there was more education and options for those of us struggling with surgical menopause.

Does anyone have information on this new blood test to detect multiple cancers? I don't want to have surgery but want to be sure any cancer is caught early.


Promoting Prevention Clinical Research

GYNECOLOGIC
ONCOLOGY

FULL LENGTH ARTICLE | VOLUME 133, ISSUE 2, P283-286, MAY 01, 2014

Acceptability of prophylactic salpingectomy with delayed oophorectomy as risk-reducing surgery among BRCA mutation carriers

Laura L. Holman   • Sue Friedman • Molly S. Daniels • Charlotte C. Sun • Karen H. Lu

Published: March 14, 2014 • DOI: <https://doi.org/10.1016/j.ygyno.2014.02.030> •  Check for updates

Highlights

Highlights

Abstract

- BRCA mutation carriers are willing to participate in a PSDO trial.

Keywords

- The majority of participants found potential PSDO study risks to be acceptable.

References

Article Info

- These results suggest that adequate accrual for a clinical trial of PSDO is possible.



Men at High Genetic Risk for Prostate Cancer

Clinicaltrials.gov identifier:

[NCT03805919](https://clinicaltrials.gov/ct2/show/study/NCT03805919)

Prevention

Study Contact Information:

Anna Couvillon, Nurse Practitioner

By phone: (240) 858-3148

or by [email](#)

Men at High Genetic Risk for Prostate Cancer

About the Study

The National Cancer Institute opened a clinical trial for [prostate](#) cancer screening in men who are at high risk for prostate cancer due to an inherited mutation.

View the study on [ClinicalTrials.gov](https://clinicaltrials.gov) or contact Anna Couvillon, NP at: (240) 858-3148 or by email.

What the Study Entails

- Screening [MRI](#) of the prostate every 2 years
- Annual [PSA](#) blood test
- Biopsy of the prostate if any MRIs are abnormal
- No cost for study-related tests or procedures
- No cost for travel

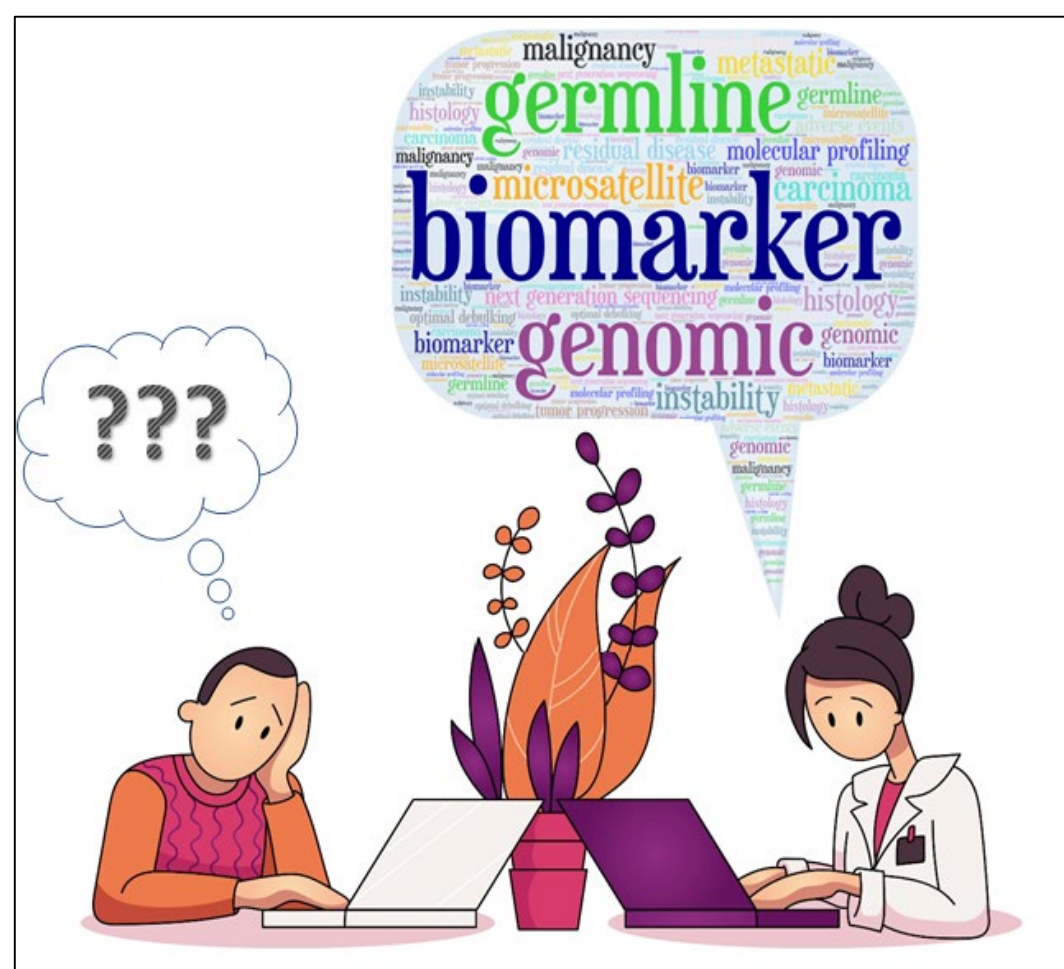
THIS STUDY IS OPEN TO:

- Men, 30 to 75 years old without prostate cancer, who have tested positive for [BRCA1](#), [BRCA2](#), [HOXB13](#), [NBN](#), [TP53](#), [Lynch syndrome](#) ([MLH1](#), [MSH2](#), [MSH6](#), [PMS2](#), [EPCAM](#)), [CHEK2](#), [PALB2](#), [RAD51C](#), [RAD51D](#), [BRIP1](#), [FANCA](#) or [ATM](#) mutation.
- Genetic testing is not offered.

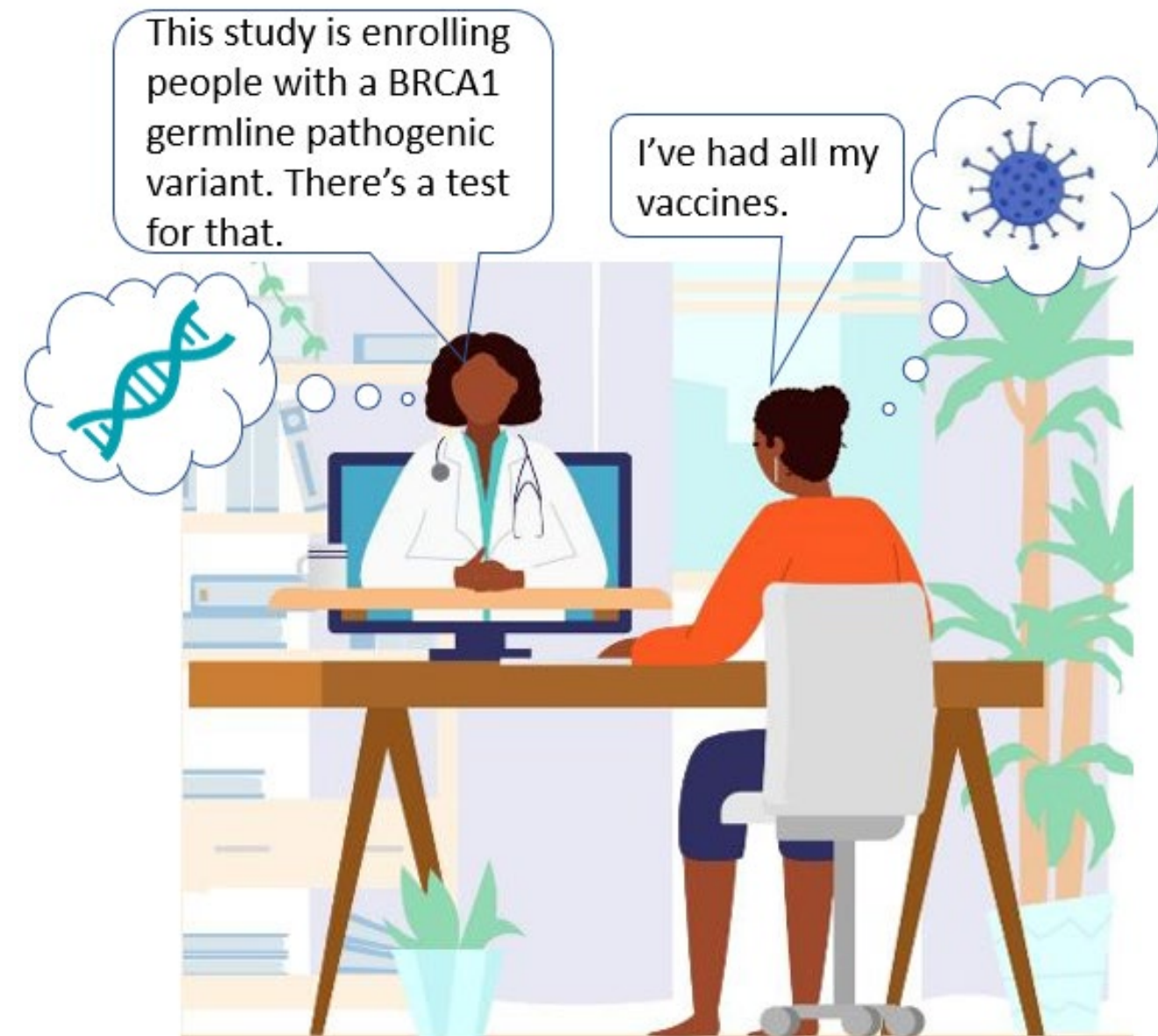
THIS STUDY IS NOT OPEN TO:

- Men who have already been diagnosed with prostate cancer

Gaps in Health Literacy



Plain Language



- “Germline just sounds bad like germs, something you catch, not inherit.”
- “Thank you for asking our opinion!”
- “Germline sounds like bacteria.”
- “Pathogenic variant is not plain language and makes me think of a disease.”
- “‘Inherited’ and ‘mutation’ are plain language.”
- “I have an unknown pathogenic variant, this has been extremely confusing.”

General Awareness and Education

THE GENES BETWEEN US:

Your guide to sharing genetic test results with relatives



FAMILY HISTORY AND OUTREACH

Through family outreach, you can help your relative learn about their health history, detect it early. You can also find out where your variant came from through genealogy research.

We've compiled expert-reviewed resources to help you identify and understand the topic below to learn more. If you need more guidance, please sign up for our newsletter, you're not alone.

Importance of Sharing Genetic Info



- > FORCE information: Importance of sharing with family
- > FORCE information: Sharing health information
- > FORCE information: Sharing information with adult relatives
- > FORCE brochure: The Genes Between Us
- > University of Washington: Understanding your Gene Variant
- > Washington Department of Health Video: Cascade Screening
- > Ohio State University: Video: BRCAShare



Genetic counseling

- > FORCE information: Genetic testing guidelines
- > National Society of Genetic Counselors: Find a Genetic Counselor
- > American College of Medical Genetics: Find a Genetics Clinic



HEREDITARY CANCER AND GENETIC TESTING

RISK MANAGEMENT AND TREATMENT

RESEARCH AND CLINICAL TRIALS

PRIVACY, POLICY AND LEGAL ISSUES

SUPPORT

EDUCATION

May 17, 2022

A NEW TOOL IS HELPING FAMILIES CONDUCT LIFE- SAVING CONVERSATIONS ABOUT HEREDITARY CANCER

by Anya Karavanov, PhD

Cancer is not an easy topic for anyone in any circumstance. But conversations about cancers that run in the family can be particularly hard. Hereditary cancer is caused by genetic mutations that are passed down in families, so learning your risk and taking action to prevent cancer requires frank conversations with people other than your doctor – namely, your family members. Just a few challenges people might face when having these conversations:

- Reluctance of certain family members to discuss cancer or personal health
- Fear of conversations or tests that might ultimately lead to bad news
- Lack of understanding of how one family member's health might impact another's
- Guilt felt by older family members who have already had cancer and fear they may pass it on
- Cultural norms within some communities that discourage talking about bad things that might happen
- Desire to push this type of conversation further into the future and not worry about it today

Practice makes it easier

I am proud to have contributed to an innovative tool called "Let's Talk," which helps families discuss hereditary cancer. It is an online communication tool that provides



Help your family make good decisions

- ✓ Be Positive as you share small chunks of info.
- ✓ Stop to see how they're doing and express empathy
- ✓ Help them understand what they can do next and respect their decisions.



Addressing the “Infodemic” Public Health Emergency

NEW AT-HOME TEST CAN FIND AND PREVENT CANCER FORCE Facing Hereditary Cancer EMPOWERED

BRCA MUTATION SURVIVAL IN YOUR CAN YOU TELL WHICH HEALTH INFORMATION IS TRUSTWORTHY?

RESEARCH
SLOW GROWTH OF CANCER CELLS IN A PAN.

HOW TO DECIDE WHAT TO BELIEVE WHEN LOOKING FOR HEALTH INFORMATION ONLINE

Before you make decisions based on health information you see online or share that information with someone else, ask yourself some questions about:



the source



the content



does this information apply
to my situation?

When you're reviewing health information online, ask yourself:

Is it trustworthy, or is it a **BOAST**?



BIASED



OVERBLOWN



AMATEUR



SALES-FOCUSED



TAKEN OUT OF
CONTEXT OR
TOO SOON TO
BE USEFUL

Recommendations

Recommendations

1. Invest equally in dissemination and implementation of innovations
2. Focus on developing prevention interventions that are safe, acceptable and accessible to high-risk individuals
3. Provide **equitable** access to, and coverage for risk-based, evidence-based preventive services for high-risk individuals
4. Develop a comprehensive, easy-to-use database of federal and state regulations related to healthcare services and coverage
5. Designate best practices for care-coordination for high-risk people
6. Improve population and organizational health literacy

Connect with FORCE

Website: FacingOurRisk.org

Helpline: 866-288-RISK

Email: info@FacingOurRisk.org

Get Social: FacingOurRisk

