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

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Disclosure

- I have no conflicts to disclose

Note: opinions expressed in this presentation are my own.

Barriers to High-Risk People Receiving Preventive Care

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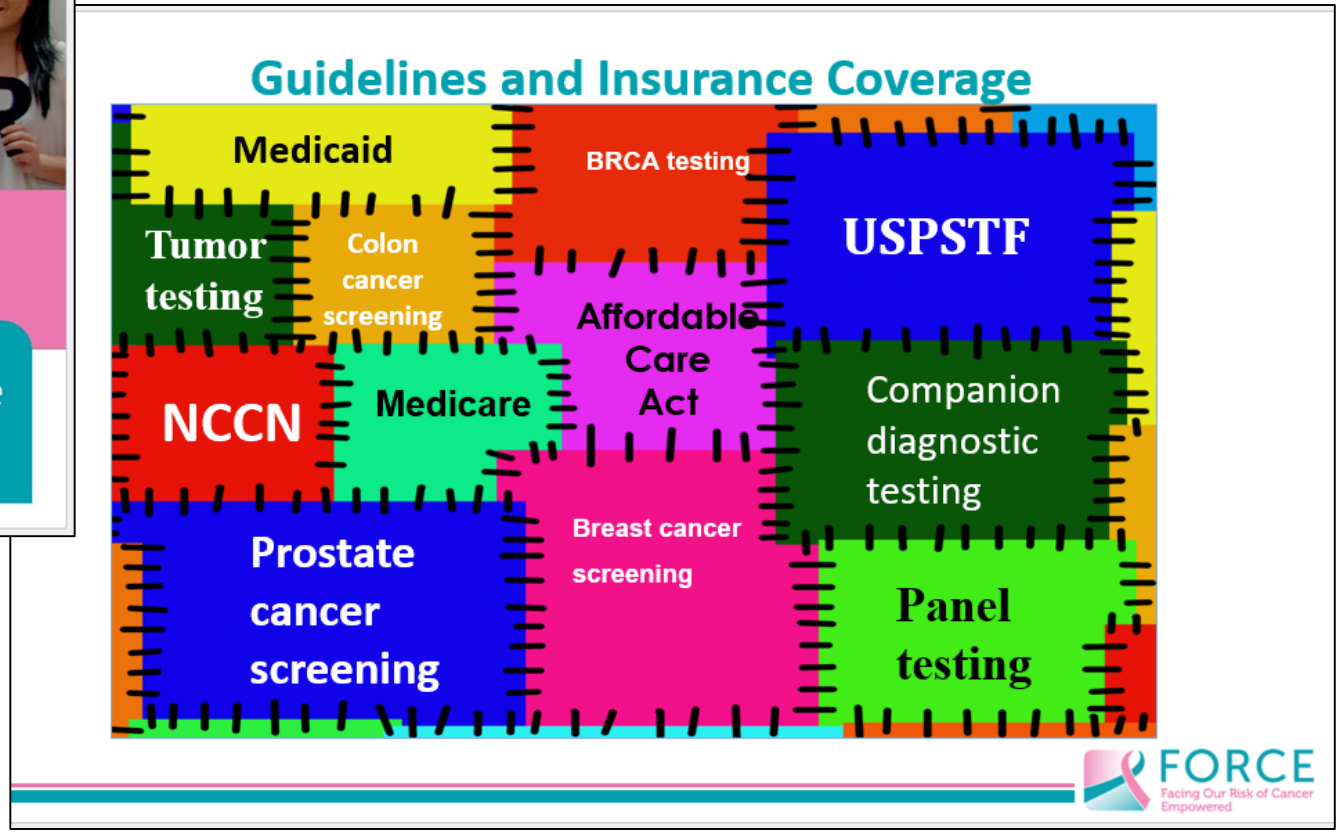
Barriers to Preventive Care for High-Risk People

- 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



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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	• 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	• 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	• 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	• 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.

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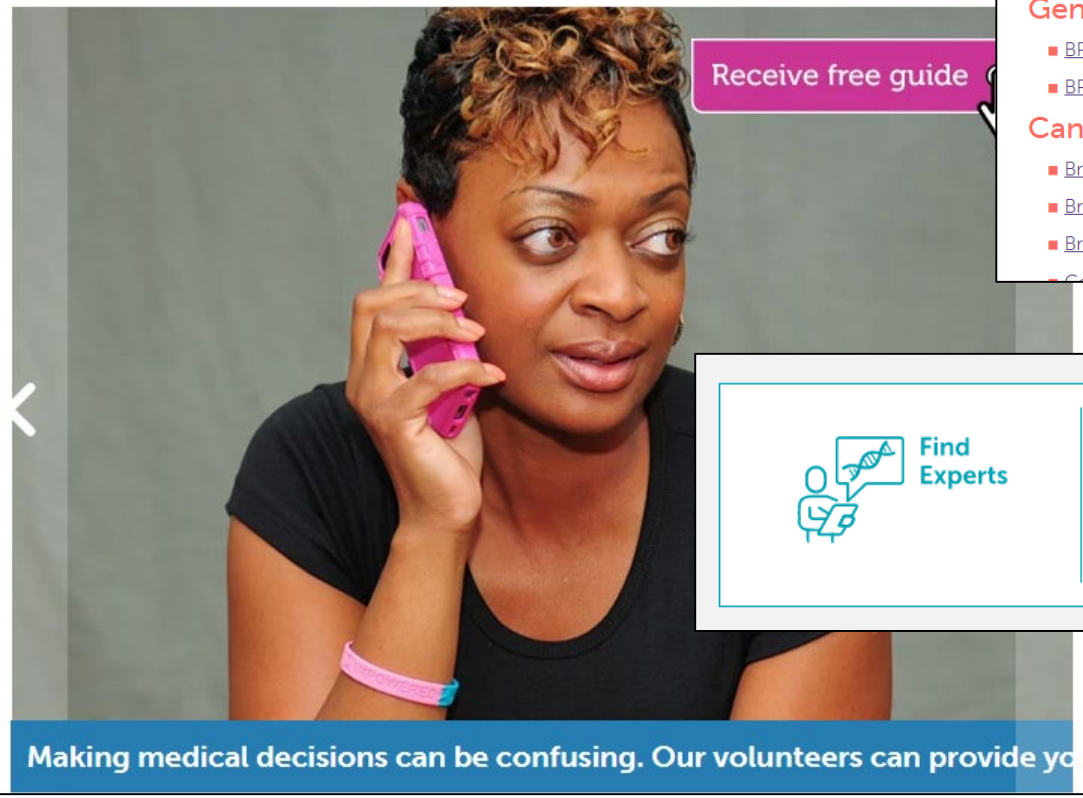
Peer Support and Navigation

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
individuals who have just learned about their hereditary cancer risk as well as those
known about it for many years.



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)

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

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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.

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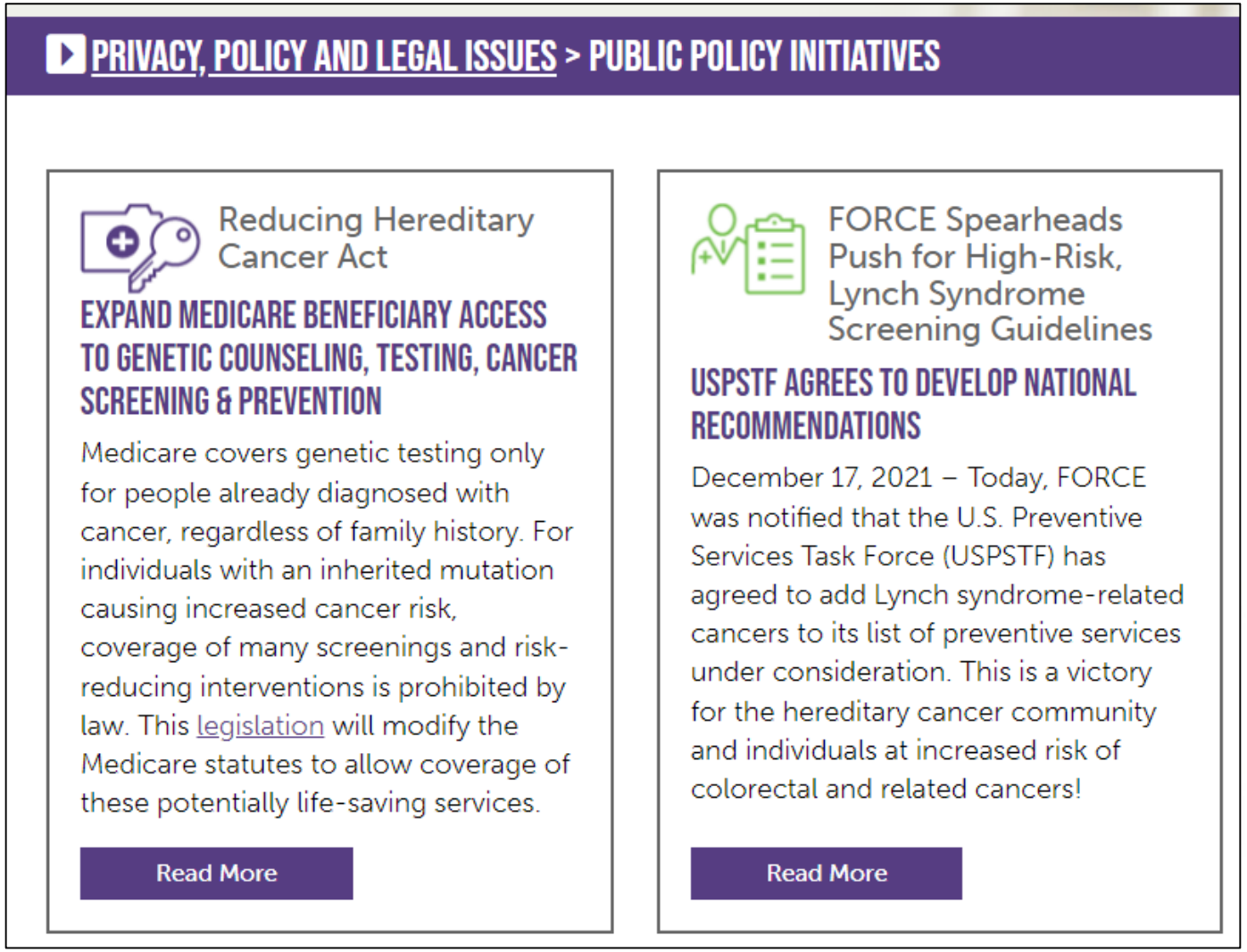
Policy Efforts to Update Guidelines and Coverage



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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

- BRCA mutation carriers are willing to participate in a PSDO trial.
- The majority of participants found potential PSDO study risks to be acceptable.
- 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

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 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

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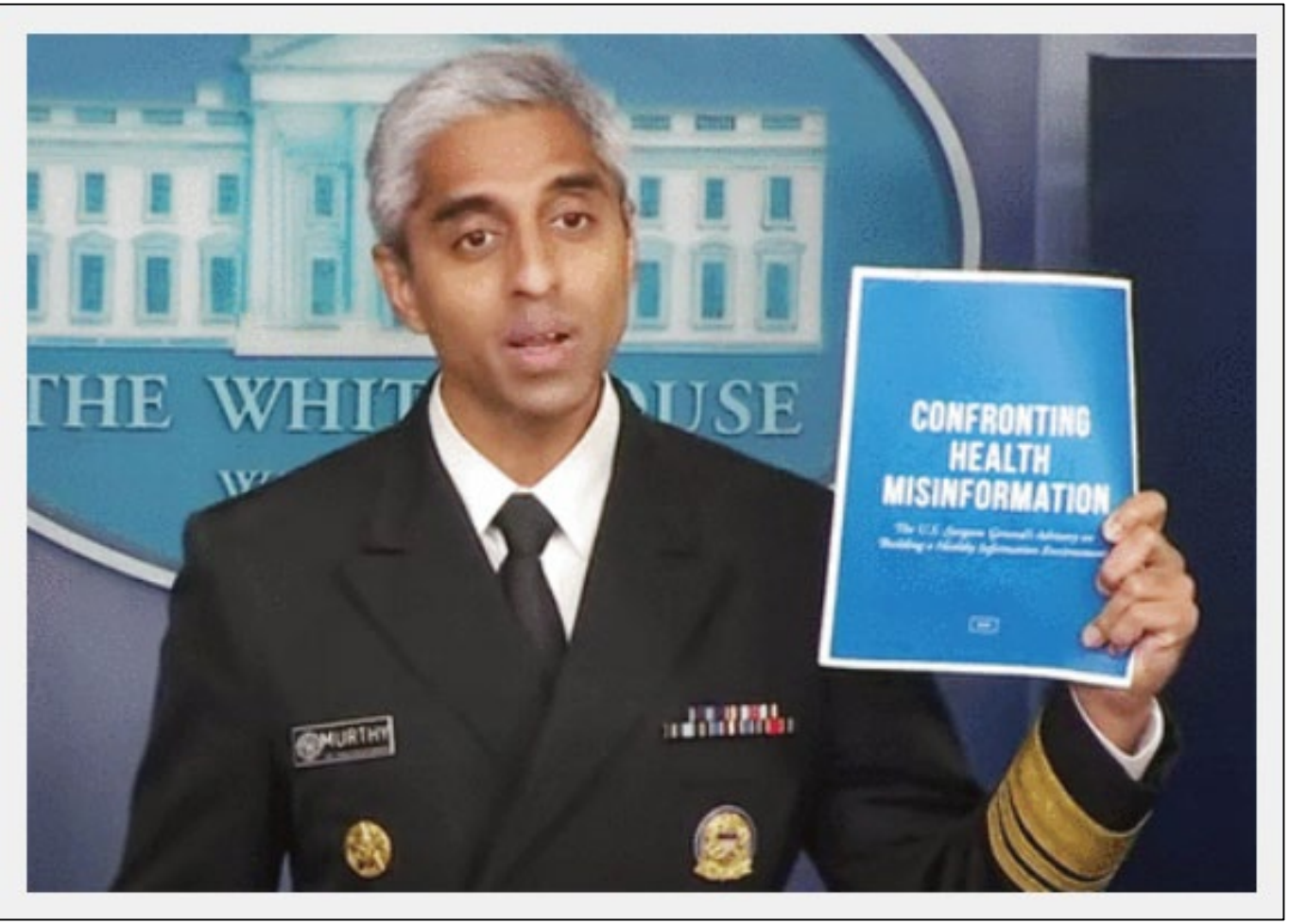
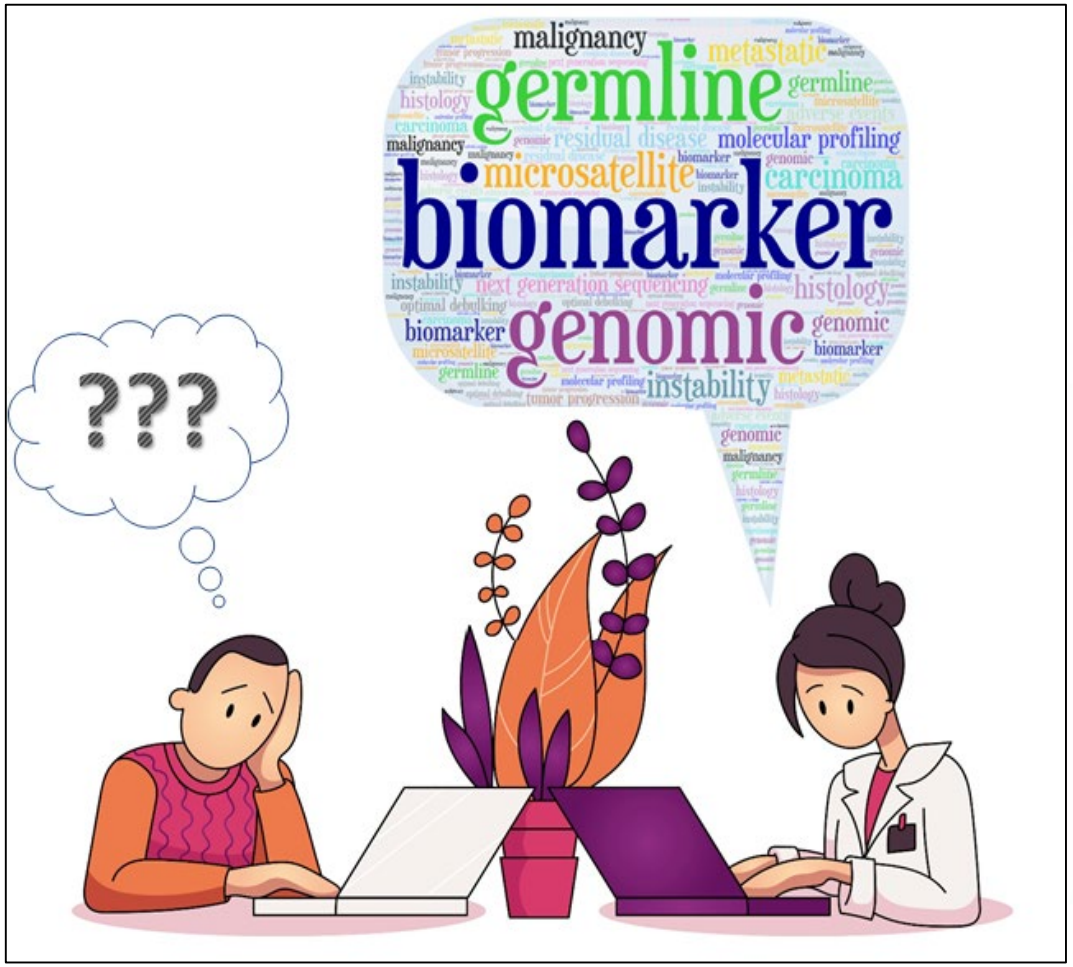
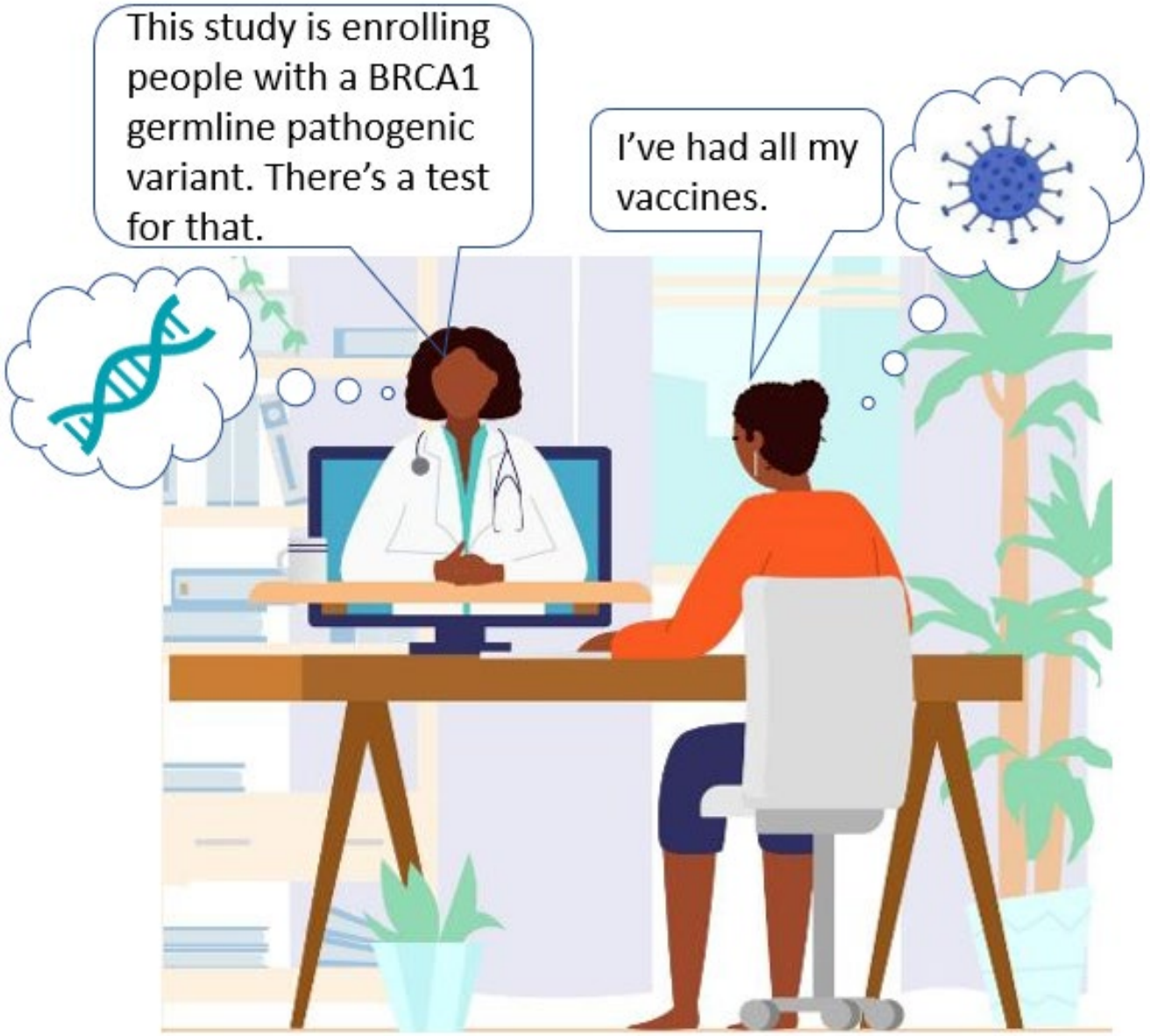
Gaps in Health Literacy





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."

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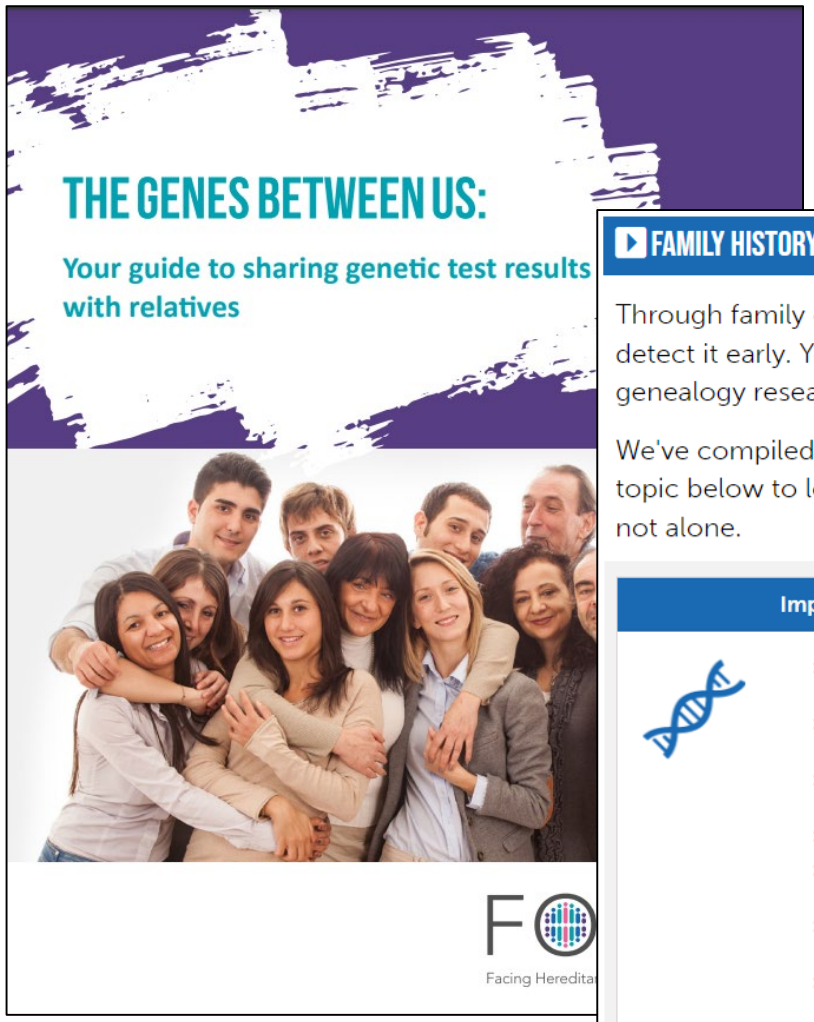
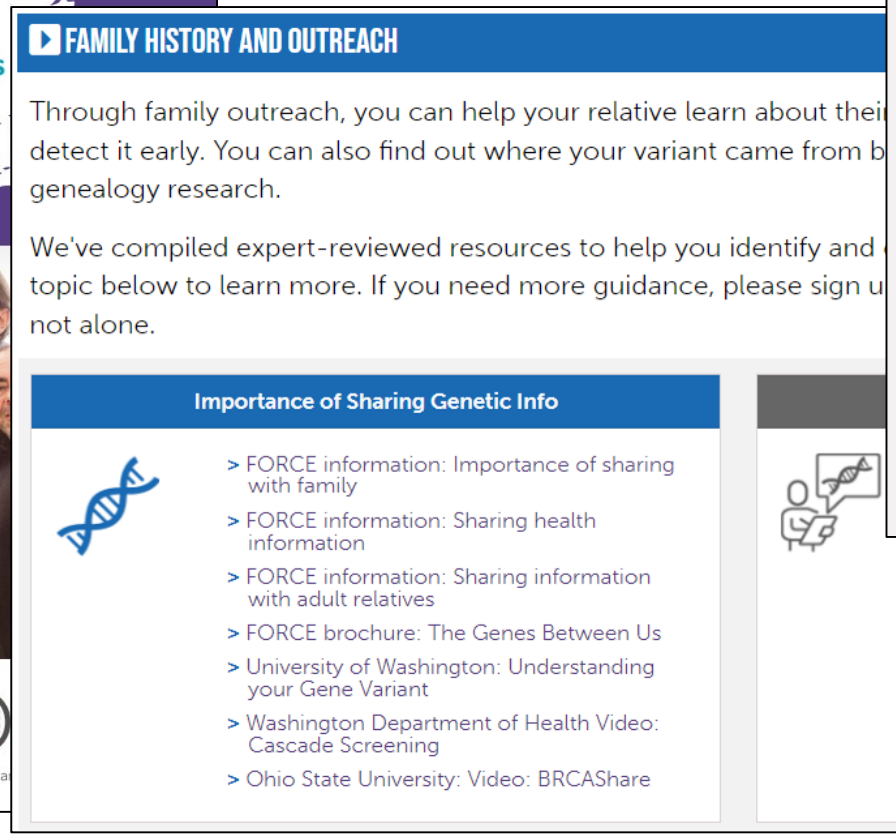
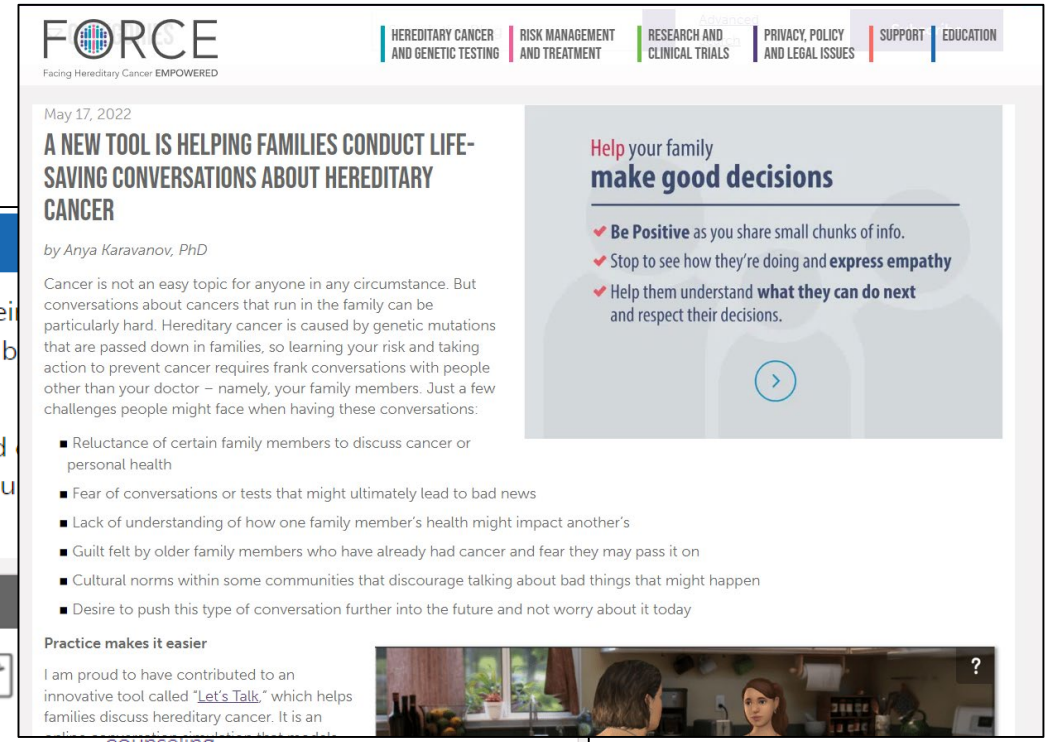
General Awareness and Education







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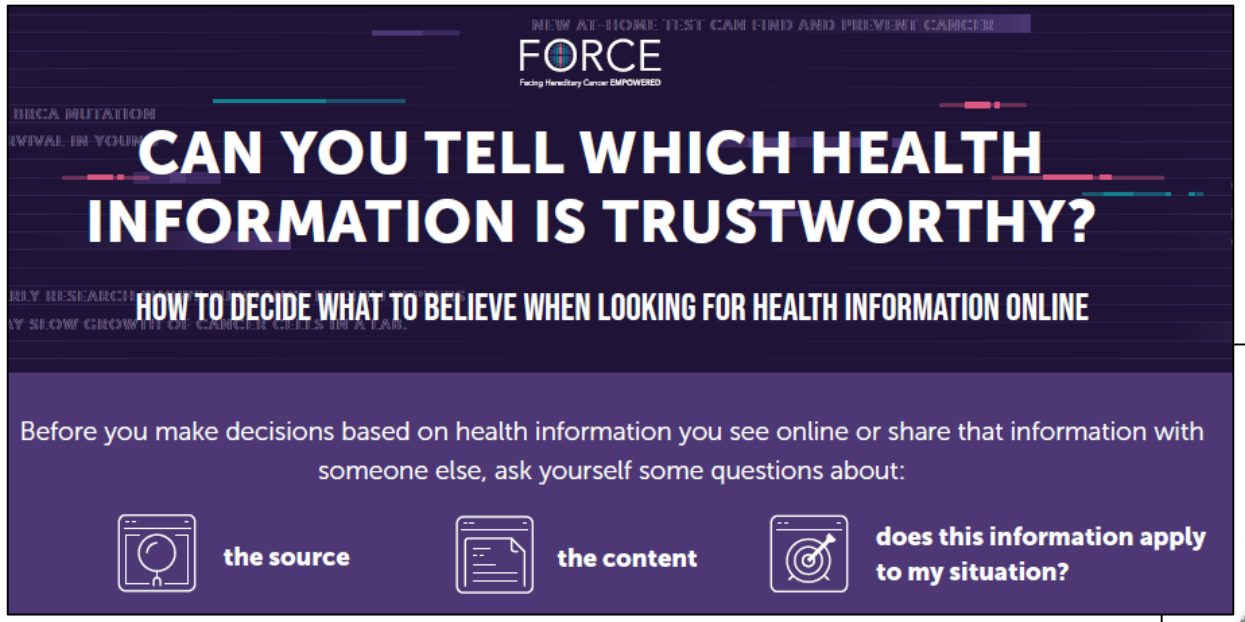
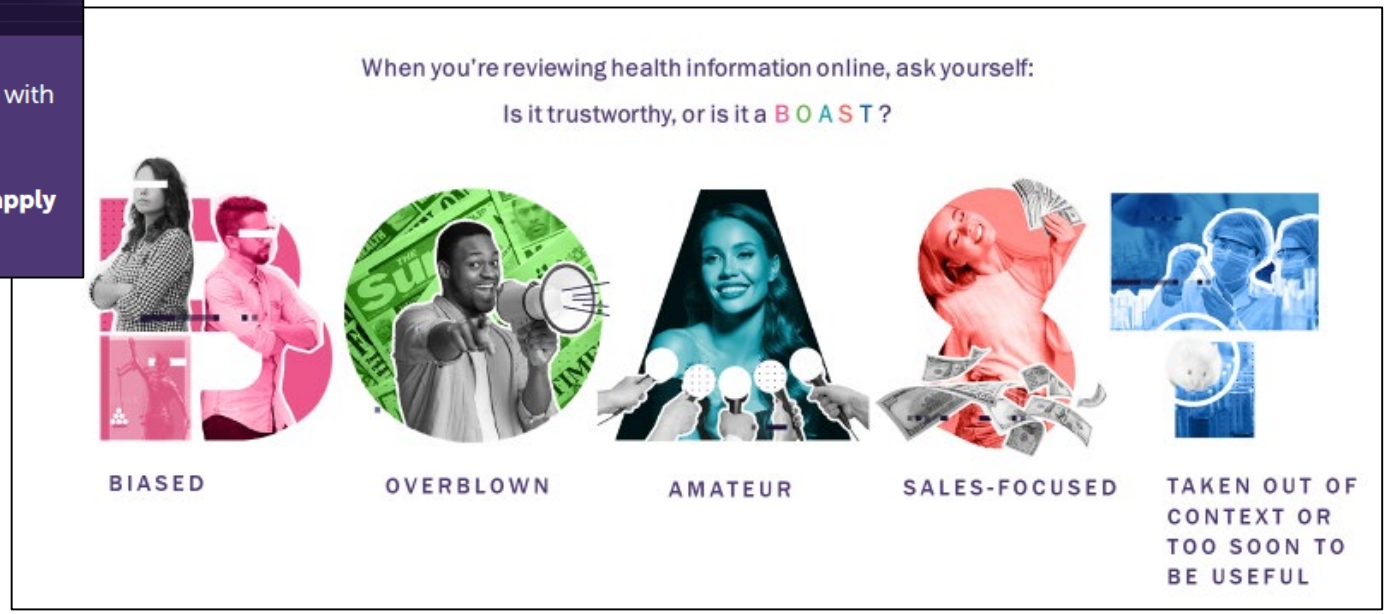
Addressing the “Infodemic” Public Health Emergency





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Recommendations

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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