

Developing a Common Cancer Testing Terminology: A Collaboration of Engaged Stakeholders

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Jargon as a Barrier to Clinical Trial Referrals

- FORCE 2020 survey of referral practices¹⁴. Of respondents who refer patients to clinical trials, the percentage of each group who chose “jargon/health literacy” as one of their top three barriers* to referral:
 - 61% of community health workers** (n=41)
 - 41% of oncology nurse navigators (n=37)
 - 21% of genetic counselors (n=49)

- * List of barriers (respondents could select up to 3 for each service):
 - financial
 - patient understanding of value
 - lack of local programs/providers
 - language barriers
 - medical jargon/health literacy
 - none

- * Community health workers includes:
 - peer navigators
 - social workers
 - promotoras
 - public health workers

14. FORCE needs assessment for PROJECT EXTRA (Cooperative agreement: NU58DP2019010210 supported by the CDC). Unpublished.

Jargon As a Barrier to Genetic Services

- Of respondents who refer patients to genetic counseling or testing services, the percentage who chose “jargon/health literacy” as a top three barrier:
 - 35% of community health workers** (n=52)
 - 25% of oncology nurse navigators (n=44)
 - 23% of genetic counselors (n=101)

- * List of barriers (respondents could select up to 3 for each service):
 - financial
 - patient understanding of value
 - lack of local programs/providers
 - language barriers
 - medical jargon/health literacy
 - none

- * Community health workers includes:
 - peer navigators
 - social workers
 - promotoras
 - public health workers

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What Is the Goal of Precision Medicine?

To deliver the right treatment to the right patient with the right dose at the right time.¹

- Testing approaches
 - Biomarker testing to determine tumor characteristics
 - Genetic testing to determine inherited cancer or cancer risk

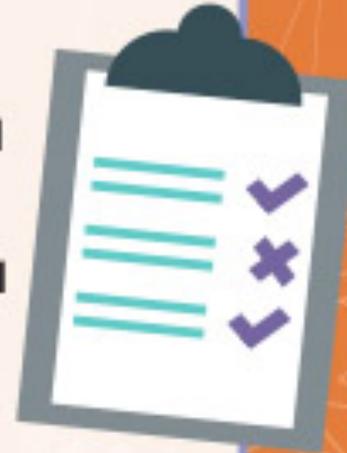
1. Schwartzberg, L., et al. (2017) *Am Soc Clin Oncol Educ Book* 37:160-9



Both Tests Are Underutilized

Recent data highlight suboptimal testing rates.

- 40% of colorectal cancer patients are not being tested for biomarkers¹
- Only 7% of eligible non-small cell lung cancer patients treated in community oncology practices were tested for all 7 biomarkers recommended in clinical guidelines²
- Germline genetic testing rates for inherited mutations and cancer risk are below 50%³



1. Gierman HJ, Goldfarb S, Labrador M, et al. Genomic testing and treatment landscape in patients with advanced non-small cell lung cancer (aNSCLC) using real-world data from community oncology practices. J Clin Oncol. 2019;37(suppl; abstr 1585). 2. Gutierrez ME, Price KS, Lanman RB, et al. Genomic Profiling for KRAS, NRAS, BRAF, Microsatellite Instability (MSI) and Mismatch Repair Deficiency (dMMR) among Patients with Metastatic Colon Cancer. JCO Precision Oncol. December 2019. 3. Allison W. Kurian, Kevin C. Ward, Nadia Howlader, et al. Genetic Testing and Results in a Population-Based Cohort of Breast Cancer Patients and Ovarian Cancer Patients. Journal of Clinical Oncology. May 20, 2019.

Patients Are Confused About These Tests and How to Talk About Them^{9,10}

- I don't understand the jargon.
- I don't understand it, despite asking my doctor to explain more than once.
- Some people talk about the TUMOR having a BRCA mutation, vs. the PERSON having a BRCA mutation. I still don't get that.
- I do not understand who qualifies for treatment with a targeted therapy.
- I wish there was a 'dictionary' for all common tumor mutations that was accessible to patients both in terms of getting it and understanding it.
- When I had testing in 1997, my result was a deleterious mutation in BRCA2. My relative with the same mutation was told she had a pathogenic variant.

9. FORCE/LBCC survey on breast cancer and personalized medicine. Published on the FORCE website, July 2019.

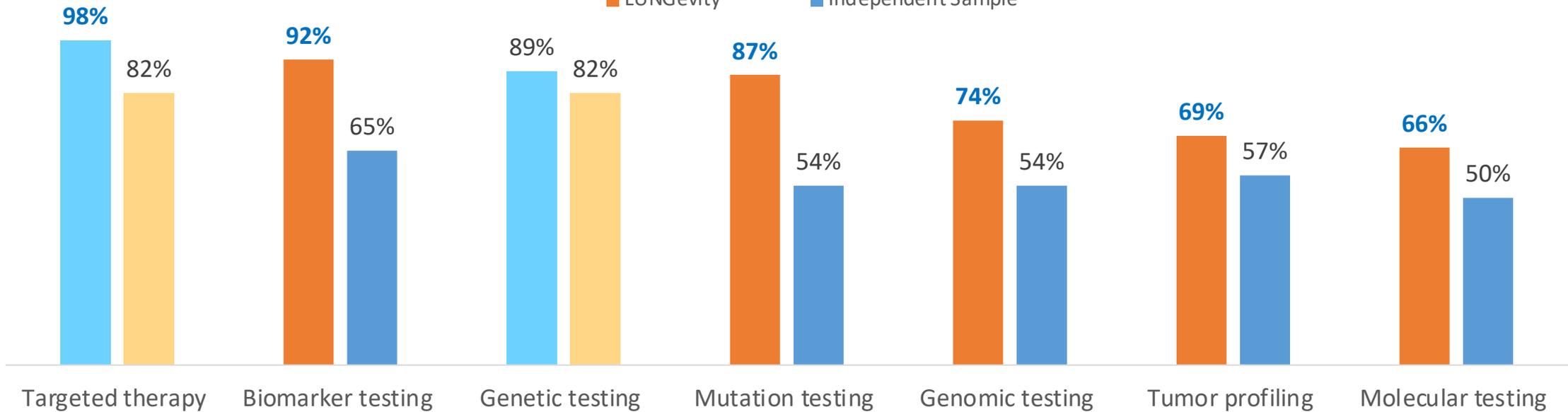
10. Personal communication.

Lung Cancer Patient Data: No Single Testing Term Rises to the Top

The myriad of terms register lower individually, but overall 88% have heard of at least one of the related testing terms.

% Heard Term Before

■ LUNGevity ■ Independent Sample



88% heard of at least 1 testing term

98% LUNGevity
83% Ind Sample

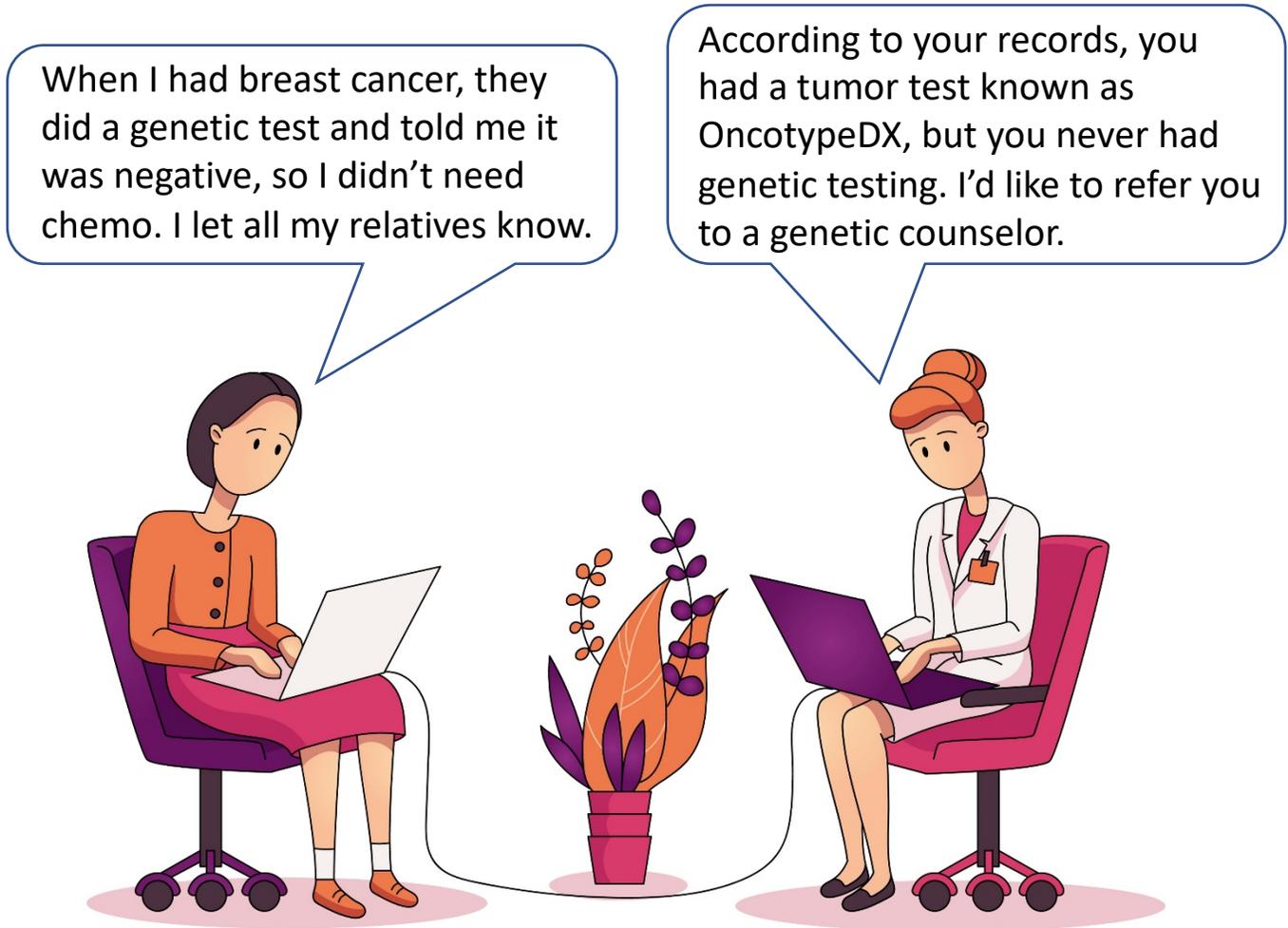
Darkers shade indicates testing term related to targeted therapy

Base:	LUNGevity	87
Total		
Sample	Independent Sample	161

Stat testing against the independent sample

How Can Consistent Terminology Help Patients?

- Align communications between patients and providers so they know when they are referencing the same test or result.
- Facilitate informed and shared decision-making.
- Decrease misunderstanding and miscommunication.



Consistent Testing Terminology Working Group

PATIENT ADVOCACY GROUPS



PROFESSIONAL SOCIETIES



INDUSTRY PARTNERS

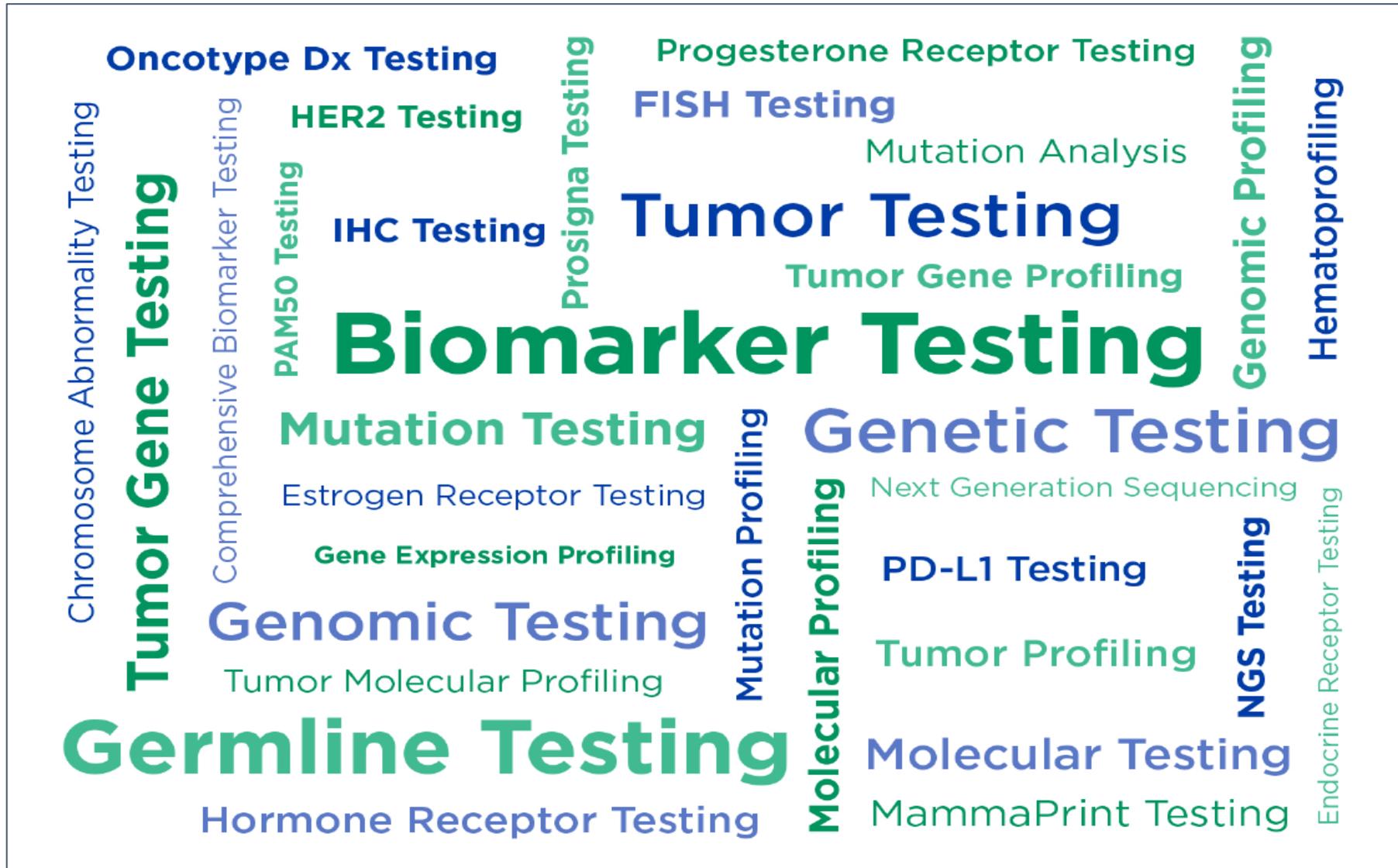


Working Group's Focus

Address a common barrier:

Confusion and lack of understanding among patients exacerbated by a multiplicity of terms used in communicating about testing

33 Terms Across 9 Different Cancer Sites



Selecting a Term for Testing for Tumor Characteristics

“Biomarker Testing” is the preferred term for testing for somatic (acquired) mutations and other biomarkers

- Covers testing of blood/solid tissue
- Includes testing for single-gene, panel, multiplex (NGS)
- Covers all testing modalities including future innovations in diagnostics
- Most commonly adopted and in use already

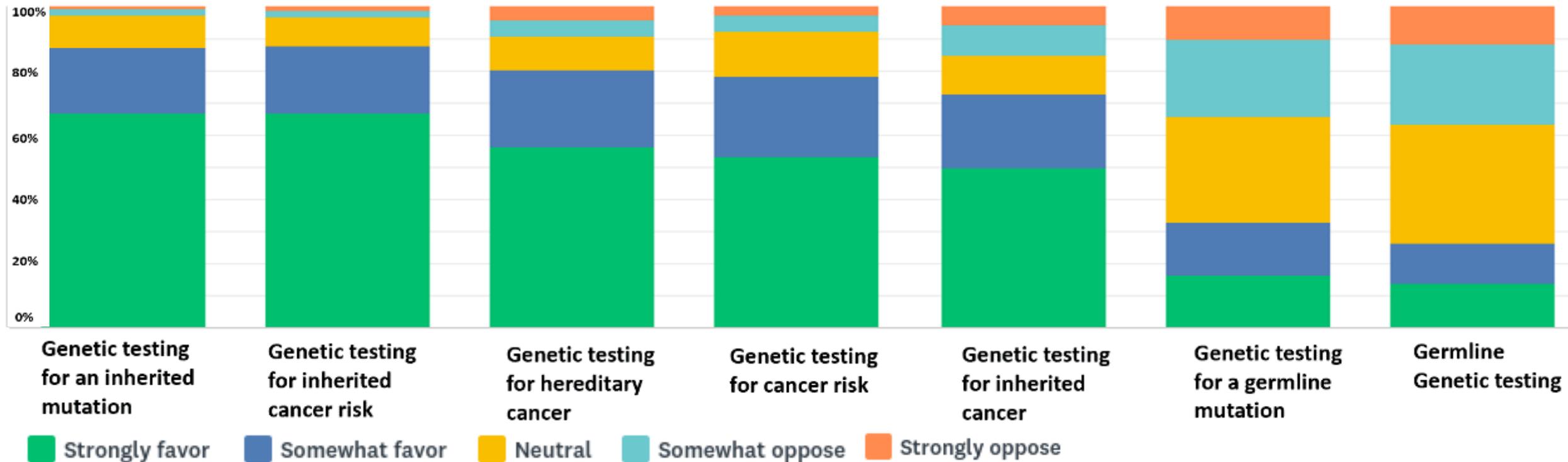
Selecting Consistent Terms for Germline Testing

The working group could not reach consensus on a preferred term for germline genetic testing.

- We conducted a broad patient survey across multiple organizations – about 1650 people responded

Survey on Patient Preference for Genetic Testing Terminology

The term “genetic testing” can be used to describe different types of tests. This can lead to confusion between patients and healthcare providers. Please rate the following terms used to describe testing for an inherited mutation on a scale from “strongly favor” to “strongly oppose.”



Survey Respondent Comments

- Germline just sounds bad like germs, something you catch, not inherit.
- Thank you for asking for 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 and immediately understood.



*We received over 1500 write-in comments!

Selecting a Term for Germline Genetic Testing

Based on the patient survey results, the working group chose:

“Genetic Testing for an Inherited Mutation” and

“Genetic Testing for Inherited Cancer Risk”

as the preferred umbrella terms for testing for inherited mutations.

Adoption of a common term for genetic test results was beyond the scope of the working group. Based on the survey, FORCE chose

“Inherited Gene Mutation”

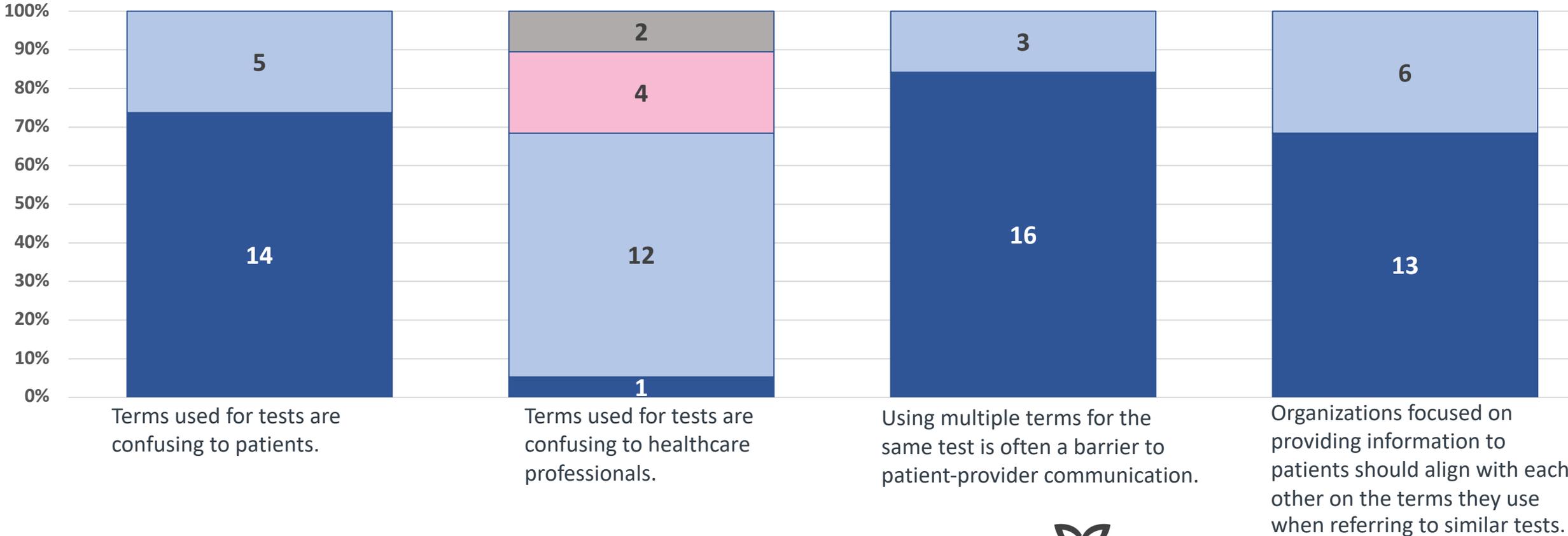
as the preferred term for our patient-facing publications.

Implementation of the
Consensus Testing Terms:
Perspective from the Breast
Cancer Community

Q. To what degree do you/does your organization agree or disagree with the following statements about tests used in cancer care?

Answered: 19
Skipped: 0

■ Strongly agree
 ■ Somewhat agree
 ■ Somewhat disagree
 ■ Strongly disagree
 ■ Uncertain



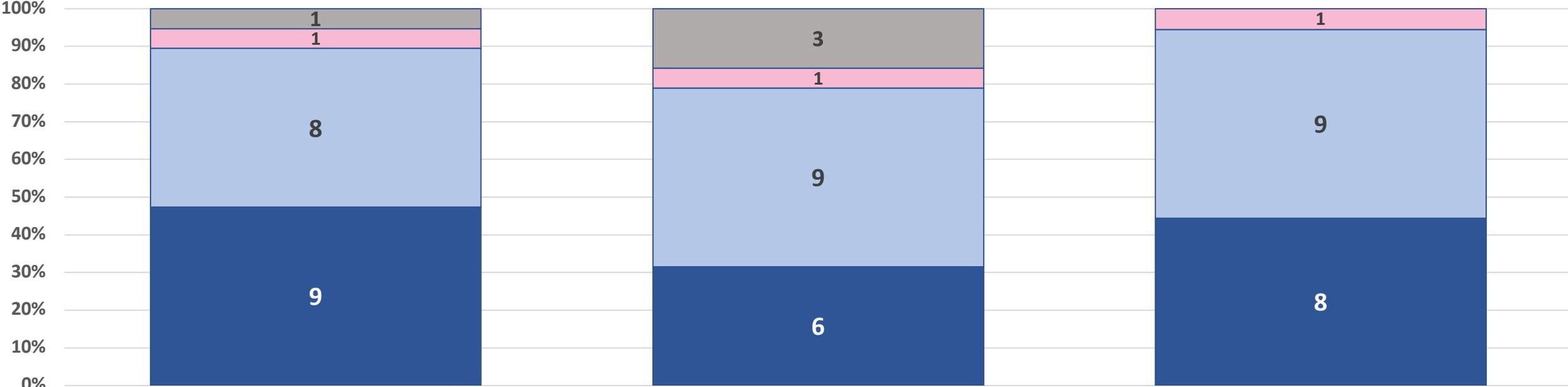
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Facing Hereditary Cancer EMPOWERED

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 ■ Somewhat agree
 ■ Somewhat disagree
 ■ Strongly disagree
 ■ Uncertain



The terms selected by the working group, if used consistently across organizations, will decrease patient confusion.

The terms selected by the working group, if used consistently across organizations, will decrease healthcare provider confusion.

The terms selected by the working group, if used consistently across organizations, will improve patient-provider communication.



Perceived barriers to using the terminology

- Complexity of selected terms: target population to be served, education level of those served
- Allocation of resources: lack of money, staff, and time to implement changes
- Consistency across large organizations: lack of control over content outside immediate teams



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How can the barriers be addressed?

- Training: examples of terms in use, educational modules, further discussion with stakeholders
- Refining the terms: discussion with colleagues, further delineation of when terms used, and how
- Defining the terms: terms always need to be defined for patient audience

“Tumor profiling is more than just describing/defining. It doesn’t matter what you call it but how you define it. That's what patients need to know. They need to know why they need these tests, what to do with the information learned, and how it will affect their care.”



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Consistent Testing Terminology Working Group Resources

CommonCancerTestingTerms.org

Common Cancer Testing Terminology

The Consistent Testing Terminology Working Group is composed of more than 40 patient advocacy organizations from solid tumors and hematologic malignancies, professional societies, pharma, biotech, diagnostics companies, and testing laboratories committed to clarifying and promoting consistent use of common terms for biomarker and germline genetic testing.

Research shows that despite widespread acceptance of the importance of testing, actual testing rates lag far behind best-practice recommendations for both biomarker testing for somatic (acquired) mutations and other biomarkers, and for germline genetic testing for identifying germline (inherited) mutations (also known as variants).

Analysis by the **Consistent Testing Terminology Working Group** indicates that varied testing terms are an obstacle to patient communication with providers about testing for their specific cancer type. The pan-cancer working group identified at least 33 terms related to biomarker, genetic, and genomic testing for cancer being used in patient education today.

This varied terminology is one patient-identified reason for confusion about testing, which impedes effective communication with providers and understanding about what testing means for their care.

BE PART OF A UNIFIED VOICE

ADOPT AND USE THE CONSISTENT TESTING TERMINOLOGY WHEN TALKING TO PATIENTS

- Biomarker Testing
- Genetic Testing for an Inherited Mutation
- Genetic Testing for Inherited Cancer Risk

A unified voice will help the medical community and patients achieve common understanding about the benefits of testing. [Join a movement to](#)

White Paper

A WHITE PAPER ON THE NEED FOR CONSISTENT TERMS FOR TESTING IN PRECISION MEDICINE

A multi-stakeholder working group of patient advocacy organizations, professional societies, pharmaceutical and diagnostic companies, and laboratories provides recommendations for adoption of consistent, plain language terms for biomarker and germline genetic testing that are applicable across cancer types to help eliminate patient confusion about testing for precision medicine.

PATIENT ADVOCACY GROUPS

PROFESSIONAL SOCIETIES

INDUSTRY PARTNERS

Infographic

Consistent Common Cancer Testing Terms

Join a movement to promote consistent use of common terms for biomarker and germline genetic testing and improve communication between patients and providers about testing needs. www.CommonCancerTestingTerms.org

- 41** patient advocacy groups, professional societies, pharma, biotech, diagnostic companies, and laboratories agree to use consistent descriptor testing terms in patient education and communication.
- Recent data highlight suboptimal testing rates.
 - 40% of colorectal cancer patients are not being tested for biomarkers*
 - Only 7% of eligible non-small cell lung cancer patients treated in community oncology practices were tested for all 7 biomarkers recommended in clinical guidelines†
 - Germline genetic testing rates for inherited mutations and cancer risk are below 50%‡
- At least 33 terms related to biomarker, genetic, and genomic testing are used in cancer patient education contributing to patient confusion & lack of engagement in discussing testing with providers.
- Adopting consistent, common terms for patient communication will minimize patient confusion about testing.
 - "Biomarker testing" refers to testing for somatic (acquired) mutations and other biomarkers
 - "Genetic testing for an inherited mutation" and "Genetic testing for inherited cancer risk" describes testing for inherited mutations
- PATIENT SATISFACTION**
With consistent use of common terms, the medical community and patients achieve common understanding about the value of testing to make care decisions.

1. Okuno, M., Hara, H., Larson, E.K., et al. Biomarker Testing for NSCLC, BLCA, BRCA, MIBC: Measures of Utility (PROMIS) among Patients with Metastatic Disease. Cancer 120 (Suppl 15): 3159-3166 (2015).
2. Chalmers, T.L., Goldstein, C., Lippman, J., et al. Genetic testing and treatment landscape in patients with advanced non-small cell lung cancer (NSCLC) using network data from community oncology practices. J Clin Oncol 33(15):1959-1966 (2015).
3. Hirsch, V., Vignani, A., Barlow, C., et al. Genetic Testing and Results in the Population-Based Cohort of Breast Cancer Patients and Ovarian Cancer Patients. Journal of Clinical Oncology, May 20, 2016.

HCP Education Card

Recommended Terms for Providers Discussing Biomarker and Germline Genetic Testing with Patients

WHAT terms should I use to discuss testing with my patient?

WHY should I use specific terms with my patients?

WHERE can I learn more about recommended terms for communicating with my patients about testing in precision medicine?

• "Biomarker Testing" to discuss tests that identify characteristics, targetable findings, or other tests results originating from malignant tissue or blood.

• "Genetic Testing for an Inherited Mutation" and "Genetic Testing for Inherited Cancer Risk" for tests to identify germline mutations (also known as variants in the genetics community).

• Patients are confused by variations in testing terms, and this limits their ability to understand the importance of testing and what to communicate with their HCP to ensure appropriate and comprehensive testing for their care.

• Visit www.CommonCancerTestingTerms.org Read the recently released White Paper on the Need for Consistent Terms for Testing in Precision Medicine

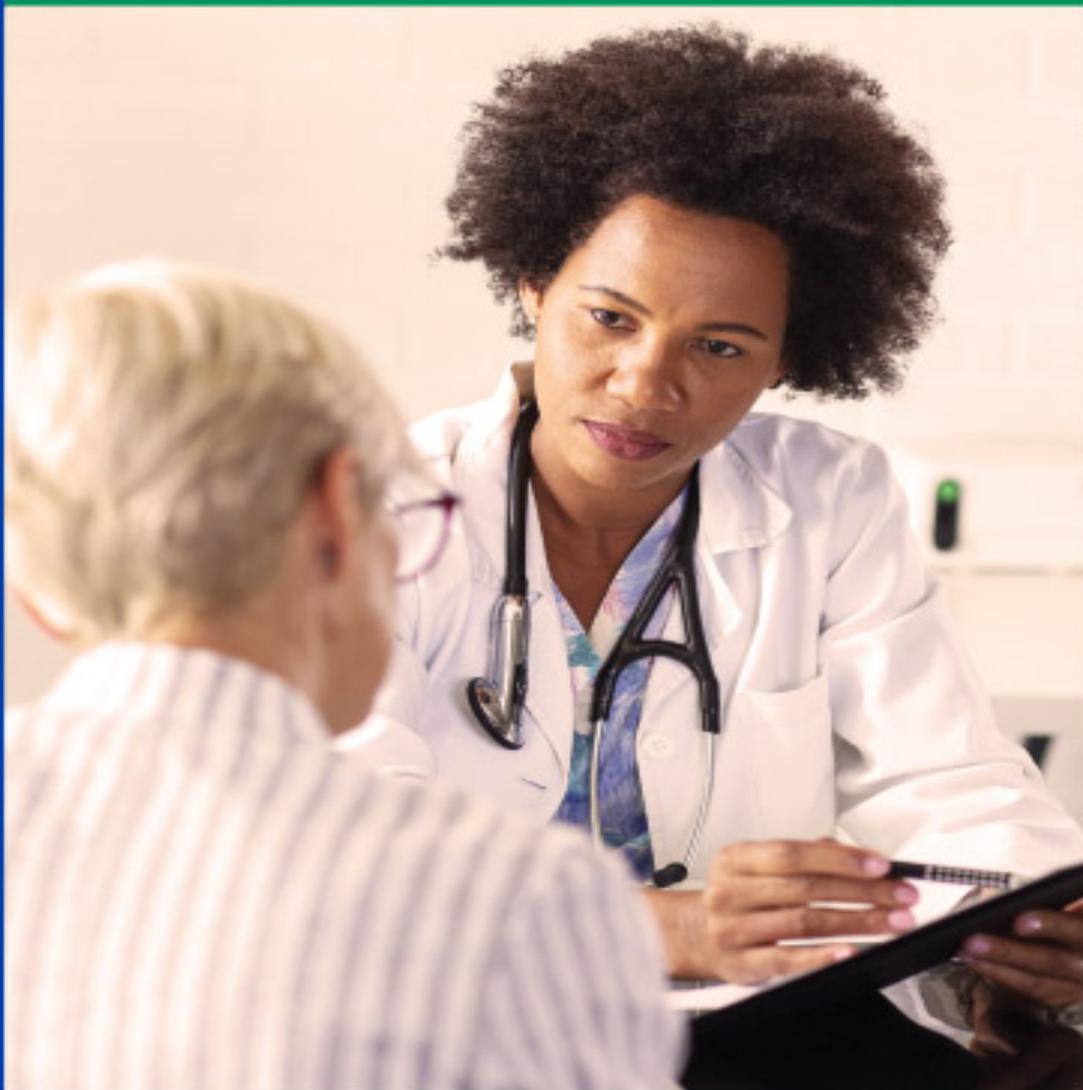
• Learn more about the multi-stakeholder group that has already endorsed this terminology

• Read the ASCO 2020 abstract on the recommended terms

Patient Survey Data

Survey on terms used for "genetic testing"

#	RESPONSES	DATE
1	No objections to terminology! "If you disagree with the logic, correct the grammar". Why would anyone question established terminology?!	3/2/2020 12:50 AM
2	N/A	3/2/2020 12:49 AM
3	n/a	2/25/2020 7:18 PM
4	Genetic testing	2/25/2020 7:17 PM
5	Like including "inherited" and "risk." Hate germline. No average person will know what that means without a definition.	2/25/2020 7:14 PM
6	I like to keep things simple and clear. The easy to understand words. "Keep it Simple"	2/25/2020 7:13 PM
7	Inherited risk is easily understood	2/25/2020 7:12 PM
8	Don't have	2/25/2020 7:11 PM
9	Simpler is better.	2/25/2020 7:05 PM
10	Genetik testing For inherited mutation	2/25/2020 7:01 PM
11	I am a genetic counselor, so germline makes sense to me, but isn't a patient-friendly term	2/22/2020 12:40 AM



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- **Biomarker Testing**
- **Genetic Testing for an Inherited Mutation**
- **Genetic Testing for Inherited Cancer Risk**

THANKS!

Any questions?

You can find us at:

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