



CANCER SUPPORT
COMMUNITY
COMMUNITY IS STRONGER THAN CANCER



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Developing a Patient-Friendly, Plain Language Precision Medicine Lexicon

Indigenous People's Navigation Network
October 2022

Agenda

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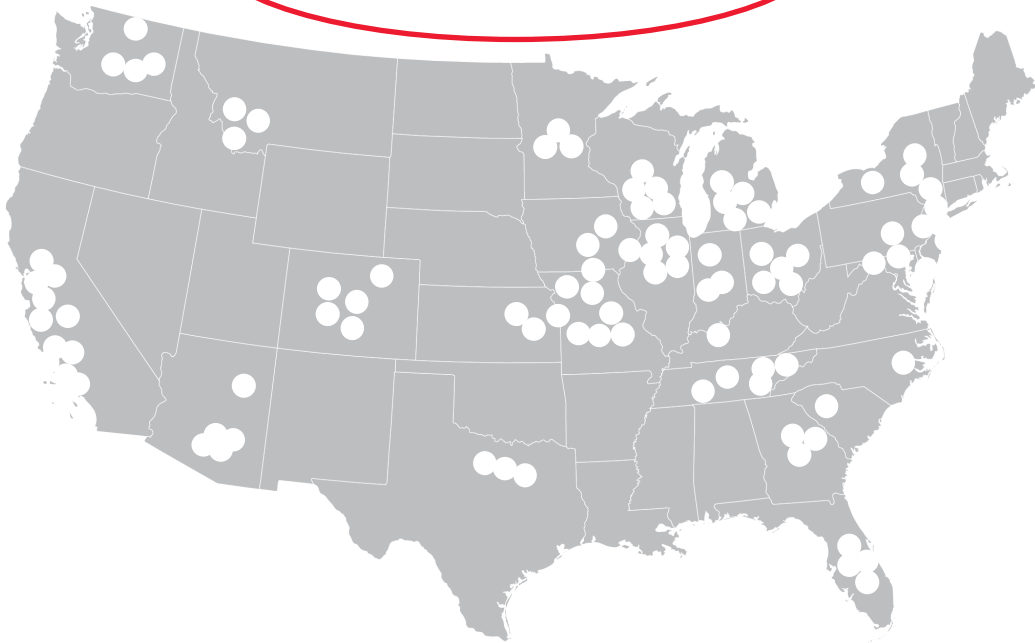
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For Navigators & for Patients/Caregivers

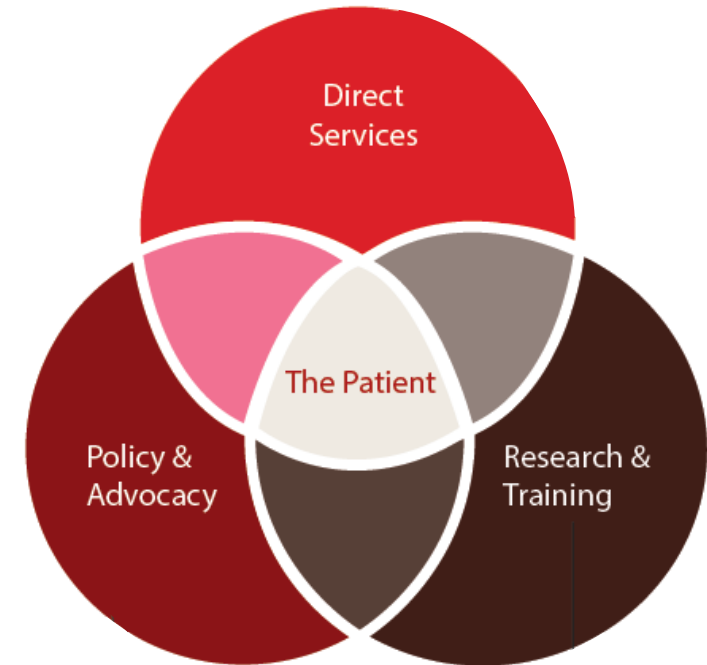
Our Mission

To ensure that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community.



Our Three Pillars

Research, Direct Services, and Advocacy



Frankly Speaking About Cancer: Precision Medicine



Targeted Therapy and Biomarker Testing for Lung Cancer



If you or someone you love has lung cancer, this booklet can help you learn about treatments called targeted therapies. For some subtypes of lung cancer, targeted therapy can be more effective and cause fewer side effects. Targeted therapy drugs “target” specific changes found in some cancers that cause them to grow, divide, and spread. Targeted therapy for lung

cancer may be. Targeted therapy drugs need to be used with care. For more information, visit www.CancerSupportCommunity.org.



Talking About Biomarker Testing



A WORKSHEET TO HELP YOU DISCUSS PRECISION MEDICINE AND BIOMARKER TESTING WITH YOUR HEALTH CARE TEAM

Precision medicine is a newer way to find the right treatment for each patient, based on cancer subtype. Before, the only option was to treat all cancers of one type (such as lung or breast cancer) with the same treatment. Instead, in precision medicine, doctors use biomarker testing to find your subtype of cancer. Cancer subtypes are smaller groups that cancer can be divided into, based on certain traits of the cancer cell. Biomarker test results show which treatment is likely to work best for you. Precision medicine is only available for certain types and stages of cancer.

It is important to know the subtype of a cancer in order to plan treatment and determine possible outcomes. Biomarker tests can find your specific subtype of cancer.

This worksheet can help you talk to your health care team about biomarker testing and decide if it's right for you. Inside, you will find more information about biomarker testing, questions to ask your doctor, and questions to ask yourself.

WHAT IS A BIOMARKER?

A biomarker is a sign of disease or abnormal function that can be measured in your blood, tissue, or bodily fluid. In cancer, biomarkers are often used to help choose the best treatment for you. These biomarkers can be proteins, genes, or gene mutations. Biomarkers tell your doctor about the subtype of cancer in your body.

Biomarkers are often referred to by a 3 or 4 letter abbreviation. Examples of biomarkers are HER2 in breast cancer or EGFR in lung cancer.

For many cancer types and stages, it is now standard of care for doctors to test the cancer's genes for biomarkers.

WHAT IS BIOMARKER TESTING?

Biomarker testing helps your doctor match the right drugs to the specific subtype of cancer you have. This can be a targeted therapy or immunotherapy.

In biomarker testing, a sample of your cancer is collected from your blood, bodily fluids, or tissue taken during surgery or biopsy. The test looks for biomarkers in your cancer sample. The test results can be used to help guide your treatment options.

Your doctor may call this type of testing biomarker testing, genomic testing, molecular profiling, tumor marker testing, mutation testing, or molecular testing. These are all the same kinds of tests.

WHAT ARE TARGETED THERAPY DRUGS?

Targeted therapy drugs keep cancer from growing and spreading with less harm to cells that are not cancer. They may have different side effects than other treatments because they are better able to attack your cancer cells and leave healthy cells alone. These drugs “target” specific cancer subtypes. They are only likely to work in those specific subtypes.

These drugs can work in several ways:

- They can find cancer cells.
- They can destroy cancer cells directly.
- Or they can cut off the blood supply that tumors need to grow and survive.



Precision Medicine



at cancer. Treatment is personalized to each person to person.

Another approach to finding the exact cancer or offers precision medicine to ask about it.

This booklet provides an overview of precision medicine, some questions to ask, and what the answers may mean. We hope that you will read it, follow up with your doctor, and share what you learn with others who may need it. Every person with cancer deserves to know all their options.



Precision Medicine: Overview

What is Precision Medicine?



Precision Medicine: Biomarker Testing

Precision Medicine: Biomarker Testing



A targeted therapy drug is a cancer treatment



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Question for the Chat

What cancer types do you work in (answer all that apply)?

- Breast
- Colorectal
- Lung
- Melanoma
- Ovarian
- Pancreatic
- Prostate
- Other

Adopting Consensus Terms for Testing in Precision Medicine

Consistent Testing
Terminology Working Group

Consistent Testing Terminology Working Group

PATIENT ADVOCACY GROUPS



PROFESSIONAL SOCIETIES

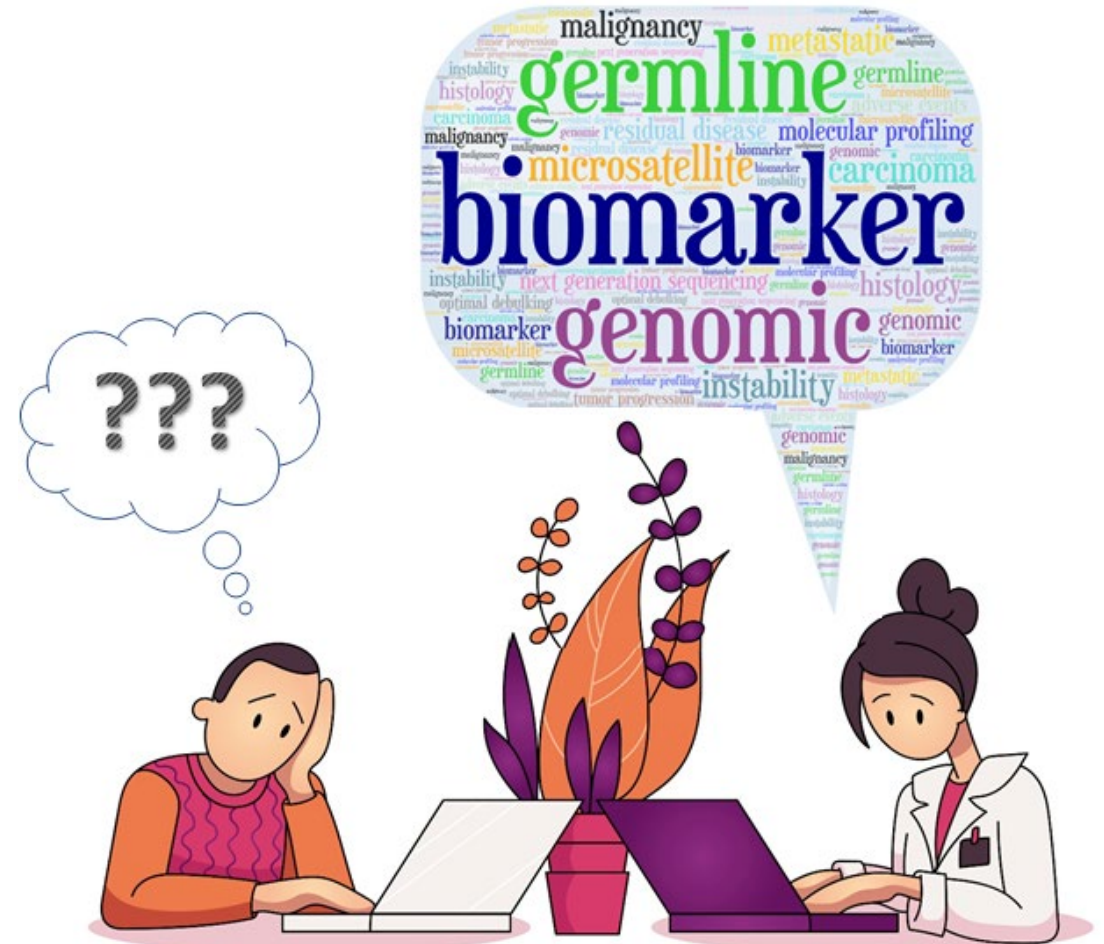


INDUSTRY PARTNERS



Health Literacy

- **Personal health literacy:**
the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.¹
- **Organizational health literacy:**
the degree to which organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.¹



1. What is Health Literacy? CDC

What Is the Goal of Precision Medicine?

To deliver the right treatment to the right patient with the right dose at the right time¹

- 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 Biomarker and Genetic Testing 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.



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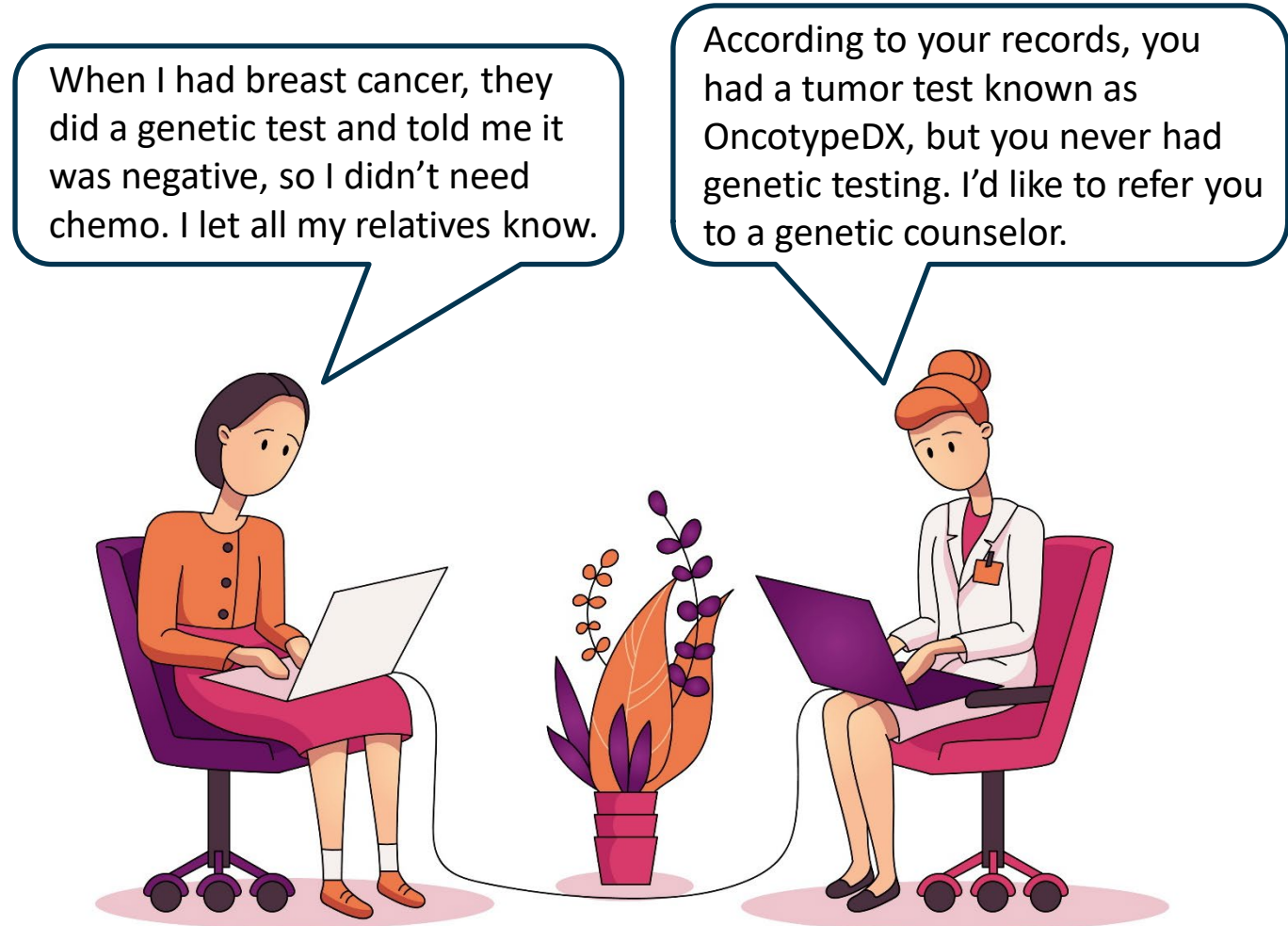
Chat Question

Do the patients & caregivers you work with have a good enough understanding of Precision Medicine, Biomarker Testing, & Genetic Testing to be active members of their health care team?

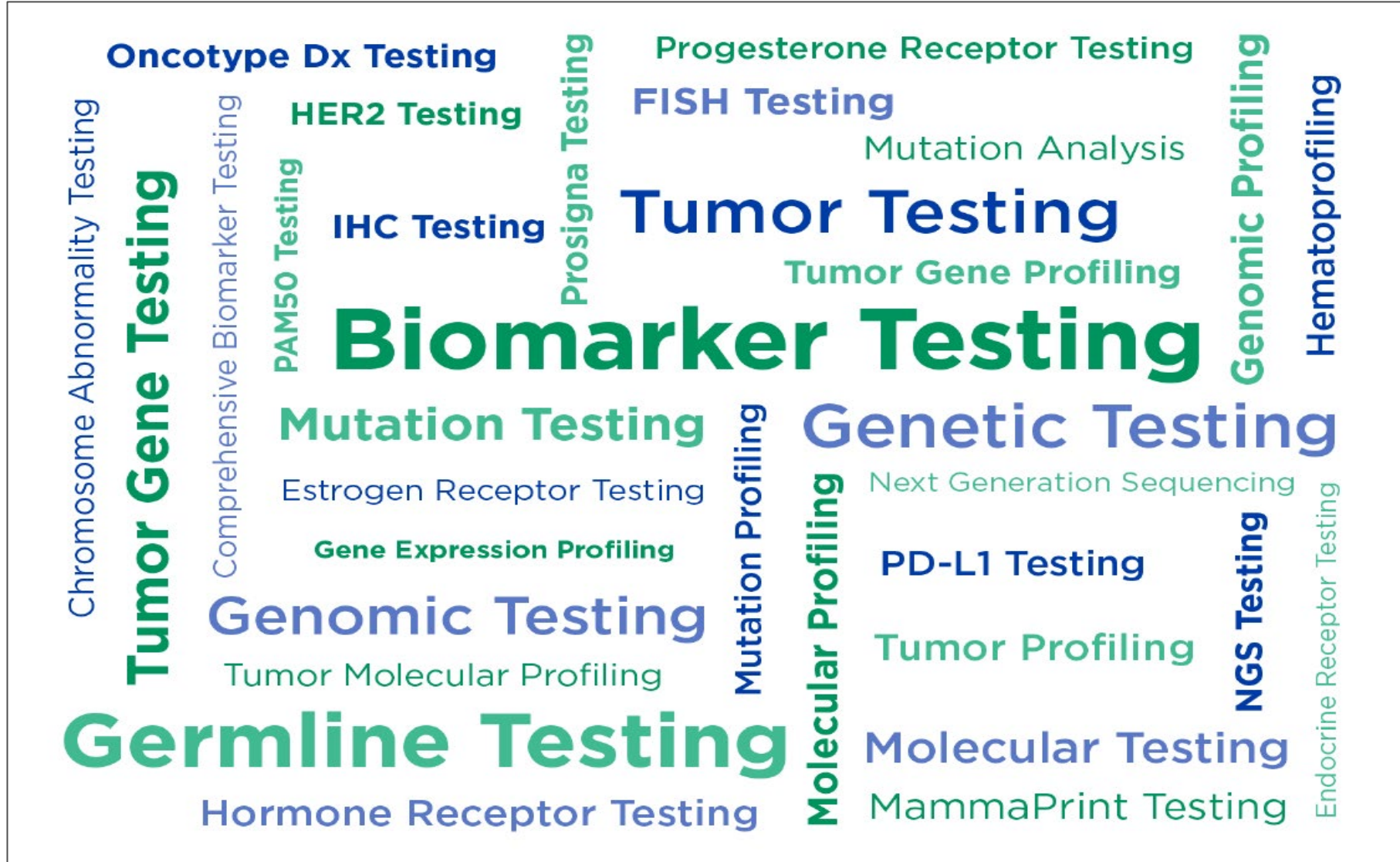
- **Most understand enough**
- **Some understand enough**
- **Few understand enough**
- **Most are confused & don't understand**

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.



33 Terms Across 9 Different Cancer Sites



Selecting a Term for Testing for Tumor Characteristics

“Comprehensive 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

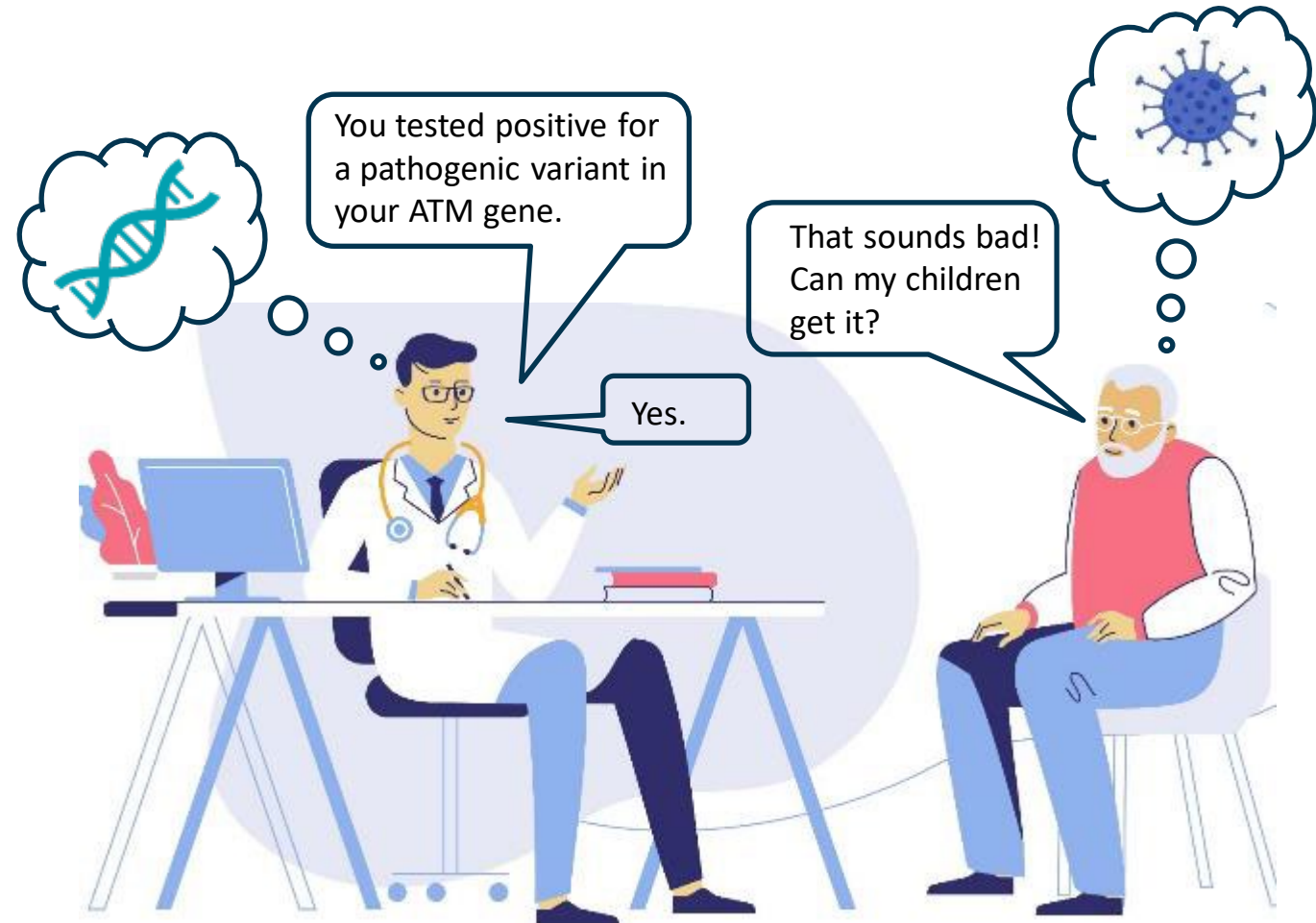
Selecting Consistent Terms for Testing for Inherited Mutations

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

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

Survey Respondent Comments

- Germline just sounds bad like germs, something you catch, not inherit.
- 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.
- Thank you for asking for our opinion!



*We received over 1500 write-in comments!

Selecting a Term for Germline Genetic Testing

**Based on the patient survey results, the working group
chose to use both:**

“Genetic Testing for an Inherited Mutation”

and

“Genetic Testing for Inherited Cancer Risk”

Public Resources

CommonCancerTestingTerms.org

Website

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**

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

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 patients?

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.

A patient group-led multi-stakeholder analysis found that there are at least 33 terms for biomarker and germline genetic testing currently being used to educate cancer patients about testing.

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

JCO® Precision Oncology
An American Society of Clinical Oncology Journal

Adopting Consensus Terms for Testing in Precision Medicine

Nikki A. Martin, MA¹; Joel E. Tepper, MD²; Veda N. Giri, MD³; Thomas E. Stinchcombe, MD⁴; Heather H. Cheng, MD, PhD^{5,6,7}; Milind M. Javle, MD⁸; and Eric Q. Konnick, MD, MS^{7,9}

DOI: 10.1200/PO.21.00027 *JCO Precision Oncology* no. 5 (2021) 1563-1567. Published online October 6, 2021.

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 tested in community oncology practices were tested for all 7 biomarkers recommended in clinical guidelines¹
- Germline genetic testing rates for inherited mutations and cancer risk are below 50%²

At least 33 terms related to biomarker, genetic, and genomic testing are used in cancer patient education contributing to patient confusion and 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

RECOMMENDED TERMS

- BIOMARKER TESTING
- GENETIC TESTING FOR AN INHERITED MUTATION
- GENETIC TESTING FOR INHERITED CANCER RISK

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.

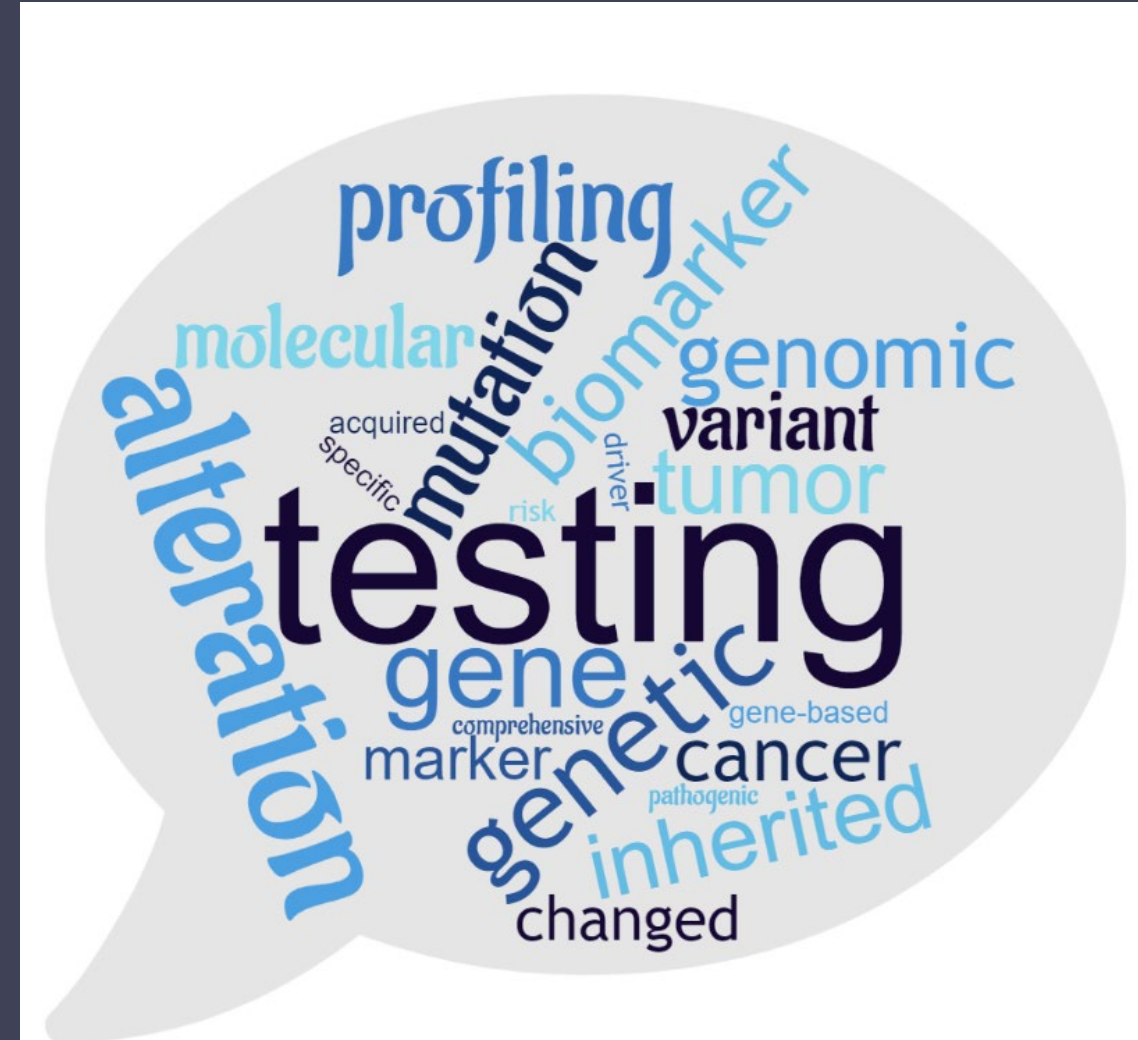
1. Williams MS, Hoadley KB, et al. Biomarker Profiling for KRAS, NRAS, BRAF, and Molecular Subtype (MSKCC) among Patients with Metastatic Colon Cancer (MSKCC). *Ann Oncol*. 2019;30(12):1985-1991.

2. Gorman JJ, Goldstein S, Leshner H, et al. Genetic testing and treatment landscape in patients with advanced non-small cell lung cancer (NSCLC) using real-world data from community oncology practices. *J Clin Oncol*. 2020;38(26):3668-3676.

3. Allison M, Huan N, 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.

Qualitative Research Results

- *Discussion boards*
- *Focus groups*



Patients and Caregivers are Confused!

Examples from CSC's Qualitative Research



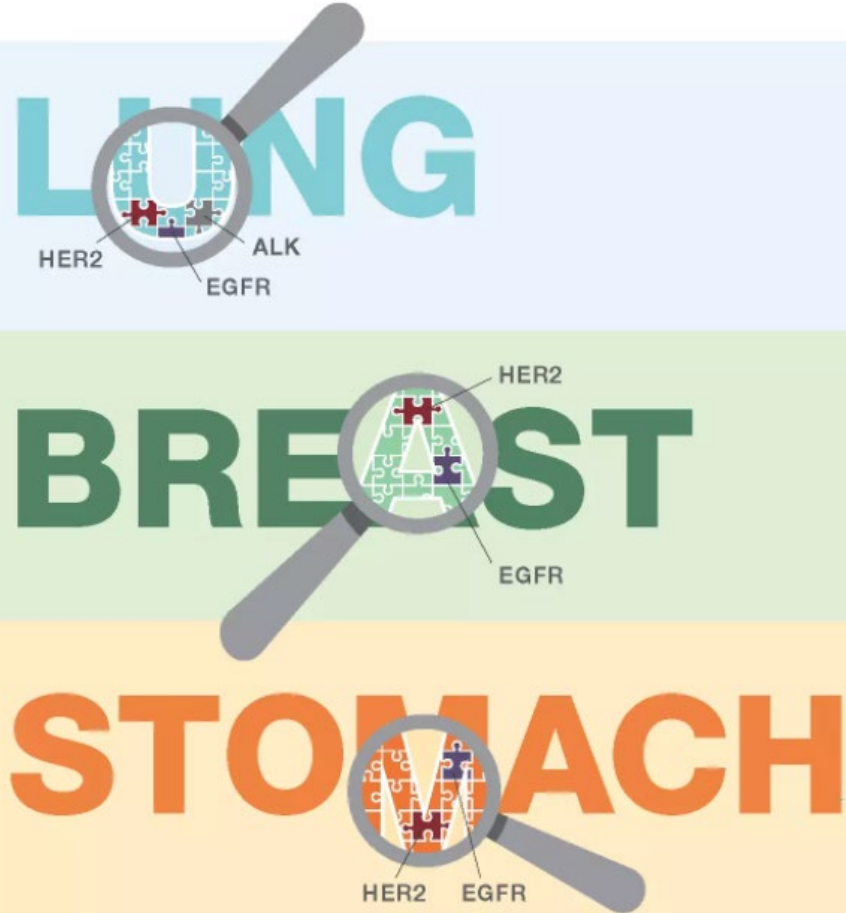
- What is “precision medicine”?
- What are “cancer subtypes”?
→ CSC developed 2 infographics
- What is “targeted therapy”?
→ CSC now always specifies “targeted therapy drugs”
- “Genetic” and “genomic” are too similar and cause confusion
→ CSC does not use the word “genomic”
- Little knowledge, and much confusion, around “liquid biopsy” -
What is it? It isn't a biopsy? It is a blood test??? When and why is it done?

Treating Cancer by Subtype

The same cancer subtype can occur in different cancer types. For example, the biomarker HER2 can be found in lung, breast, and stomach cancers. This means, these cancer types have HER2+ cancer subtypes. Some drugs that are created to treat HER2+ breast cancer, may also work if you have HER2+ stomach cancer or HER2+ lung cancer.

CANCER SUBTYPES

- ALK
- HER2
- EGFR

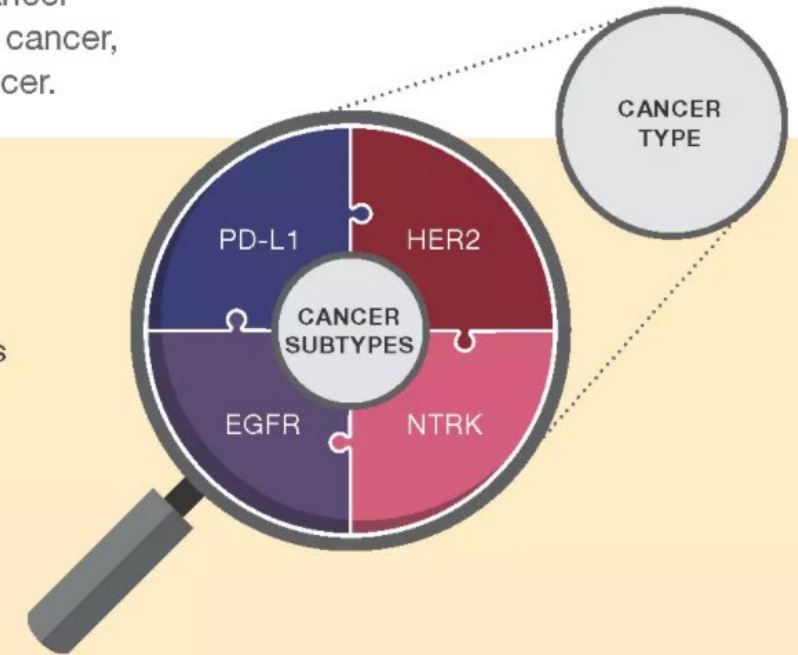


Cancer Types & Subtypes

The newest way to treat cancer is based on the subtype of cancer, rather than just type of cancer.

CANCER TYPES are often named for the organs or tissues where the cancer forms. Common cancer types are lung, breast, colorectal, prostate and skin cancers.

CANCER SUBTYPES are even smaller groups that cancer can be divided into, based on certain traits of the cancer cells.



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How to Reduce Patient and Caregiver Confusion

- The sequence of introducing terms is important!
 - Provide the most necessary information at the beginning and try to hold off on layering additional terms right away
- Patients and caregivers are confused by the “alphabet soup” of biomarkers and by jargon. But not using jargon may require more words to explain:
 - “If you have a positive HER2 test result (HER2+), Herceptin is likely to work well for you” is understandable
 - “Herceptin targets HER2” is confusing jargon
- Use biomarker acronyms (alphabet soup) sparingly
- Focus on what the patient needs to know to be an active member of their health care team. Do they need to know what KIND of test to ask if the test has been done?

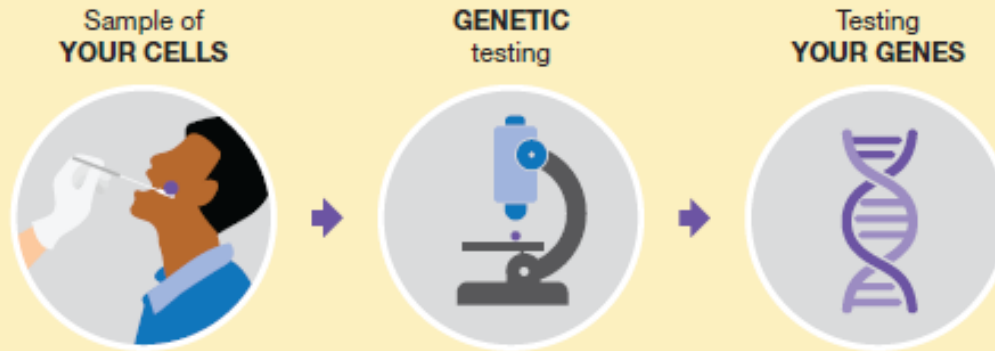
Other Findings from CSC's Qualitative Research

- Patients and caregivers (and the general public) are comfortable with the terms “gene,” “genetic mutation,” and “inherited mutation.”
- Testing is stressful. Waiting on results is stressful. No matter your results, biomarker testing can be scary, confusing, and disappointing.
- If you use more than 1 term for a concept, patients & caregivers will think you are trying to describe 2 different concepts! (Comprehensive biomarker testing & molecular profiling sound like 2 very different tests)
- Patients & caregivers asked for graphics to help explain concepts and definitions.

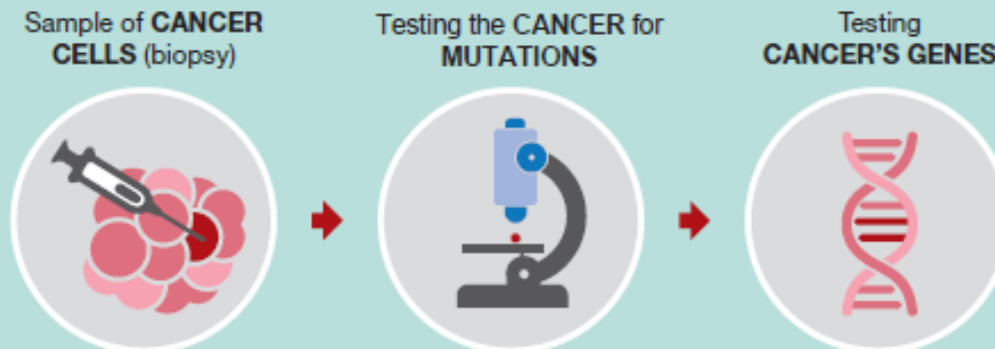
Genetic Testing vs. Testing the Cancer for Mutations

Genetic testing looks for mutations in your genes and testing the cancer for mutations looks for mutations in the cancer's genes.

GENETIC TESTING



TESTING THE CANCER FOR MUTATIONS





Quantitative Research Results

Precision Medicine Patient Preferences Survey

Support Group
Mary Smiths

SURVEY RESPONDENT CHARACTERISTICS

Total sample size: 614

~ 50% Cancer patients and/or caregivers

~ 50% General population

Average Age: 46.7 years old (SD=18.1 years)

Gender: ~ 50% Female

Race/ethnicity: 69% White / 21% Black /
6% Asian or South Asian / 0.3% American Indian /
2% multiracial / 2% Other / 14% Hispanic

Household Income: 36% <\$50K / 34% \$50K-\$100K / 30% >\$100K

Education: 3% <HS / 44% HS or some college / 53% Bachelor's+

Respondents were selected to be representative of US cancer patients & caregivers in:

- gender
- race/ethnicity
- household income

Blacks & Hispanics were oversampled to test differences by race and ethnicity.

Also sampled the general public to validate the lexicon with respondents who were diagnosis-naïve.



Creating & Validating Lexicon Terms & Definitions



Familiarity

- ☐ Never heard of
- ☐ Heard of, but don't know about
- ☐ Heard of & have basic understanding



Clarity

- ☐ On a scale of 1-10, how clear are our Lexicon definitions?
- ☐ We report % who chose 7 or higher



Preference

- 5-point Likert scale
- ☐ Strongly Oppose
 - ☐ Somewhat Oppose
 - ☐ Neutral
 - ☐ Somewhat Favor
 - ☐ Strongly Favor

Overall Familiarity Results



Familiarity

- ☐ Never heard of
- ☐ Heard of, but don't know about
- ☐ Heard of & have basic understanding

- Blacks tended to report higher familiarity and understanding of terms than whites
- Caregivers tended to report higher familiarity and understanding of terms than patients
- Patients & caregivers tended to report higher familiarity and understanding of terms than the general public
- Respondents with lower household income and education attainment were significantly less likely to report familiarity with, understanding of, and preference for terms

Overall Familiarity Results



Familiarity

- ☐ Never heard of
- ☐ Heard of, but don't know about
- ☐ Heard of & have basic understanding

Top Terms For	% Familiar	% Understood
Tissue Biopsy	89%	61%
Inherited Mutation	81-89%	46-52%
Genetic Testing for Inherited Cancer Risk	84-89%	48-55%
Mutation in the Cancer	80-85%	39-44%
Testing the Cancer for Mutations	68-78%	32-37%
Cancer Subtypes	60%	24%
Liquid Biopsy	56%	25%

Overall Clarity Results

SURVEY RESULTS

CONCEPT AS DEFINED IN LEXICON	CLARITY SCORE*
Genes	90%
Inherited Mutation	87%
Genetic Testing for Inherited Cancer Risk	86%
Genetic Testing for an Inherited Mutation	83%
Biomarker	83%
Acquired Mutation	81%
Comprehensive Biomarker Testing	84%
Cancer Subtypes	81%
Liquid Biopsy	81%
Tissue Biopsy	85%



Clarity

- ☐ On a scale of 1-10, how clear are our Lexicon definitions?
- ☐ We report % who chose 7 or higher



Overall Clarity Results



Clarity

- On a scale of 1-10, how clear are our Lexicon definitions?
- We report % who chose 7 or higher

- Definitions were scored by most survey respondents as highly understandable (clarity of 7+ out of 10)
- No significant differences between patients, caregivers, & general public.
- Lower scores correlated with:
 - Hispanic ethnicity (5%-14%↓)
 - Lower (<\$50k) household income (5%-12%↓)
 - Lower (<Bachelor's) education (5%-12%↓)

Overall Preference Results



Preference

5-point Likert scale

- ☐ Strongly Oppose
- ☐ Somewhat Oppose
- ☐ Neutral
- ☐ Somewhat Favor
- ☐ Strongly Favor

- Although Black respondents reported higher preference scores for many terms than white respondents, this didn't affect rankings significantly for most terms
- Although Hispanic respondents reported lower preference scores for some terms than non-Hispanic respondents, this didn't affect rankings significantly for most terms
- Respondents with lower household income and education attainment were significantly less likely to report familiarity with, understanding of, and preference for terms

Preferred Terms Used in Precision Medicine Plain Language Lexicon



Preference

5-point Likert scale

- ☐ Strongly Oppose
- ☐ Somewhat Oppose
- ☐ Neutral
- ☐ Somewhat Favor
- ☐ Strongly Favor

- **Genetic Testing for Inherited Cancer Risk/ Genetic Testing for Inherited Mutation**
- **Biomarker Testing** (testing for biomarkers that are NOT inherited, including mutations in the cancer)
- **Inherited Mutation** (Genetic or Gene Mutation) - *tested 13 terms*
- **Mutations in the Cancer** - *tested 14 terms*
- **Testing the Cancer for Mutations** - *tested 18 terms*
- **Tissue Biopsy**
- **Cancer Subtype**
- **Liquid Biopsy**

Public Resources: Precision Medicine Plain Language Lexicon



Precision Medicine Plain Language Lexicon available at:
www.CancerSupportCommunity.org/PMPlainLanguage



Public Resources

Precision Medicine Plain Language Lexicon

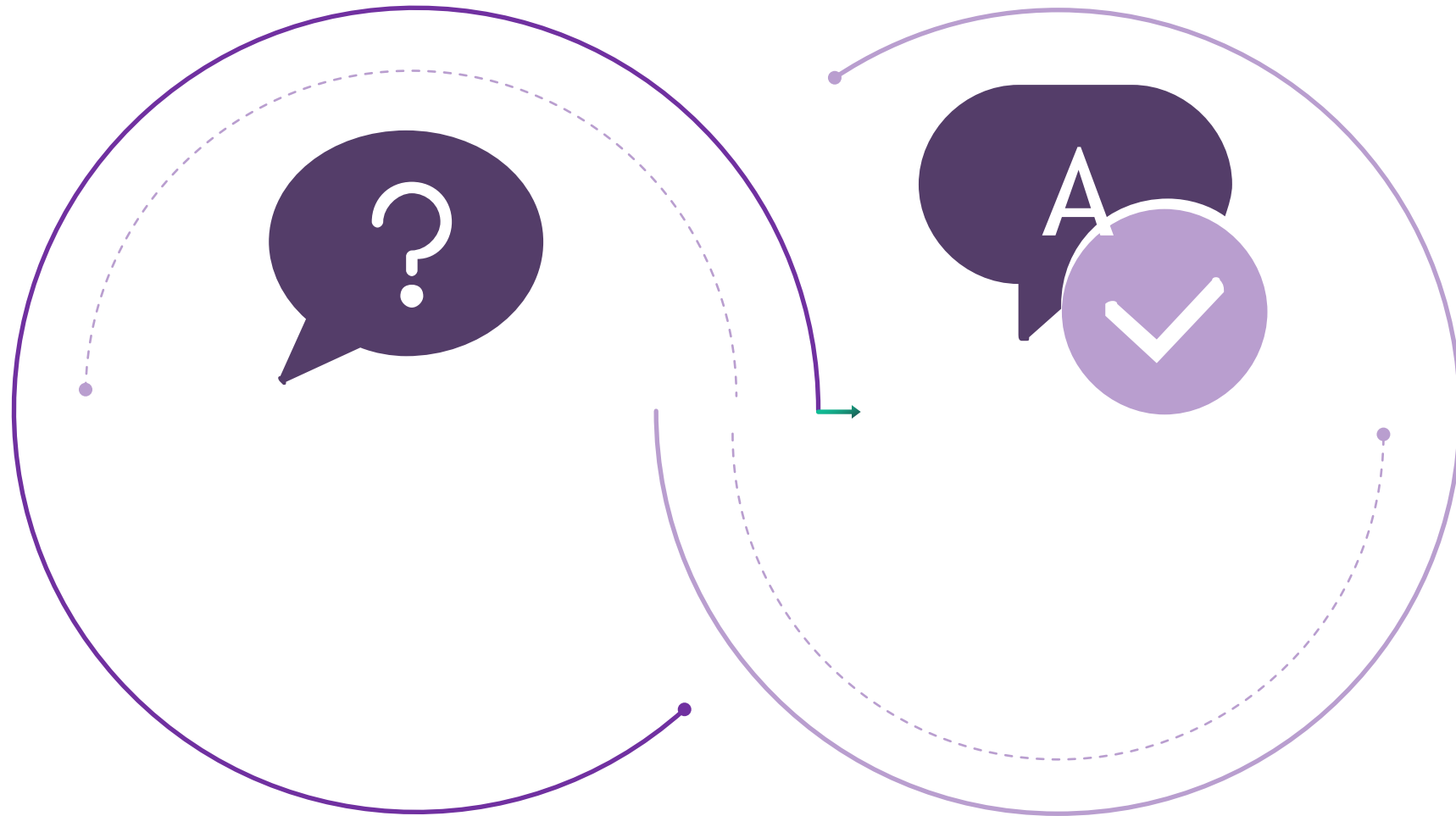
- Living Document to be Updated Over Time
- Created with Oncology Professionals
- Iterative Focus Groups & Discussion Boards with Patients & Caregivers
- Validated with Survey
- Example Term & Definition:

Precision Medicine

Precision medicine is a newer way to find the right treatment for each patient, based on cancer subtype. Before, the only option was to treat all cancers of one type (such as lung or breast cancer) with the same treatment.

Instead, in precision medicine, doctors use biomarker testing to find your subtype of cancer. Results of these tests show which treatment is likely to work best for you. Precision medicine is only available for certain types and stages of cancer.

Q&A



Name: Claire Saxton

Contact: csaxton@CancerSupportCommunity.org



Common Cancer Testing Terminology:
www.CommonCancerTestingTerms.org

Refer your patients or
order FSAC materials to distribute to them:
www.CancerSupportCommunity.org/Precision-Medicine

Precision Medicine Plain Language Lexicon available at:
www.CancerSupportCommunity.org/PMPlainLanguage

www.CancerSupportCommunity.org

