Developing a Patient-Friendly, Plain Language Precision Medicine Lexicon

Indigenous People’s Navigation Network
October 2022
Agenda

1. Background
   Who is CSC?

2. Consistent Testing Terminology
   Importance of being consistent & recommended umbrella terms

3. Creating the Lexicon: Qualitative Research
   Results from Discussion Boards & Focus Groups

4. Creating the Lexicon: Quantitative Research
   Survey Results

5. Resources
   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
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
• **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

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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 time\(^1\)

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

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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

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.

According to your records, you had a tumor test known as OncotypeDX, but you never had genetic testing. I’d like to refer you to a genetic counselor.

When I had breast cancer, they did a genetic test and told me it was negative, so I didn’t need chemo. I let all my relatives know.
33 Terms Across 9 Different Cancer Sites

- Oncotype Dx Testing
- HER2 Testing
- Progesterone Receptor Testing
- FISH Testing
- Mutation Analysis
- Genomic Profiling
- Hematoprofiling

- Biomarker Testing
- Tumor Testing
- Tumor Gene Profiling

- Mutation Testing
- Estrogen Receptor Testing
- Gene Expression Profiling

- Genomic Testing
- Tumor Molecular Profiling

- Germline Testing
- Hormone Receptor Testing
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!
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

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 Genomic Testing with Patients

- What
- Why
- Where

- "Biomarker Testing" or "Genomic Testing" for targetable, actionable, and treatable cancer-related genetic mutations
- "Inherited Cancer Risk" or "Genetic Testing for Inherited Cancer Risk" for inherited mutations that can be transmitted

Visit our website at commoncancertesting.org

Consistent Common Cancer Testing Terms

- Consistency cannot be maintained in the absence of a consistent terminology
- Consistent testing terminology increases patient satisfaction
- Consistent testing terminology leverages existing patient education tools

JCO Precision Oncology
An American Society of Clinical Oncology Journal

Adopting Consensus Terms for Testing in Precision Medicine

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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 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.
How to Reduce Patient and Caregiver Confusion

• The sequence of introducing terms is important!
  o 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:
  o “If you have a positive HER2 test result (HER2+), Herceptin is likely to work well for you” is understandable
  o “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**

- Sample of **YOUR CELLS**
- GENETIC testing
- Testing **YOUR GENES**

**TESTING THE CANCER FOR MUTATIONS**

- Sample of **CANCER CELLS** (biopsy)
- Testing the **CANCER** for **MUTATIONS**
- Testing **CANCER'S GENES**
Quantitative Research Results

Precision Medicine Patient Preferences Survey
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.

<table>
<thead>
<tr>
<th>SURVEY RESPONDENT CHARACTERISTICS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total sample size: 614</td>
</tr>
<tr>
<td>~ 50% Cancer patients and/or caregivers</td>
</tr>
<tr>
<td>~ 50% General population</td>
</tr>
<tr>
<td>Average Age: 46.7 years old (SD=18.1 years)</td>
</tr>
<tr>
<td>Gender: ~ 50% Female</td>
</tr>
<tr>
<td>Race/ethnicity: 69% White / 21% Black / 6% Asian or South Asian / 0.3% American Indian / 2% multiracial / 2% Other / 14% Hispanic</td>
</tr>
<tr>
<td>Household Income: 36% &lt;$50K / 34% $50K-$100K / 30% &gt;$100K</td>
</tr>
<tr>
<td>Education: 3% &lt;HS / 44% HS or some college / 53% Bachelor’s+</td>
</tr>
</tbody>
</table>
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

- 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

<table>
<thead>
<tr>
<th>Top Terms For</th>
<th>% Familiar</th>
<th>% Understood</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tissue Biopsy</td>
<td>89%</td>
<td>61%</td>
</tr>
<tr>
<td>Inherited Mutation</td>
<td>81-89%</td>
<td>46-52%</td>
</tr>
<tr>
<td>Genetic Testing for Inherited Cancer Risk</td>
<td>84-89%</td>
<td>48-55%</td>
</tr>
<tr>
<td>Mutation in the Cancer</td>
<td>80-85%</td>
<td>39-44%</td>
</tr>
<tr>
<td>Testing the Cancer for Mutations</td>
<td>68-78%</td>
<td>32-37%</td>
</tr>
<tr>
<td>Cancer Subtypes</td>
<td>60%</td>
<td>24%</td>
</tr>
<tr>
<td>Liquid Biopsy</td>
<td>56%</td>
<td>25%</td>
</tr>
</tbody>
</table>
### Overall Clarity Results

#### Survey Results

<table>
<thead>
<tr>
<th>Concept as Defined in Lexicon</th>
<th>Clarity Score*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Genes</td>
<td>90%</td>
</tr>
<tr>
<td>Inherited Mutation</td>
<td>87%</td>
</tr>
<tr>
<td>Genetic Testing for Inherited Cancer Risk</td>
<td>86%</td>
</tr>
<tr>
<td>Genetic Testing for an Inherited Mutation</td>
<td>83%</td>
</tr>
<tr>
<td>Biomarker</td>
<td>83%</td>
</tr>
<tr>
<td>Acquired Mutation</td>
<td>81%</td>
</tr>
<tr>
<td>Comprehensive Biomarker Testing</td>
<td>84%</td>
</tr>
<tr>
<td>Cancer Subtypes</td>
<td>81%</td>
</tr>
<tr>
<td>Liquid Biopsy</td>
<td>81%</td>
</tr>
<tr>
<td>Tissue Biopsy</td>
<td>85%</td>
</tr>
</tbody>
</table>

#### Clarity

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

- 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

• 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

- **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

Preference
5-point Likert scale
- Strongly Oppose
- Somewhat Oppose
- Neutral
- Somewhat Favor
- Strongly Favor
Precision Medicine Plain Language Lexicon (as of November 2021)

INTRODUCTION

Developing Plain Language, Patient-Friendly, Consistent Precision Medicine Terminology

The Cancer Support Community (CSC) is pleased to share our Precision Medicine Lexicon – a set of plain language terms and definitions that help explain precision medicine, biomarker testing, and genetic

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
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