

Consistent Testing Terminology Use Cases Workshop

March 11, 2021

Consistent Testing Terminology Working Group

PATIENT ADVOCACY GROUPS



PROFESSIONAL SOCIETIES



INDUSTRY PARTNERS



Use Case – Breast Cancer

Presented by Janine Guglielmino, Vice President, Mission Delivery and Sue Friedman, Founder and Executive Director, Facing Our Risk of Cancer Empowered (FORCE)

Using Consistent Terminology in the Breast Cancer Setting

Results from LBBC-FORCE survey of organizations

Sue Friedman – FORCE

Janine Guglielmino – Living Beyond Breast Cancer



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Background on precision medicine in breast cancer

- Germline genetic testing
 - Used pre-diagnosis to make decisions about risk management (screening, pharmacoprevention, risk-reducing surgery)
 - Used post-diagnosis to make decisions about surgical management (lumpectomy vs. mastectomy/bilateral mastectomy)
 - Used post-diagnosis to make decisions about treatment
 - Metastatic breast cancer treatment with PARP inhibitor
 - Clinical trial eligibility
 - Used for cascade testing to help identify high risk relatives



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Background on precision medicine and breast cancer

- Biomarker testing
 - All tumors tested for specific biomarkers
 - Estrogen, progesterone and Her2neu receptors (ER/PR/Her2) for systemic treatment options
 - Prognostic testing
 - Gene expression profiles (often called “genomic tests” in breast cancer)
 - Several are commonly used and similar
 - Used to determine need for chemotherapy and hormonal therapy, length of hormonal therapy treatment
 - Treatment selection in metastatic setting
 - PIK3CA: Testing for this biomarker (somatic gene mutation) can help identify people most likely to respond to the medication PIQRAY (alpelisib)
 - PD-L1: This biomarker (protein) can help identify people who are most likely to respond to the immunotherapy drugs Tecentriq (atezolizumab) and Keytruda (pembrolizumab)
 - Clinical trial eligibility



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Activities

- Individually and collaboratively FORCE and LBBC have pursued activities to increase use of consistent testing terminology
 - [ASCO Connection](#) article
 - As part of our mutual efforts to improve outcomes and reduce disparities for young women, we reached out to partners to brainstorm ways to improve uptake. This outreach revealed challenges to universal adoption of the terms in breast cancer
 - FORCE and LBBC developed a joint survey to describe these challenges, with the goal of presenting our findings to CTTWG



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Goals of our survey

- To grow awareness of the process used and terms developed by the CTTWG among the breast and related hereditary cancer communities
- To assess the likelihood of colleagues utilizing the CTTWG terms
- To gather information about the barriers to utilizing the terms



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Who responded to our survey

- Current partners of FORCE or LBBC
- Members of CTTWG whose constituency includes people affected by breast cancer
- 28 organizations invited (survey still open)



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Who responded to our survey

- 24 organizations (as of 3/21)
- 7 members of CTTWG
- All provide some resources focused on breast cancer
- All develop and share educational information about cancer for patients, caregivers, health care professionals or the general public
- All indicated they influence decision-making in developing educational materials



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Q. Do any of the following comprise 25% or more of the population your organization aims to serve ? (please select all that apply)

Answered: 24 Skipped: 0

Population	Responses
People with a disease or condition	23 (96%)
Caregivers for people with a disease or condition	14 (58%)
General public	13 (54%)
Healthcare or public health professionals	11 (46%)
Researchers	5 (21%)
Other	0



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Q. About how many people did your organization’s educational materials reach in the last year?

Answered: 22 Skipped: 2

People reached	Responses
100,000 or more	10 (45%)
10,000 – 99,999	5 (23%)
1,000 – 9,999	3 (14%)
500 – 999	1 (5%)
100 - 499	3 (14%)
<100	0



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Q. Which of the following best describes your organization's focus?

Answered: 24 Skipped: 0

People reached	Responses
We focus on multiple diseases or conditions, including cancer	1 (4%)
We focus on all types of cancers	5 (21%)
We focus on a few or certain types of cancer (Please describe)	6 (25%)
We focus on one type of cancer (Please describe)	10 (42%)
We do not have a disease focus	1 (4%)
Other (We focus on cancer prevention through policy, advocacy and we also focus on tobacco prevention)	1 (4%)

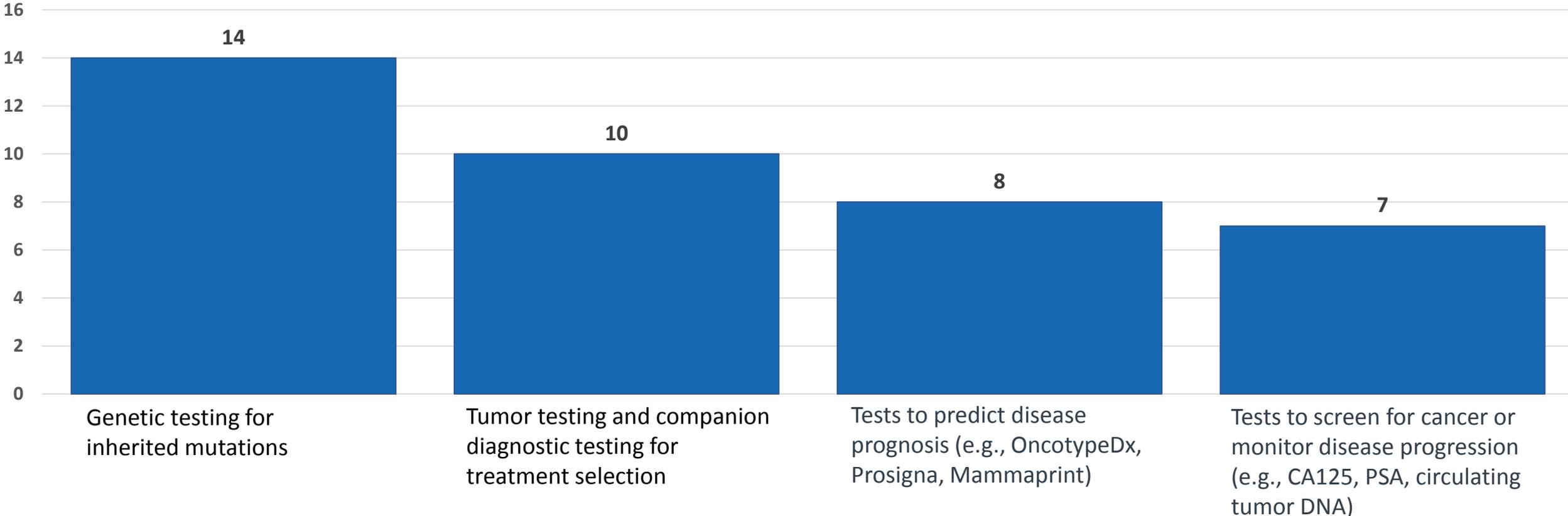


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Q. For which of these tests has your organization developed educational resources? (select all that apply)

Answered: 17 Skipped: 7

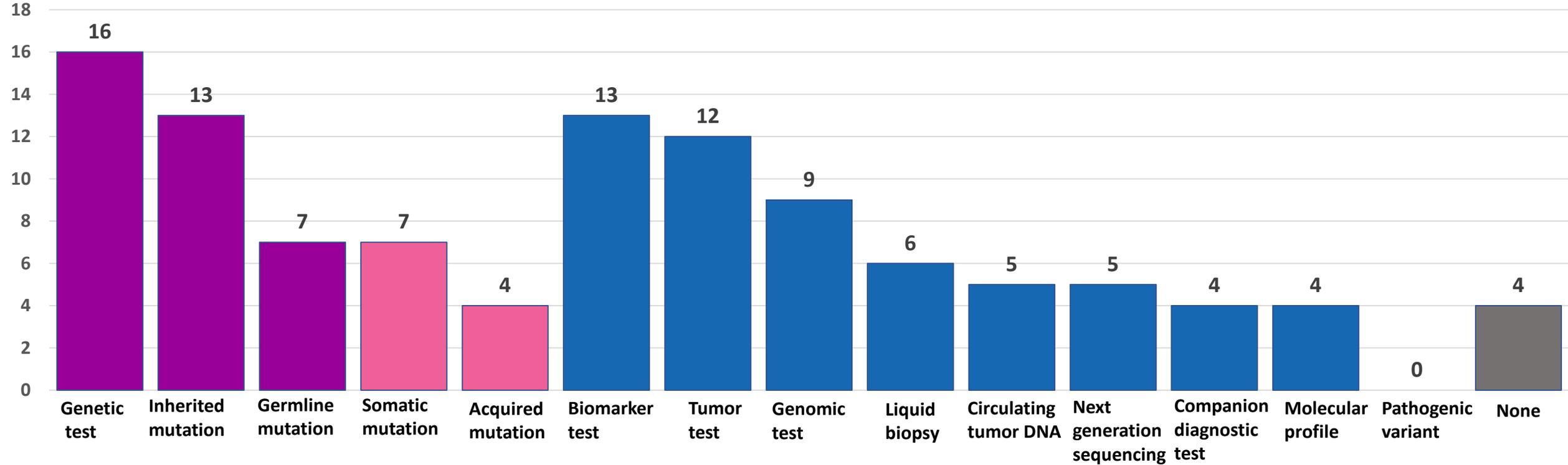


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Q. Which terms do you use in your educational materials? (select all that apply)

Answered: 24 Skipped: 0



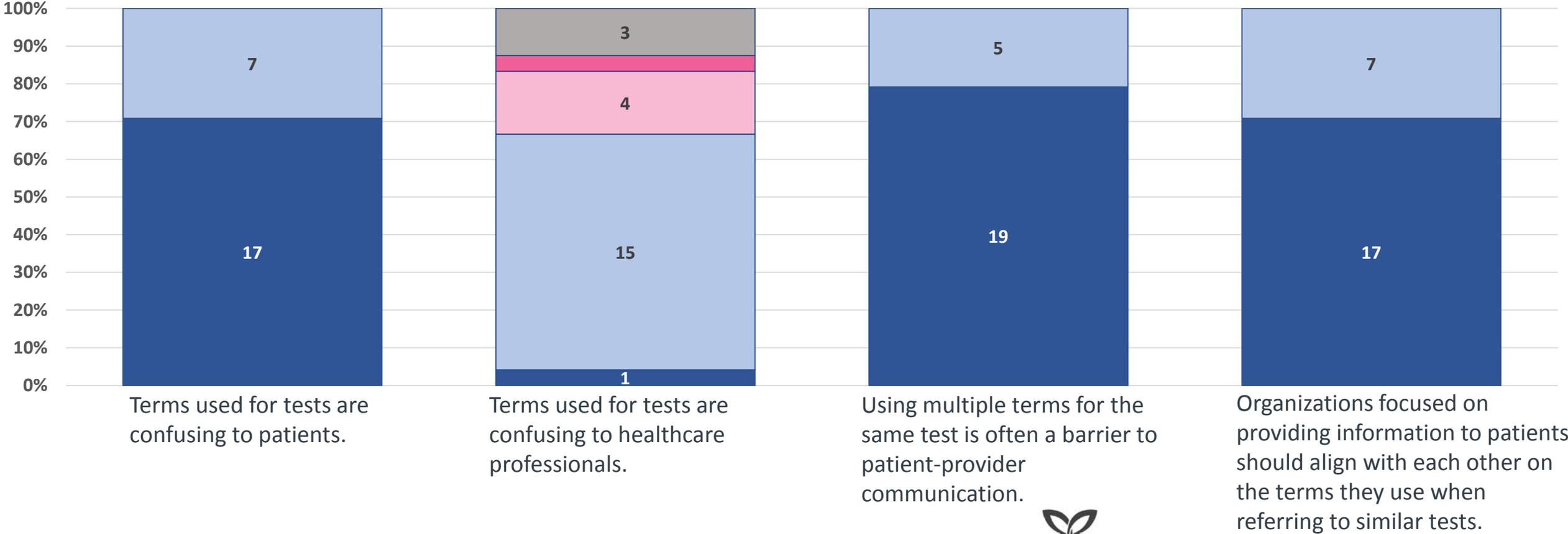
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Q. To what degree do you/does your organization agree or disagree with the following statements about tests used in cancer care?

Answered: 24 Skipped: 0

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



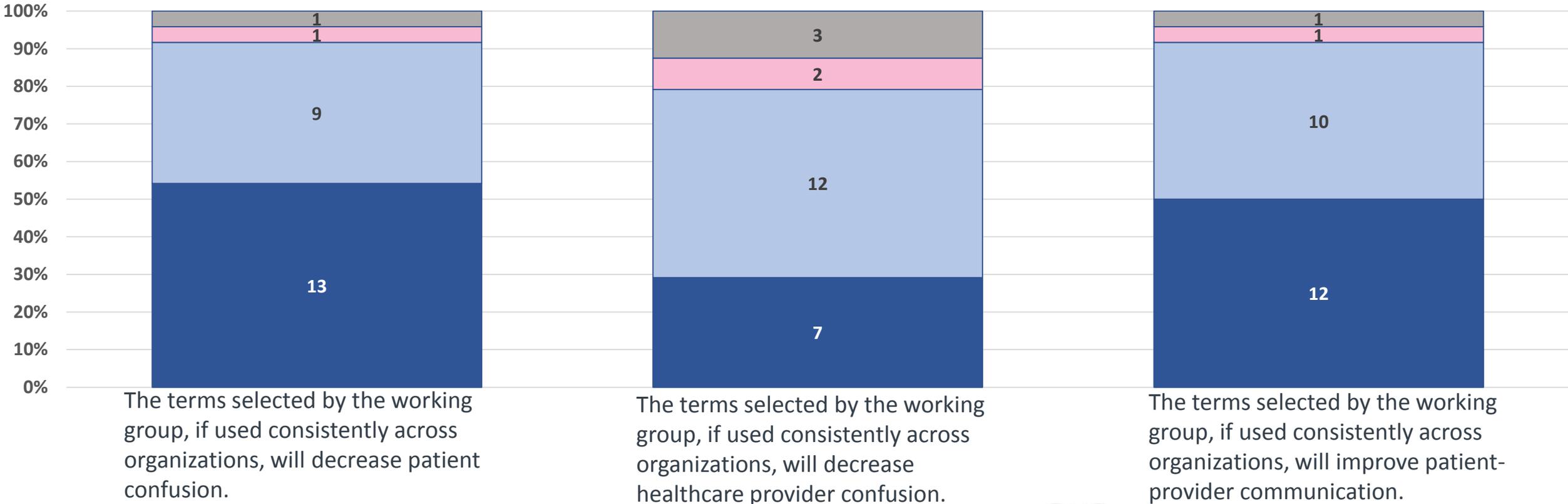
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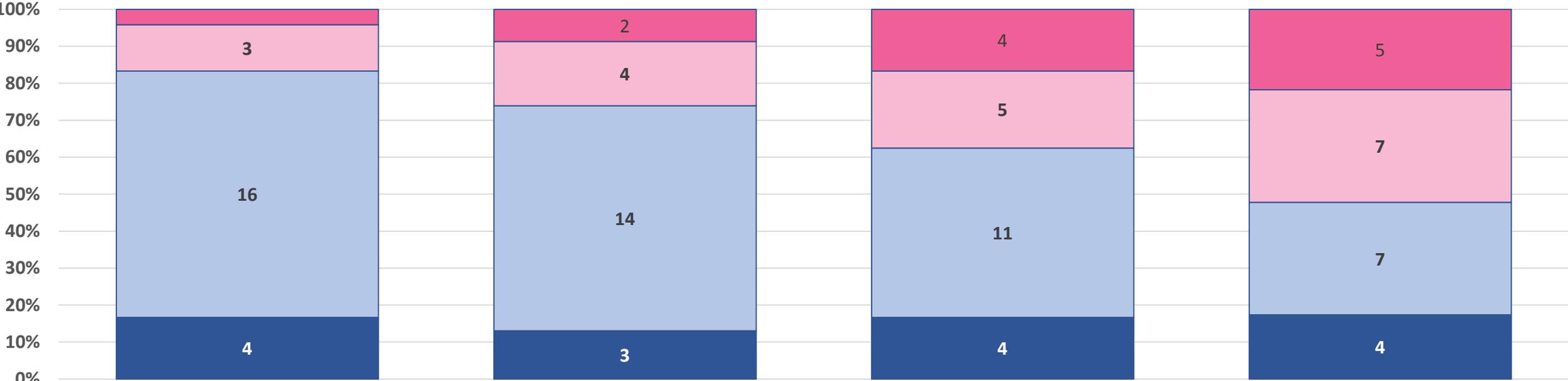
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Q. Please select the answer you most agree with regarding your organization's use of these terms.

Answered: 24 Skipped: 0

Always Sometimes Never Uncertain



My organization currently uses "genetic testing for inherited cancer risk" or "genetic testing for an inherited mutation" when referring to these tests in patient materials.

My organization currently uses "genetic testing for inherited cancer risk" or "genetic testing for an inherited mutation" when referring to these tests in healthcare provider materials.

My organization currently uses "biomarker testing" when referring to these tests in patient materials.

My organization currently uses "biomarker testing" when referring to these tests in healthcare provider materials.



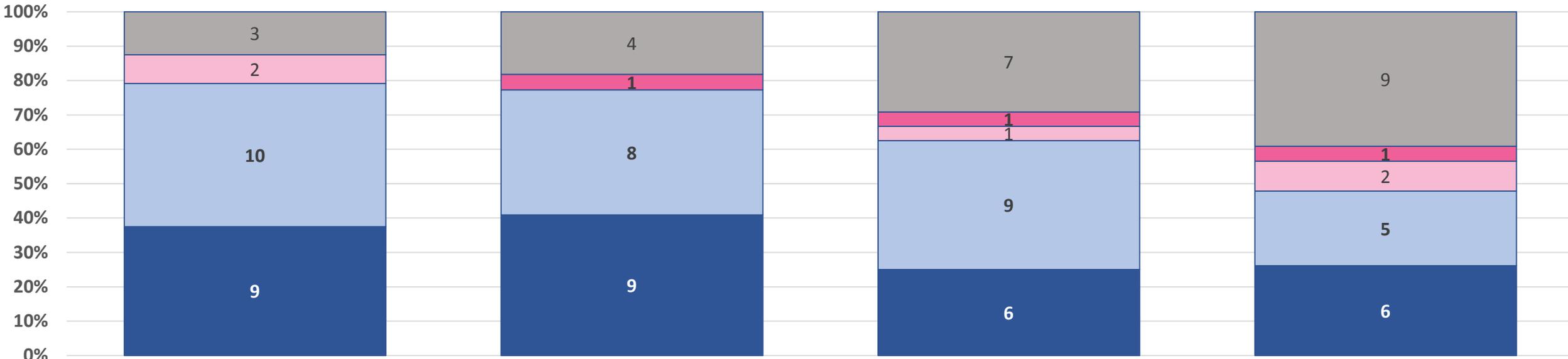
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Q. How much do you agree or disagree with these statements about your organization using these terms in the future?

Answered: 24 Skipped: 0

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



We are likely to use "genetic testing for inherited cancer risk" or "genetic testing for an inherited mutation" consistently when referring to these tests in patient educational materials.

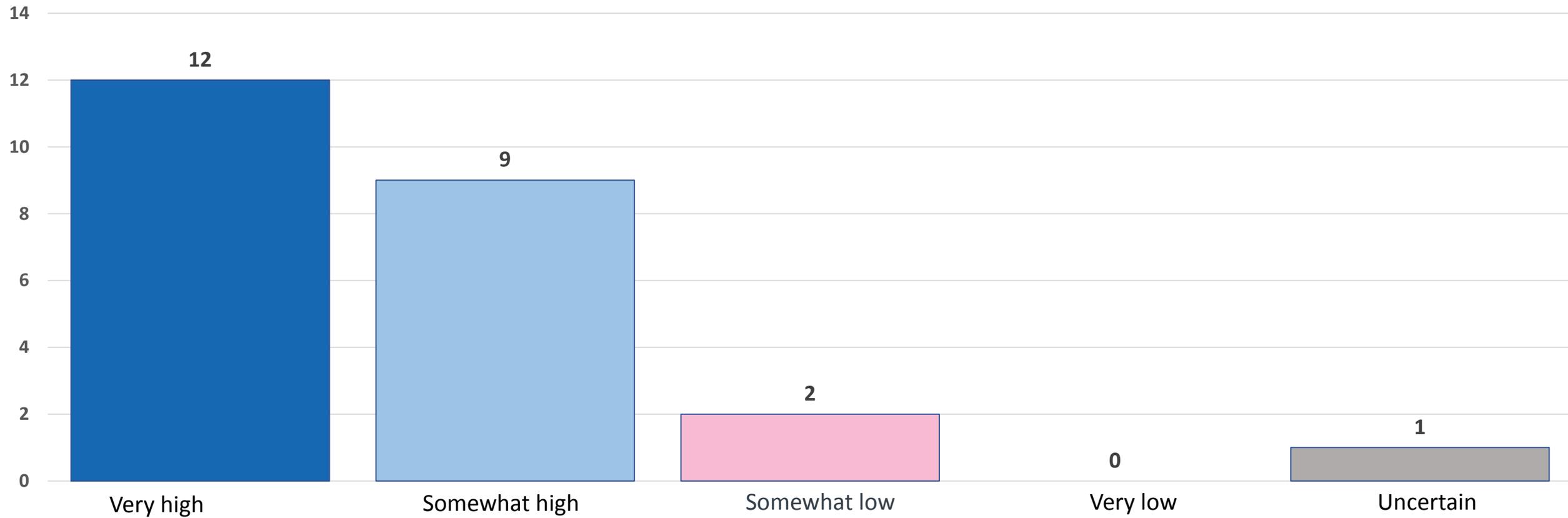
We are likely to use "genetic testing for inherited cancer risk" or "genetic testing for an inherited mutation" consistently when referring to these tests in healthcare provider educational materials.

We are likely to use "biomarker testing" consistently when referring to these tests in patient educational materials.

We are likely to use "biomarker testing" consistently when referring to these tests in healthcare provider educational materials.

Q. How high a priority is using consistent terminology to your organization?

Answered: 24 Skipped: 0



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What are the 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

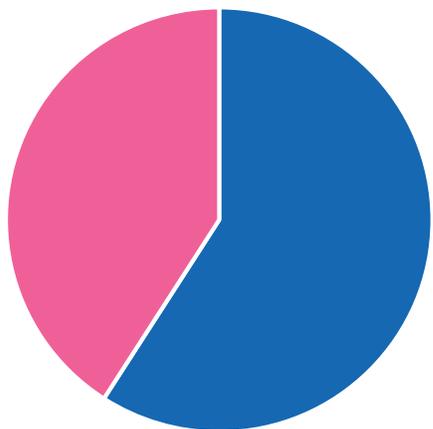


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Q. Do you see any barriers to your organization implementing the recommendations of the CTTWG in your educational materials?

Answered: 22 Skipped: 2



■ Yes ■ No

“While manageable, there is a lift in updating web-based and print materials that would require dedicated personnel and resources.”

“We have found that going to a 5th grade education works the best, and even these terms are too complicated.”

“I believe all these terms need to be explained.”

“Genetic testing is pretty straightforward. For biomarker testing, it’s challenging to add in the term ‘biomarker’ every time you are describing one. It adds more length to a description of a test, which may add rather than remedy confusion.”

“While we can be consistent easily at the organizational level, we have many HCP developing resources that we may not always be aware of.”



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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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Our summary findings

- Current practices suggest multiple terms that are confusing remain in use, even by members of the CTTWG.
- There is consensus on the need for consistent terminology to lower patient confusion.
- There is a bit more uncertainty about adopting these terms for provider-facing materials and for biomarker testing.
- There remain challenges in aligning on terminology, how and when to use the terms, and the need for additional definitions and qualifiers.



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Our experiences in implementation

- Challenge of training staff and implementing broad text-based changes
- New interview-based video content demonstrated impracticality of using terms without description; speaker defined upon repeated use
- Easier to talk about “biomarker testing” when referring to many different tests.
 - Example, “Biomarker tests and cancer treatment” section of website. *“Many types of “biomarkers” are found in cancer cells, surrounding tissues or the blood. Doctors use biomarker tests to help detect cancer, select the best treatment, predict how fast the cancer will grow and monitor response to therapy.”*
- Not all biomarker tests are tumor tests, but when they are, “tumor test” is more plain language.
 - Example *“Oncotype DX is a type of tumor test. It looks at which genes are active in cancer cells compared to healthy cells.”*



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Questions for group

- Does this survey inform any of your current efforts?
- Would partnering to open this survey up to more cancer types be helpful to any stakeholders present?
- If we widened the survey, would you change any questions or answer options? (For example: asking which terms the organization prefers to use)
- How important do we feel it is to align provider educational materials with patient materials to improve patient-provider communication?
- Does this survey suggest directions for continuing CTTWG efforts?



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