On March 11, 2021, approximately 70 members of the Consistent Testing Terminology Working Group (CTTWG) convened for a two-hour virtual session to review five Use Case examples of efforts to implement the CTTWG's recommended umbrella terms. The five Use Cases were presented by representatives of leading patient advocacy organizations focused on Prostate Cancer, Pancreatic Cancer, Ovarian Cancer, Lymphoma, and Breast Cancer. Each Use Case was designed to briefly describe the context for biomarker testing and genetic testing for an inherited mutation or genetic testing for inherited cancer risk in precision medicine within the specific cancer type, efforts to implement the consistent terms, barriers to implementation and opportunities for additional progress. The group was also given two additional Use Cases (Colorectal Cancer and Lung Cancer) as an additional resource, although these were not presented.

Based on the experiences shared through the Use Cases, remaining barriers for engaging key audiences in embracing the recommended consistent testing terminology emerged as an important theme. Meeting participants were divided into four virtual, facilitated break-out groups to further discuss these barriers and identify opportunities for next steps with guidelines organizations, healthcare providers, testing companies/diagnostic laboratories, and internal constituencies.
MEETING AGENDA

- Welcome, Roll Call via Chat
- Working Group’s Focus and Output
- Use Case Presentations and Questions
  - Prostate Cancer: Prostate Cancer Foundation
  - Pancreatic Cancer: PanCAN
  - Ovarian Cancer: Ovarian Cancer Research Association
  - Lymphoma and Chronic Lymphocytic Leukemia: Lymphoma Research Foundation
  - Breast Cancer: Living Beyond Breast Cancer/FORCE
- Break Out Sessions
- Group Discussion of Key Takeaways
- Next Steps: Development of Summary

BACKGROUND & CONTEXT

IN 2020, in culmination of more than a year of work (beginning in March 2019), a multi-stakeholder group of more than 50 non-profit, patient advocacy, professional society, and industry partner organizations (the Consistent Testing Terminology Working Group or CTTWG) released recommendations for the use of consistent umbrella terms for testing for acquired tumor characteristics and inherited germline mutations in cancer.

Consistent Testing Terminology Working Group
The CTTWG’s recommended umbrella terms are:

- **“Biomarker testing”** to discuss tests that identify characteristics, targetable findings, or other test results originating from malignant tissue or blood.
- **“Genetic testing for an inherited mutation”** or **“genetic testing for inherited cancer risk”** for tests to identify germline mutations (also known as variants in the genetics community).

As follow up to the release of the CTTWG recommendations whitepaper (A White Paper on the Need for Consistent Terms for Testing in Precision Medicine found at commoncancertestingterms.org), members of the group proactively engaged in a variety of outreach and education activities within their constituencies and expansive networks to catalyze adoption of the consistent terms.

To provide an opportunity for shared learning and identification of common barriers and opportunities across the cancer landscape, the CTTWG held its final meeting on March 11, 2021 to focus on multiple Use Cases within differing cancer types. The goal of this meeting was to share learnings and identify additional activities that can be undertaken by individual CTTWG member organizations (on their own or collectively) to continue to advance the effort. The March 11, 2021 meeting was the final formal gathering of the CTTWG, providing this report as a resource compilation for the entire community as individual organizations continue their efforts to drive use of the consistent terms.
More Education and Awareness on Testing in Precision Medicine Is Needed Using Common Cancer Testing Terms

- To fully realize the potential of precision medicine in oncology, it is necessary to expand understanding and use of available biomarker testing and genetic testing for an inherited mutation or genetic testing for inherited cancer risk in concordance with guideline recommendations.
- A key barrier to achieving optimization of precision medicine continues to be caused by confusion among patients relating to the multiplicity of terms used to describe the appropriate testing.
- All stakeholders – from patients to providers to industry and payers – can benefit from the use of consistent terms. When everyone is using the same language to talk to patients about testing, it can streamline the first step to make sure they understand what is needed to make the best care and treatment decisions.

Working Group Members Have Made Great Strides and Encountered Challenges in Adopting the Terms

- Efforts by CTTWG members in the past 6 months have greatly increased visibility for the recommended consistent terms, with adoption being a “work in progress” for many cancer types.
- Aligning (and sometimes changing) collective language is challenging especially within a complex ecosystem and within many organizations of all sizes and structures (including large companies where people can be very siloed).
- While there is significant support for streamlining terminology used to discuss biomarker and genetic testing, challenges relating to patient education and adoption by key stakeholders have emerged relating to the nuances within specific cancer types and addressing “legacy” tests in conjunction with newer approaches.

Challenges with Adoption of the Recommended Terms

- Testing companies and laboratories are continuing to use a variety of different terms within their reports and marketing efforts, contributing to patient confusion.
- Clinical guidelines organizations are continuing to produce practice guidelines (and patient-facing guidelines) that use a range of different terms and are not consistent across cancer types.
- Healthcare providers including oncologists, nurses practitioners, physicians assistants, pharmacists, nurse navigators, pathologists, and genetic counselors are still using an array of different terms when communicating to patients about testing and the implications for treatment decisions.
- More patient education is needed to help patients understand the difference between genetic testing for inherited mutations and cancer/tumor testing for biomarkers, especially in certain disease types where the same mutation is tested in both (e.g. BRCA found in ovarian, prostate, breast, pancreatic cancers, etc.).
- In some communities, where certain prognostic biomarkers have been identified (e.g. CA-125 in ovarian cancer), there is added confusion about how to implement the recommended umbrella terms.
- Within certain cancer types, there remains work to be done in aligning all stakeholders, including community-based healthcare advocates, within a specific patient advocacy community around the consistent umbrella terms.
- Practical challenges exist within patient advocacy organizations with limited resources and among patient populations that are especially hard to reach.
During the four breakout sessions, participants identified opportunities to address remaining barriers to adoption of the recommended consistent terms among guidelines organizations, testing companies/laboratories, health care providers and within key disease area communities. During the 25-minute sessions, each breakout group addressed the following questions:

**Discussion Questions for the Breakout Groups**

- **What are the barriers with the target audience?**
  - How can patient groups/provider organizations overcome inertia in the ecosystem?
    - What would incentivize the change we want to see?

- **What opportunities exist with the target audience?**
  - Difference in various tumor types – is biomarker driven diagnosis and treatment established or emerging?

- **How can our individual organizations move the needle with this audience?**
  - What can each of us do? Where is there room for future collaborative efforts?
  - What tools could be developed (within one tumor type or pan-tumor)?

- **How might we measure success?**

Among the proposed opportunities for moving forward in these areas, the group suggested the following:

**Approaching Guidelines Committees**

- Patient advocacy organizations can engage with key members of guidelines committees and encourage the guidelines entities (e.g. focusing first on NCCN and ASCO, with others following suit) to adopt the CTTWG recommended consensus terms. It is also important to engage with American College of Medical Genetics and Genomics (ACMG).
- Opportunities exist to connect the patient advocacy organization representatives across the different cancer type guidelines committees to work together to advance adoption of consistent terms.
- It could be beneficial to explore cancer agnostic clinical guidelines in concordance with scientific evidence for biomarker testing of cancer patients agnostic of cancer type.

**Improving and Augmenting HCP and Patient Awareness and Education**

- There is a need to help healthcare providers have the most fruitful conversations with their patients about testing.
- It could be useful to create an infographic resource to provide a “terminology chart” that can facilitate the conversation between providers and patients, using the recommended consistent terminology and providing clear explanations. Each cancer type/patient advocacy organization could customize this for their own communities.
- It would be helpful to patients to have a resource that indicates “other words that may be used” with explanations that tie those variations back to the consistent terms.
- There is continuing need for collaboration among members of the CTTWG (especially patient advocacy organizations from different cancer types) and sharing best practices for implementing consistent testing terminology and advancing patient and provider education. This could include a joint education/awareness campaign.
Increasing Buy-In Among Labs/Testing Companies

- It is important to continue working with testing companies/laboratories and their trade association(s) to promote use of consistent terms for testing, while addressing the companies’ interest in differentiating themselves within the marketplace.
- Patient advocacy groups can pursue direct engagement with testing companies/laboratories to encourage them to adopt consistent terminology, perhaps by collaborating on a joint statement or letter.

Leveraging Industry to Advocate for Adoption of Common Testing Terms

- Industry can advance efforts to implement these terms through patient and provider education projects companies fund with patient advocacy and professional society partners.

Influencing Other Critical Stakeholders

- It may be necessary to work with payers to ensure that coding for testing incorporates the recommended consistent terminology.
- There have been some successful pilots to leverage new technologies that can be used to homogenize various testing terms within an EMR.

Measurement

- It will be important to develop metrics to measure impact of these ongoing efforts to determine how adoption of consistent terms advances patient understanding and appropriate use of biomarker and genetic testing for an inherited mutation/genetic testing for inherited cancer risk.
Becky Campbell (Prostate Cancer Foundation, PCF) presented PCF’s experience with the umbrella terms, noting that prostate cancer is the second most-diagnosed cancer in men in the United States. While most prostate cancers diagnosed at a local or local regional stage, in advanced disease, prostate cancer is still fatal for a projected 34,000 men this year. There are currently multiple biomarkers available to inform diagnostic pathways and treatment planning for prostate cancer, with active research continuing to identify additional biomarkers. Likewise, inherited mutations are also common in patients with advanced prostate cancer so efforts are underway to incorporate genetic testing for inherited cancer risk to inform screening decisions, including among key patient populations such as Black/African American men. NCCN guidelines for prostate cancer generally use the terms “germline genetic testing,” “pathogenic variants,” and “genetic testing.”

PCF has embarked on a variety of activities to advance adoption of the consistent terminology. For example, the organization is updating its existing comprehensive prostate cancer patient guide to include additional call-out boxes and definitions to help patients distinguish among the various terms. PCF has circulated the CTTWG whitepaper among its clinician-researcher network and is exploring its use in upcoming conferences. Additionally, the organization is supporting a team of researchers to develop and test a web-based patient education tool that incorporates the recommended terms. Finally, there is opportunity for these terms to be incorporated into the ongoing initiative PCF has undertaken with the VA and VA Medical Centers, working to deliver precision oncology care, biomarker testing, and genetic testing for an inherited mutation/genetic testing for inherited cancer risk to all veterans with metastatic prostate cancer. Additional efforts are planned to fully update the PCF website and, ideally, to develop metrics to evaluate the use of more consistent terminology on patient understanding.
Pancreatic Cancer

Emily McLaughlin presented the pancreatic cancer use case on behalf of the Pancreatic Cancer Action Network (PanCAN). In 2021, more than 60,000 individuals are expected to be diagnosed with the disease, which has only limited known biomarkers at this time:

- Only an estimated 10% of those with pancreatic cancer have inherited a biomarker that increases their risk of developing the disease.
- There are 5-6 known biomarkers for treatment that are relevant for guiding therapy for a small sub-group of patients.

There are currently no biomarkers used for early detection of pancreatic cancer. There are, however, some studies researching potential biomarkers that may be used to detect pancreatic cancer early. There is a small percentage of the 160-170 pancreatic cancer-specific clinical trials ongoing that require testing for enrollment. NCCN guidelines currently recommend genetic testing for an inherited mutation for all patients diagnosed with exocrine pancreatic cancer. Those guidelines refer to genetic testing as “germline testing” and include a recommendation for cascade genetic testing for inherited cancer risk among family members of patients with a genetic mutation. Biomarker testing is also recommended for those with advanced pancreatic adenocarcinoma. The guidelines use terms like “gene profiling” or “somatic gene profiling” instead of biomarker testing.

PanCAN undertook an initial audit of its website and call center materials to identify and then modify terminology to meet the recommendations of the CTTWG. The organization sent out email communication and posted an article on its blog discussing biomarker and genetic testing, utilizing the consensus terminology. In addition, through PanCAN’s call center, there is the opportunity for trained specialists to help patients and caregivers understand the meaning of the terms being used. One challenge that arose was related to some of the organization’s signature programs, including its registry and tumor testing program (*Know Your Tumor*). Both of these programs are using IRB-approved materials that have not yet been updated to align with the consistent terminology recommendations. Additionally, in updating its materials with expert input, PanCAN did find some resistance from some of its advisory board members regarding the adoption of the selected consistent terms. Finally, since individual testing companies are generally continuing to use their own language and terminology, there is potential for ongoing confusion even once PanCAN has aligned its own materials.

- A biomarker testing service that we offer to patients (*Know Your Tumor*) uses an IRB-approved informed consent form and recruitment script which contains the old terminology.
- Updating this has been delayed due to competing priorities. For the time being, our team is using both our old terminology and new terminology when talking about the testing service, because we have not yet updated the informed consent form and recruitment language and submitted it for formal review.
- IRB-approved Patient Registry platform is undergoing a transition to a new platform, so also contains old terminology.
- Internal systems that our Patient Central case management team utilizes also contain old terminology due to competing resources and priorities.

**Implementation challenges of common cancer testing terms in pancreatic cancer**

- Genetic/biomarker testing companies still use their own terminology. When providing information about these companies and their tests to patients, there is the potential for some confusion.
- With a lack of approved biomarker-driven therapies, biomarker testing is less compelling in this disease.
- NCCN guidelines utilize other terminology, i.e., germline testing, gene profiling of tumor tissue, tumor/somatic gene profiling.

**Barriers that remain for adoption of common cancer testing terms in pancreatic cancer**
Ovarian Cancer

Vanessa Cramer presented the ovarian cancer experience on behalf of the Ovarian Cancer Research Alliance (OCRA). In 2021 there will be more than 20,000 new cases of ovarian cancer diagnosed, with ovarian cancer being the most lethal gynecologic cancer. There have been several highly significant biomarker discoveries, starting with the identification of BRCA-1 and BRCA-2 and expanding to a total of 12 risk-carrying mutations. This progress has led to issuance of important testing guidelines for women that include both tumor biomarker testing and genetic testing for an inherited mutation/genetic testing for inherited risk. Despite this history, genetic testing for an inherited mutation and genetic testing for inherited cancer risk rates among women with a history of ovarian cancer have been low, with a recent survey finding that only about one-third of women received testing for inherited BRCA-1 and BRCA-2 mutations in compliance with guidelines. There remains significant lack of awareness and understanding of tumor biomarker testing and genetic testing for an inherited mutation and genetic testing for inherited cancer risk among women within the ovarian cancer community.

Within the ovarian cancer space, there is also complexity relating to the role of CA-125, which is a traditional, prognostic biomarker measured in the blood. The role of this biomarker is well-understood within the ovarian cancer community but may not fit clearly under the two sets of umbrella precision medicine biomarker terms developed by the CTTWG. For this reason, OCRA has been working to customize the umbrella terms to incorporate appropriate reference to CA-125 and its clinical applications.

The sticky intersection between CA-125 testing & biomarker testing:
- CA-125 is a glycoprotein (sugar associated protein) commonly referred to as a “biomarker” or “tumor marker”. The CA-125 provides information via a blood sample.
- It can assist in diagnosing and following ovarian cancer (& has multiple other clinical applications.
- Limitations —> CA-125 is only elevated in 50% of women w/ early-stage ovarian cancer and 85% of women w/ advanced cancer.
- The CA-125 can be elevated in someone who does not have cancer.
- The number does not correlate with the extent of disease.
- How is the CA-125 used in ovarian cancer? It is used as tool to detect changes in CA-125 levels. If elevated in a woman with ovarian cancer, it can represent disease status.

Make no mention of CA-125 tests in context of “biomarker testing”
- OC population is already familiar with CA-125 tests and its application & discussing as part of “biomarker testing” in context of precision seemed to serve no real purpose and caused confusion.

Gaps in education and awareness are considerable
- OC patients/survivors who are in the know when it comes to “biomarker testing” are highly sophisticated in their knowledge and understanding.

- BUT overall awareness and understanding is alarmingly low. As the JCO study found, nearly two-thirds of OC survivors haven’t received basic biomarker tested for inherited cancer risk in BRCA1/2 genes (in compliance with guidelines).
- Geographic disparities are a particularly significant barrier for OC patient population.
Lymphoma and CLL

Speaking on behalf of the Lymphoma Research Foundation (LRF), Kinya Harte presented her organization’s experience with these topics relating to lymphoma and chronic lymphocytic leukemia (CLL), which will see more than 111,000 diagnoses in 2021. Lymphoma - the most common type of blood cancer - is a complex disease with more than 85 subtypes of non-Hodgkin lymphoma (NHL). Biomarker testing for lymphoma and CLL is a new approach, with biomarker testing available only for a small subset of lymphoma subtypes and no guideline-recommendations for genetic testing for an inherited mutation/genetic testing for inherited cancer risk.

While the field is still emerging, there are opportunities to pioneer the consensus terms within newly developed patient education materials and resources. LRF has been leveraging existing communications opportunities to promote the recommended consistent terms, including through its patient-facing newsletter and social media channels. There are, however, challenges caused by the newness of this field for lymphoma, especially with getting the medical community to use the consistent terms. To address this potential barrier, LRF is exploring ways to leverage its CME programs.

• Limited knowledge and use of biomarker testing in lymphoma and CLL remain a challenge among many in the medical community

• Example: Medical reviewers for a recent update of one of our disease guides did not incorporate suggestions to include the term “biomarker testing” in the diagnostics section, likely due to a lack of awareness of the term

Challenges with adoption of common cancer testing terms in lymphoma and CLL

• The medical community, including HCPs and researchers, need to be engaged for their buy-in

• A potential opportunity is to have a discussion about the term “biomarker testing” in LRF’s professional education program/CME, Lymphoma Rounds

Lessons learned and ongoing needs and gaps in adoption of common cancer testing terms in lymphoma/CLL
Breast Cancer

Janine Guglielmino of Living Beyond Breast Cancer (LBBC) and Sue Friedman of Facing our Risk of Cancer Empowered (FORCE) jointly presented the breast cancer use case, as well as recent survey data from the breast cancer community. With an expected 281,000 cases of newly diagnosed invasive breast cancer this year, breast cancer is a common cancer for which there are multiple NCCN guidelines, including an array of recommendations relating to genetic testing for an inherited mutation in patients with a variety of circumstances, including for people with metastatic breast cancer. There are also guidelines for cascade genetic testing for inherited cancer risk within families where a mutation has been identified. All breast cancers are tested for specific biomarkers (estrogen, progesterone and Her2/neu overexpression) during initial pathology to make decisions about systemic therapy. Additional biomarker testing recommendations relating to treatment with targeted therapy and eligibility for enrollment in certain clinical trials are available.

LBBC has been transitioning to video-based and interview-based content, which provides a platform from which to promote and explain the recommended umbrella terms and help people understand the details of testing. FORCE just completed a website redesign, which provided the organization with opportunities to implement and incorporate this language. Both organizations have faced challenges in adding the word “biomarker” to terms frequently used to describe a specific type of test. Often people use the shorthand of “tumor test” as an easier to understand description.

FORCE and LBBC have partnered to advance adoption of the consensus terms and identify challenges that still need to be overcome. To better understand where the roadblocks are, the two organizations fielded a short survey among key informants within the breast cancer arena to engage them in the CTTWG efforts, solicit feedback on the CTTWG terminology, and help educate people about the consensus recommendations. Among the organizations that responded, many have developed educational resources on genetic testing for an inherited mutation/genetic testing for inherited cancer risk, while some also have resources related to tumor testing for treatment selection, screening, and prognosis.

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All respondents agreed that use of multiple terms for the same test is a barrier to patient-provider communication and it is important for organizations to align on terms that they use when referring to similar tests. However, the survey yielded an array of terms that are being used by the various organizations who responded. Although there was support for the recommended terms for genetic testing for an inherited mutation and genetic testing for inherited cancer risk, there was less consensus and understanding of the recommended biomarker testing terminology, with respondents noting the need for more explanation to accompany the term. Additionally, respondents noted potential barriers relating to the complexity of recommended terminology (especially for low literacy populations) and the challenge of making broad terminology changes across existing programs and services to align with the recommended umbrella terms.

Opportunities to address these challenges include providing training in the form of examples that use the terminology, providing education, and further discussion with some of the leaders in this space to advance understanding of how the terms were selected. There is also the potential opportunity to further refine the terminology specifically for breast cancer.

**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.**

- 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.”
- When talking about a specific test. “Biomarker” vs. “tumor test”. 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.”

FORCE and LBBC’s experience with implementation of common cancer testing terms
Lung Cancer

A lung cancer use case for the common cancer testing terms was developed by Nikki Martin at LUNGevity Foundation as another resource, but not presented due to time constraints at the meeting. With more known targetable driver mutations than any other cancer, lung cancer is at the forefront of precision medicine. More than 90% of adenocarcinomas, a subtype of non-small cell lung cancer, may have a known mutation. Not including immunotherapy, 28% of NSCLC patients are on a targeted treatment. Biomarker testing is standard of care and recommended for all NSCLC patients. NCCN guidelines direct clinicians to test advanced stage patients for a minimum of nine driver mutations using a multi-plex panel such as next generation sequencing (as of March 2021) and to also conduct an immuno-histochemistry test to measure levels of the protein PDL1. Early stage patients should receive single-gene testing for EGFR. Unlike cancers such as breast, ovarian, pancreatic, and prostate cancer, there is no guideline-recommended genetic testing for inherited cancer risk or inherited mutations at this time.

Adoption of the term “biomarker testing” has been a continuous effort undertaken by many stakeholders in the lung cancer space since 2015 following LUNGevity-led research and a multi-stakeholder roundtable to address patient confusion about testing and terminology. In 2018, CancerCare published a white paper highlighting the need for consistent testing terms in lung cancer, citing LUNGevity’s research; in 2019, the Lung Cancer Action Network or LungCan, an umbrella organization comprising 20 member organizations, secured nearly 100% agreement by its members to use “biomarker testing” or “comprehensive biomarker testing”.

With the recommendation of “biomarker testing” by the CTTWG, LUNGevity reviewed its materials with the goal of updating them to use “biomarker testing” as the introductory term, followed by an explanation of “comprehensive biomarker testing,” defined as testing for “multiple biomarkers at one time.” This drill down to explain comprehensive biomarker testing is an important distinction because of the challenge of securing high quality tissue in the lung, and the urgent need to test for 10 biomarkers per NCCN guidelines, which if tested using single gene tests, can easily exhaust tissue, requiring additional biopsies or resulting in only a few biomarkers being tested for.

While the broad lung cancer community, such as patient advocacy groups, providers, the pharmaceutical/biotech industry, and some labs and testing companies, have committed to adoption of the term “biomarker testing” for patient communication and education, there are still numerous stakeholders that require additional encouragement. Having the major labs and testing companies pull this term into patient-facing education, television commercials, patient portals, and results reports will significantly improve patient and provider recognition of the term and connect this term to the desired outcome: a personalized treatment decision such as a targeted therapy, immunotherapy, or chemotherapy. Having payers and guidelines also align their testing language with “biomarker testing” and drill down as needed to explain the specific type of test (broad multi-gene panel or FISH or IHC) will be highly beneficial to improve communication and increase adoption of common cancer testing terms.

Re-aligning expectations within LUNGevity that we would introduce the umbrella term “biomarker testing” before diving into the concept of “comprehensive biomarker testing”

Encouraging the consistent use of “biomarker testing”

- Providers appear willing to adopt in patient communication when encouraged, but reaching providers to encourage this action can be challenging
- Misalignment of terms within clinical guidelines including NCCN, CAP/AMP/IASLC guidelines for NSCLC care
- Payers, testing companies/labs need more encouragement to eliminate laboratory jargon from reports/materials that patients may be accessing for more information about their disease
Colorectal Cancer

A colorectal cancer use case for the common cancer testing terms was developed by Reese Garcia at FightCRC as another resource, but not presented due to time constraints at the meeting. There are expected to be nearly 150,000 new cases of colorectal cancer (CRC) in 2021, accounting for almost 53,000 deaths. Many individuals with CRC have genomic mutations, with some mutations accounting for about 10% and others accounting for as much as 30-50% of CRC. Most CRC tumors are sporadic (70-80%), while approximately 20% are hereditary.

Biomarker testing is critical to guiding treatment decisions in CRC and is recommended for patients with CRC who are being considered for certain treatments and for prognostic stratification and to identify those at high risk for Lynch syndrome. Biomarker testing can also be used to determine clinical trial eligibility.

Fight CRC developed the Biomarked campaign in 2017 when it was clear that few resources existed for patients with CRC to learn about and understand the importance of biomarkers. Focus groups were held with patient communities to determine wording, terminology, content, and the look and feel of resources being developed. After findings from the CTTWG were released, Fight CRC audited its print and web materials to determine their consistency with the CTTWG’s recommendations, finding that most resources utilized “biomarker testing” and “genetic testing” or “germline testing.” Fight CRC plans to revamp its resources and host additional focus groups to align with CTTWG recommendations (i.e. update “genetic testing” language to include “for an inherited cancer risk”).

Within the CRC space there are ongoing challenges given that consistent testing terminology is not fully implemented, and patients still have confusion with terms such as somatic testing, tumor testing, genetic, and germline testing. There is also the need to advance implementation of consistent terms across various stakeholder groups, including providers, patients, patient organizations, regulatory agencies, laboratories, industry partners, and academia, while addressing still nuances in terminology within the CRC space. These objectives can be advanced by leveraging patient advocacy groups across the CRC community to adopt these terms and create simple, effective communication for provider education and incorporation into guidelines.
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- **Martha Raymond**, MA, Founder

#### Sharsheret (The Jewish Breast & Ovarian Cancer Community)
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RESOURCES
- Use Case for Prostate Cancer
- Use Case for Pancreatic Cancer
- Use Case for Lymphoma/CLL
- Use Case for Ovarian Cancer
- Use Case for Lung Cancer
- Use Case for Colorectal Cancer
- Use Case for Breast Cancer and Complete Survey Data

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