

# Consistent Testing Terminology Use Cases Workshop

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# Consistent Testing Terminology Working Group

## PATIENT ADVOCACY GROUPS



## PROFESSIONAL SOCIETIES



## INDUSTRY PARTNERS



# Use Case – Lymphoma and Chronic Lymphocytic Leukemia (CLL)

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# Use Case: Lymphoma and CLL

Presenter: Lymphoma Research Foundation

- More than 111,600 new cases of lymphoma and CLL are expected to be diagnosed in 2021
- There are many different types of lymphoma, with over 85 types of NHL alone according to the World Health Organization
- Treatments for these cancers vary greatly, and a number of indolent lymphoma subtypes do not require immediate treatment

# Use Case: Lymphoma and CLL

- Biomarker testing is still in its infancy in the blood cancer space, but we expect it to become increasingly important
  - CLL- 17p del
  - DLBCL- MYC, BCL 2, BCL 6 (Double or triple hit lymphomas)
  - ALCL- ALK+/-
  - Although treatments may not necessarily target these biomarkers, we know that testing for them is critical due to treatment implications
  - Right now, “NGS sequencing” or “genomic testing” are terms that some patients may hear from their HCPs to refer to biomarker testing for genomic mutations

# Use Case: Lymphoma and CLL

- At this time, there is no guideline-recommended genetic testing for inherited cancer risk or inherited mutations in lymphoma/CLL

# Use Case: Lymphoma and CLL

- The Summer 2020 issue of LRF's premier publication, PULSE, featured an article on biomarker testing terms with quotes from Nikki Martin
- LRF has promoted the work of the CTTWG through its social media channels
- Patient education programs will now include breakout sessions on biomarker testing, and discussions are underway on the development of factsheets discussing biomarker testing
- LRF remains committed to consistent use of the "biomarker testing" term in education materials and programming

# Use Case: Lymphoma and CLL

- 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



# Use Case: 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