

Consistent Testing Terminology Use Cases Workshop

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Consistent Testing Terminology Working Group

PATIENT ADVOCACY GROUPS



PROFESSIONAL SOCIETIES



INDUSTRY PARTNERS



Use Case – Lung Cancer

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Use Case: Lung Cancer

Presenter(s): LUNGeivity Foundation

- 540,000 Americans living with lung cancer
- There are a multitude of genomic mutations in the non-small cell lung (NSCLC) sub-type
- More than 90% of adenocarcinomas, a subtype of NSCLC, may have a known mutation¹
- Not including immunotherapy, 28% of NSCLC patients are on a targeted treatment²

1. Skoulidis F, Heymach JV. Co-occurring genomic alterations in non-small-cell lung cancer biology and therapy. *Nat Rev Cancer*. 2019;19(9):495-509.

2. Greg Riely: *J Natl Compr Canc Netw* 2017;15(5.5):686–688)Greg Riely: *J Natl Compr Canc Netw* 2017;15(5.5):686–688

Use Case: Lung Cancer

- Biomarker testing is used to direct treatment in non-small cell lung cancer (NSCLC)
- NCCN guideline recommendations for testing
 - Advanced stage NSCLC: test with multi-plex panel such as next generation sequencing for EGFR, ALK, ROS-1, BRAF, NTRK, RET, MET, HER-2, KRAS and test with immuno-histochemistry test to measure levels of the protein PDL1
 - Early stage NSCLC: single gene test for EGFR
 - NCCN uses these testing terms: molecular testing, biomarker testing, broad molecular profiling, NGS-based testing
- Biomarker testing is used for determining clinical trial eligibility; even for first line, newly diagnosed patients, a clinical trial for a promising new targeted therapy may be their best option
- Biomarker testing is not standard of care for prognosis in lung cancer
 - Early stage NSCLC prognostic biomarker testing (similar to OncotypeDx) is an option, but not yet in guidelines

Use Case: Lung Cancer

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

Use Case: Lung Cancer - LUNGeivity

- In 2019, we worked with members of LungCan, a lung cancer patient group umbrella organization that ~20 groups participate in, to align on the use of “biomarker testing” and “comprehensive biomarker testing”
- We reviewed LUNGeivity materials and multi-media education campaigns to ensure consistent use of biomarker testing as the umbrella term
- After the umbrella term is used, we pivot to utilizing “comprehensive biomarker testing”, as preferred within lung cancer space
 - Patients need to understand the critical need for multi-plex panel testing (testing for multiple biomarkers at one time) before making treatment decisions
- We define “comprehensive biomarker testing”
 - We list biomarkers that should be tested for in accordance with NCCN guidelines
- We have ensured that the patient education team knows about umbrella terms for genetic testing, but no action was taken as this testing is not currently recommended for our patients

Use Case: Lung Cancer

- Re-aligning expectations within LUNGeivity that we would introduce the umbrella term “biomarker testing” before diving into the concept of “comprehensive biomarker testing”
 - The wider lung cancer patient advocacy community, including LUNGeivity, had started to use “comprehensive biomarker testing” (rather than just 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

Use Case: Lung Cancer

- Keep it simple – biomarker testing with a clear explanation may be more powerful for certain patient communities than saying “comprehensive” biomarker testing
- Continued pressure on all stakeholders to make consistent use of common terms
- Align terminology with a consistent definition for better access
 - Different payers define biomarker testing differently which leads to testing inequities
- Keep an eye out for the introduction of germline testing in the lung cancer space and ensuring that the patient education utilizes recommended umbrella terms consistently