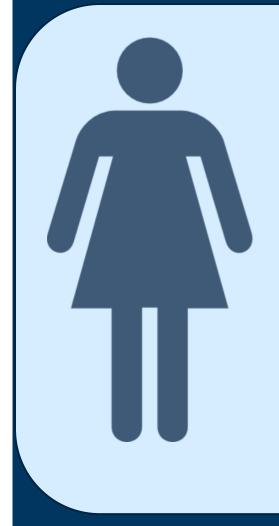
Need for Consistent Language around Biomarker Testing in the Diagnosis and Treatment of Lung Cancer LUNGEVITY Andrea Ferris, MBA; Susan Mantel, MBA; Margery Jacobson, MBA; Upal Basu Roy, PhD, MPH Find it. Treat it. Live.

Lung cancer treatment options have expanded significantly in the past decade, beginning with the increased understanding of specific gene mutations that drive or enable growth of the cancer. The testing to identify these mutations is the first step in determining if a patient can benefit from the targeted therapies currently approved or in development in clinical trials. Despite the enthusiasm around the potential of using targeted therapy in the treatment of lung cancer, evidence suggests that not all eligible patients are benefiting from targeted therapy, due in part to lack of tumor testing. To help assess whether inconsistent communications could be a contributor to the suboptimal rates of testing for biomarkers related to lung cancer treatment, we conducted a communications audit. The aims of the audit was: 1. Identify and inventory the various terms being used to reference molecular tumor testing 2. Identify the audiences organizations are addressing, i.e., Who is talking to patients and who is talking to the medical community? 3. Catalog the message and calls to action, to identify any differences in the way the many organizations with a stake and interest in molecular testing and/or targeted therapy are communicating 4. Identify the implications of these differences for patient and medical community understanding, and application of, molecular testing for lung cancer



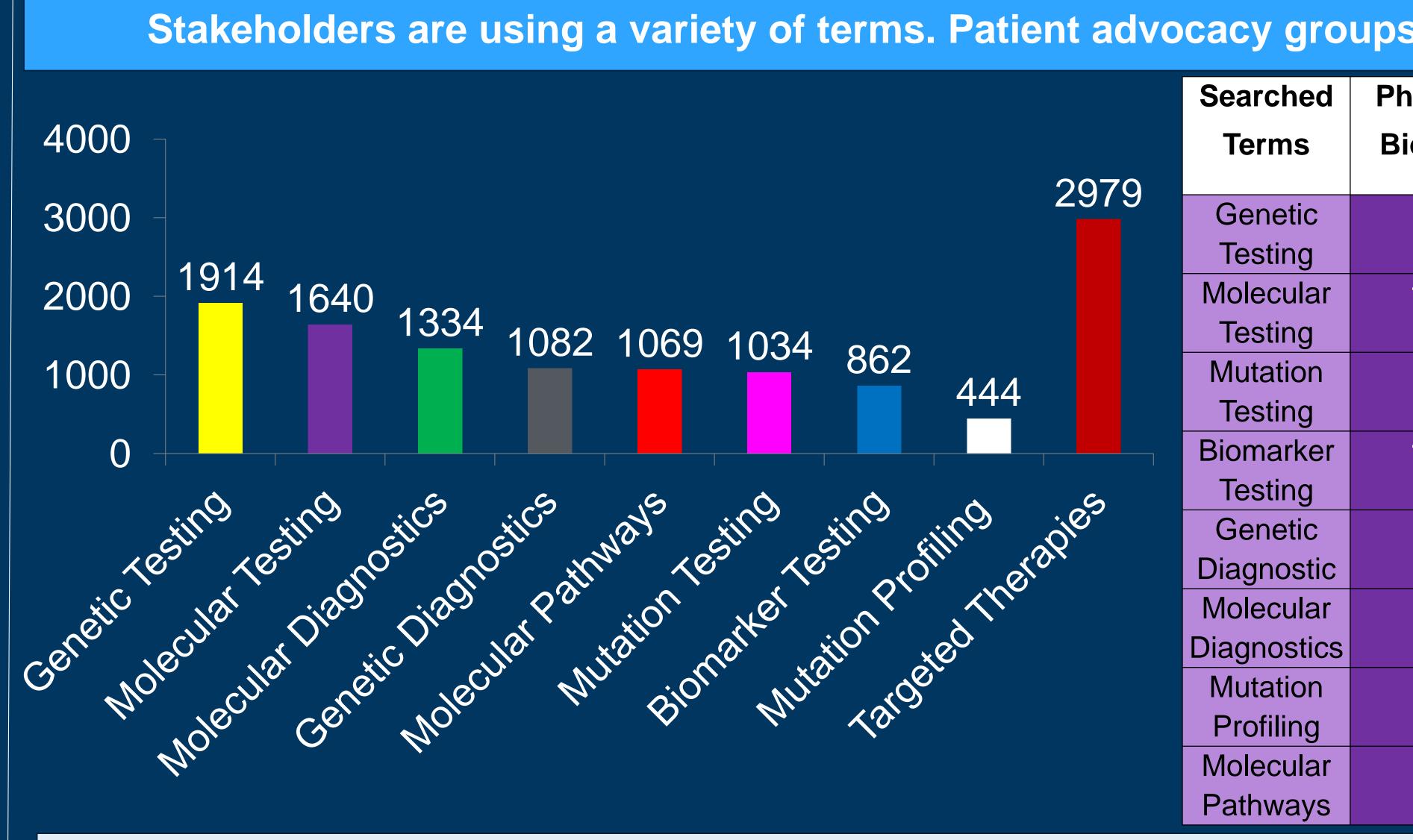
Getting the patient perspective

In-depth interviews with 15 lung cancer patients to gain insights into their understanding and experiences with molecular testing and related procedures and therapies

Terms inventoried:

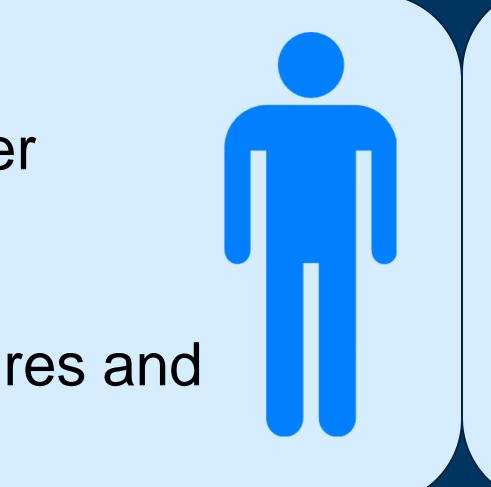
Molecular testing Molecular diagnostics Biomarker testing Molecular pathways Personalized medicine Genetic testing and/or genetic diagnostic Mutation testing/mutation profiling Targeted therapies

Biomarker panel, Companion Cenetic decuments Sanostic, Comprehension genomic profiling, Genomic profiling, Genomic testing, Individualized medicine, Molecular companion diagnostic, Personalized medicine, Precision medicine, Tumor gene panel testing, Tumor marker tests



- 4.
- 5.

ABSTRACT



Language audit of major organizations

 28 organizations were included in the audit • Cancer organizations, lung cancer advocacy groups, government and general health sites, pharmaceutical and biotech companies (including patient-focused microsites), and testing companies

MAJOR FINDINGS AND IMPLICATIONS

Patient confusion created by use of term "genetic testing." This implies a hereditary component. **Overall there are too many terms, inconsistently used.**

Divisions between terms used to talk to health care practitioners and those used to talk to patients – setting up a communications gap. Lack of information in the clinical setting means learning about and understanding of testing is often left to word-of-mouth. Patients and stakeholders realize the need for CONSISTENT terminology. Proposed term for use is **BIOMARKER** testing



What	s make an effort to bridge the terms.				
"When people are cancer and what t	Lung Cancer Orgs	Cancer Orgs	Gov't/ Private	Testing	harma/ iotech
of a sudden we ar to find them quick	395	295	1082	65	77
"I don't think a lot information to be you know 'I'm ALF know the targeted All agreed on th community and BIOMARKER "biology" of the testing is also a MOLECULA agreed to use o	331	124	742	270	173
	274	143	485	111	21
	156	29	390	172	109
	109	111	770	66	26
	98	94	798	231	113
	88	2	254	78	22
	88	35	787	91	74

t are patients saying? - Too many terms used without adequate explanation

e diagnosed, they don't know any of these terms.... We don't go around studying to do when it hits us, because we don't think it will ever happen to us. Then all re faced with a life threatening disease. We need to find answers, and we need k. It makes it difficult that there is not standard terminology."

of people understand the science, nor are they interested. I would like ore in layman's terms. You start to care after you know your mutation, when K positive.' People want to know this is the cancer I have and then they want to therapies.

Stakeholder engagement

ne importance of a more unified voice and message to help the medical patients.

R TESTING was the strong favorite. It integrates the concept of tumor, and is more inclusive than "molecular testing," now that PD-L1 a consideration

R TESTING was favored by a smaller subset, although they also of biomarker testing. All of the other terms dismissed for various reasons