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Using consistent terms in precision medicine to eliminate patient confusion.

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Background:

Biomarker testing has advanced precision medicine in cancer. However, not all eligible patients benefit from biomarker-driven therapies due to suboptimal testing rates. A working group of 20 patient advocacy groups representing solid/hematologic malignancies, three professional societies, and 18 pharmaceutical and diagnostics companies identified patient confusion inconsistent testing terms as a possible contributing factor to biomarker testing underutilization. The group aimed to address patients' confusion by identifying and adopting consistent, plain language terms for biomarker and germline genetic testing that are applicable across cancer types.

Methods:

Following a stakeholder roundtable discussion on barriers to precision medicine, working group members participated in interviews on their goals for consistent testing terminology for their constituents. We then conducted a framework analysis covering five themes: available testing by cancer type; purpose of test; biospecimen source; terms used in patient education; and preferred plain language term. Working group members were surveyed on preferences for germline testing terminology and also deployed a preliminary patient survey to their constituents to gain insight on preferences for germline testing terms.

Results:

Interviews, framework analysis, and surveys revealed notable differences across cancer communities. We identified at least 33 different terms related to biomarker, genetic and genomic testing being used in patient education and clinical care among the different cancer communities and stakeholders. Terminology was complicated by the variety of testing modalities and gene mutations tested for across cancers. Following multiple discussions, working group members agreed on two umbrella terms to distinguish between somatic and germline testing with additional context for specific cancer communities. "Biomarker testing" was selected as the somatic testing term. "Genetic testing for an inherited mutation" and "genetic testing for inherited cancer risk" were selected as preferred germline testing terms.

Conclusions:

Our findings highlight the disparate testing terminology landscape and the need for consistent te **Print**
reduce patient confusion, improve communication, facilitate shared decision-making and assure concordance in policy development.

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