



2021 NCCN Patient Advocacy Summit Policy Report: *Advancements in Precision Medicine and Implications for Quality, Accessible, and Equitable Cancer Care*

In recent years, targeted medicines have offered dramatic advancements in cancer care outcomes across a wide variety of cancer types. However, as cancer care becomes increasingly personalized, access to biomarker testing and targeted therapies remains inequitable. The effective use of biomarker testing for both germline or inherited, and somatic testing is still highly dependent on health care coverage and reimbursement; patient and provider education; and access barriers based upon a patient's geographic location, socioeconomic status, insurance status, and provider type. To explore these issues and potential policy solutions, the National Comprehensive Cancer Network (NCCN®) conducted a patient advocacy scan with representatives from fourteen patient advocacy organizations and used the findings to inform the subsequent Patient Advocacy Summit *Advancements in Precision Medicine and Implications for Quality, Accessible, and Equitable Cancer Care*. The findings of the scan and summit discussions are contained in this policy report.

Common challenges reported by patient advocates include:

- *Testing terminology challenges:* Patient advocates report that terms used regarding biomarker testing is often inconsistent. This can result in confusion for patients, payers, and providers. This confusion can result in both access and communication challenges.
- *Timely access to testing:* Patient advocates note that receiving biomarker testing at the appropriate time is crucial, whether it is related to testing for hereditary risk or testing to guide treatment decisions. Delays are common and result in missed or improper care.
- *Need for patient and provider education:* Personalized medicine is rapidly evolving with frequent innovation and changes to the standard of care. Healthcare professionals and patients need access to high-quality and continuously updated information to stay current with the evidence.
- *Coverage and access:* Insurance coverage of biomarker testing is still widely variable across payers. This impedes patient access and can widen disparities across income, insurance status, and race and ethnicity.
- *Tissue scarcity:* Some cancers face challenges with having enough tissue for the appropriate biomarker tests. Lung and other cancers require significant surgical intervention to get tissue and additional biopsies may not be feasible. When payers require multiple single test assays or small panels rather than broad panel testing, patient advocates report that this can cause major challenges with insufficient tissue availability.

What you can do:

- *Invest in patient and provider education:* Funding and support is needed for both patient and provider education on the role of biomarker testing as a crucial part of cancer care.
- *Insurance coverage:* Support legislation to improve access to comprehensive biomarker testing according to nationally recognized guidelines.