
CONSUMER AND PATIENT PRINCIPLES
FROM THE CONSUMER AND PATIENT AFFINITY GROUP LEADERSHIP COMMITTEE

The purpose of these Principles is to inform and guide the work of the LAN Guiding Committee and Work Groups. As new models and frameworks emerge for value-based payment, the following Principles should serve as guideposts for ensuring that these models address the needs and priorities of patients and families.

1. Patients and family caregivers are collaboratively engaged in all aspects of design, implementation and evaluation:

New payment models should ensure the collaborative engagement of patients, family caregivers and consumer representatives in all aspects of care, including in the design of models, the governance process, in oversight and evaluation, as well as at the point of care (including shared care planning and decision-making), and in the interface with the communities where care is delivered.

- Collaborative engagement should be sensitive to the varying needs, capacities and preferences of individual patients and family caregivers. Patient engagement efforts should seek to meet patients where they are and include family caregivers as appropriate.

2. Positive impact on patient care and health is paramount:

The central consideration in all payment design should be improving patient health outcomes, experience of care, and health equity, while also ensuring the most effective use of health care resources. Improved payment models should foster:

- Improved patient access to timely, safe, affordable and high quality care that includes better coordination and continuity of care;
- Care that integrates behavioral health, dental health, vision and hearing care as well as non-clinical health factors; and
- Care that is consistent with patients' needs, preferences, values and goals.

3. Measures of performance and impact are meaningful, actionable and transparent:

New payment models should be assessed using measures that are meaningful to patients. These models should prioritize the use of measures derived from patient-generated data that address both care experience and outcomes.

- Patient, family and consumer representatives should be involved in the development and selection of measures.
- Measures should include clinical outcomes and outcomes defined by patients, e.g. functional status, quality of life, and symptom burden.
- There should be full transparency of both cost and quality measures, and measures should be publicly reported in a manner that is understandable and actionable for patients and consumers.
- New payment models should use measures that drive quality improvement and are meaningful to users, including patients as well as providers, payers and purchasers. To the extent possible, measures should be aligned across payers in order to maximize improvement, reduce burden and conserve resources.

- Assessment of payment models should go beyond clinical measurement, and should consider a broad and diverse set of data and information sources, including consumer reported information, surveys, and metrics; as well as measures of access and barriers to access (such as numbers of treatments prescribed and denied, numbers of complaints and appeals filed, provider network statistics, etc.). Assessment should also include stratification of all data to identify disparities and differential outcomes for subpopulations.

4. Primary care is foundational:

Payment models should foster patient- and family-centered care that is anchored in comprehensive primary care. Effective primary care is essential to better care experience, optimal patient engagement, better health, and increased health equity. This grounding in primary care should facilitate:

- The ability to access care from trusted community providers in the communities where patients live;
- Whole person care that encompasses the non-clinical and social determinants of health and integrates behavioral health, dental care, vision and hearing care and community supports into the care plan;
- Care that reflects good communication, coordination and continuity across clinicians, settings, and lifespan;
- Care that fosters collaborative engagement with patients and families and a shared care planning process that ensures that care and treatment is aligned with patient needs, values, preferences and goals. Such care should incorporate use of decision aids that provide information on all treatment options and their risks and benefits as they relate to individual needs, preferences, values, and goals and associated out-of-pocket costs. (Decision aids should be developed in collaboration with patients and families.); and
- Care that reliably includes the leading indicators of well-coordinated primary care, such as patient-centered medical home standards, health IT capability, care planning, transition planning and interdisciplinary team support.

5. Health equity and care for high-need populations are improved:

New payment models should foster health equity. They should collect data that allows for assessment of differential impacts and the identification and redress of disparities in health, health outcomes, care experience, access, and affordability.

- New models should have protections against stinting, cherry-picking, and discrimination, especially for vulnerable, high-risk and high-need populations.
- Safeguards should be consistent with the increasing levels of risk assumed by providers. Vulnerable populations should not face additional barriers to care or cost burdens.
- Care and information should be linguistically and culturally appropriate and tailored to the health literacy level of patients and families.
- To ensure educational materials and notices are well-designed, materials should be collaboratively developed and vetted by patients, families and consumer representatives.

6. Patients can easily access their health information:

New payment models should facilitate the sharing of electronic health information with patients and families across settings and providers for a seamless flow of information. This is essential to patient and family engagement and collaboration with their clinicians and care team.

- Patients and designated family caregivers should have easy access to their electronic health information, without cost, in useable formats, and in their preferred language.
- Health IT should support not only enhanced provider-to-provider communication, but also two-way communication between patients and their clinicians/care team.
- Patients and family caregivers should be informed about data sharing practices.
- Providers should continue to also make health information available in paper-based formats as needed to ensure access for patients without access to electronic platforms and to accommodate patient preference.

7. Financial incentives are disclosed and promote better quality as well as lower costs:

In new payment models, financial incentives for providers and patients should be fully disclosed to patients and families. Financial incentives should be developed in partnership with patients and consumers to reflect the value of care to patients.

- Quality should be assessed based on outcomes and goals that matter to patients, as defined by patients. Achievement of patient goals and outcomes should be assessed through measures of clinical care and outcomes as well as patient-generated measures.
- Incentives should not create financial barriers to needed care, especially for vulnerable, high-risk or high need patients. Nor should incentives be used to steer patients or provider referrals toward lower cost care without regard for quality.
- Financial design should encourage access to appropriate primary and preventive care, particularly for high-risk patients and those with chronic conditions.