OVERVIEW

On April 28, 2016 the first in-person meeting of the Accountable Care Learning Collaborative (ACLC) – Patient-Centeredness Workgroup was convened in Washington, DC. The workgroup focused its discussion on the objectives outlined below. This guide, written by workgroup chair Michael Millenson (mm@healthqualityadvisors.com) and workgroup manager Tom Merrill (tom.merrill@leavittpartners.com), takes the work done by the group and organizes and builds upon it. It also lists the group members and those who were able to attend the in-person meeting.

- **ACLC’s Mission**: Accelerate the adoption of a range of accountable care delivery models throughout the country
- **ACLC’s Vision**: Create a comprehensive list of competencies that a risk-bearing provider entity will need to succeed in a value-based payment environment

ACLC Patient-Centeredness Workgroup In-Person Meeting Objectives

- **Review domain name**: Discuss domain name “patient-centeredness” and decide whether the name is appropriate or should be revised.
- **Identify Categories of Competencies**: Guided by the ACLC’s framework and literature review of patient-centeredness, the workgroup will develop a list of categories of patient-centered competencies and descriptions for each category.
- **Identify and Define Competencies**: Specific competencies for each category will be identified. Competencies will be refined, and terminology will be defined as needed.
Domain Name and Definition: Patient-Centeredness in Accountable Care

In 1987 the Picker/Commonwealth Program on Patient-Centered Care was established and brought the term into the health care mainstream. In 2001 Institute of Medicine *Crossing the Quality Chasm* report endorsed patient-centeredness as one of six attributes of a 21st-century health care system and summarized the concept this way: “Patient-centeredness encompasses qualities of compassion, empathy and responsiveness to the needs, values and expressed preferences of the individual patient.”

In seeking to define that term in a manner useful to accountable care organizations looking to operationalize specific competencies, the patient-centeredness workgroup began with three unique challenges:

- **The concept grew out of the traditional clinical encounter.** In its original context, patient-centeredness had limited applicability to organizational obligations or the care continuum.

- **There is no agreed-upon definition.** One academic review found four separate types of patient-centered care models “that are neither entirely compatible nor entirely incompatible.” Another review found three core themes, but “few common definitions.”

- **The word “patient” can be controversial.** To some, the word “patient” seems to reinforce a relationship based upon traditional roles. Alternative terms include patient- and family-centered care, person-centered care and many others.

We want to address these three issues separately:

1) “Patients” Are Still Persons (With Families)

Our workgroup discussion seemed to prefer the term, “person-centered,” a preference that resonated with us, as well. Nonetheless, after additional discussion and research we support retaining the term “patient-centered” for two very practical reasons:
• *Patient-centered care is the term commonly used in statutes and in accreditation requirements.* In particular, the Affordable Care Act requires the Secretary to demonstrate that an ACO “meets patient-centeredness criteria...such as the use of patient and caregiver assessments or the use of individualized care plans.” As this shows, however, use of “patient-centeredness” does not negate involvement of caregivers subject to the patient’s preferences.

• *The English language does not provide any word but “patient” to characterize an individual for whom an organization has clinical responsibility.* Importantly, we are not talking here only about the relationship of an individual doctor to a patient. Our specific charge from the ACLC is “to accelerate the successful adoption of accountable care by identifying and encouraging industry-wide adoption of a comprehensive list of competencies necessary for risk-bearing provider entities to succeed in value-based payments.” Those entities have “patients” for whom they are responsible, even if that person never shows up at the doctor’s office. “Member” doesn’t really capture the relationship, particularly in ACOs, where individuals generally have no idea they are even in one.

Therefore, given the mission of the ACLC, and with the caveats that we’re hemmed in by law and language and don’t mean to define individuals by their illness, the recommendation to the group is to continue using “patient-centeredness.”

2) Avoiding a Definitive New Definition

Because there are multiple definitions of patient-centeredness, our suggestion is that we avoid proposing a new, “universal” one. Instead, we suggest proposing a definition that is broad enough to align with that of other important groups that have done work in this field (Picker, National Partnership for Women and Families, etc.) but is designed for the accountable care context. Detailed specifics will then emerge from our recommended categories and competencies for this domain. Our recommendations should also avoid subjecting ACOs to conflicting goals, as has happened with the general proliferation of quality measures. For that same reason, we also suggest a definition that draws upon the legally binding language used by the Centers for Medicare & Medicaid Services (CMS) in its rule and, in addition, taking into account the recommendations in the *Roadmap for Patient and Family Engagement in Healthcare.* That 2014 document
resulted from the American Institute for Research convening a large, multiple stakeholder group with funding from the Gordon and Betty Moore Foundation.

3) Beyond the Clinical Encounter

Accountable care involves a new type of health care organization that engages with individuals across the care continuum and into the community setting. Our Workgroup discussion made clear this involves more domains and competencies than the well-defined acute-care or doctor’s office settings.

Suggested Definition

Drawing upon the results of our Workgroup discussion, below is a proposed definition and categories of competencies in this domain specifically targeted towards being implementable by risk-bearing provider entities.

**DEFINITION:**

“A patient-centered organization helps individuals stay healthy and return to health when they are sick or injured while incorporating the patient perspective into governance, care system design and individual interactions at all times in all settings.”

A few comments about this wording: First, it obviously refers to organizational activities, which is our purview. Second, “helps” was deliberately chosen to reflect partnership, shared accountability and an implicit commitment to quality improvement and patient safety. At the same time, “helps” signifies that no clinician or organization can guarantee either health or healing from sickness or injury. Finally, the categories of governance, care system design and individual interactions parallel the MSSP rule (providing reinforcement rather than conflict), but are also broad enough to incorporate the categories of competencies decided upon by our Workgroup that relate to both the culture of an organization and “in the trenches” interactions with clinicians.
Categories and Competencies

As our Workgroup agreed, patient-centeredness is a concept that needs to infuse all the work an organization does rather than being confined to a particular set of activities. Reflecting that consensus, the organizational categories below attempt to break out our recommendations regarding competencies into some unique areas that are in our purview and then into areas that other ACLC Workgroups have addressed. (This is not to imply, by the way, that on their own these groups did not consider patient-centeredness as part of their competencies.)

In addition, the wording used in these proposed categories tries to refer to specific actions rather than “understanding” or “knowing” something about the patient. The categories and competencies all build on the Workgroup content that we reviewed, although sometimes including additional specificity of language. We’ve also modified some competencies, understanding that resource constraints in rural and inner city areas in particular are as real for ACOs as for other organizations.

Finally, while we believe getting the categories right is important for organizing competencies and producing a useful set of recommendations, we also recognize that groups may choose different labels and organizational schemes that better fit their operational culture. Therefore, we encourage work group members to remember that these categories are means to an end and to be flexible as we continue our work on them. (Note: the competencies list below are meant to be illustrative and not comprehensive.)

Unique Patient-Centeredness Categories

- Whole person orientation
  - Physical and behavioral health integration
  - Use of individualized care plans that incorporate individual cultural, socio-economic and other relevant contextual factors
  - Use of measures, tools and processes that maximize the individual’s self-defined quality of life and potential for wellbeing
  - Building a culture of empathy and compassion, with attention to emotional and spiritual needs
• **Patient Involvement**
  - Policies and processes to involve family, caregivers and support networks as appropriate
  - Shared decision making methods and tools enabling patients to assess treatment options in the context of their values
  - Assessment of patient activation and the ability to communicate to patients appropriately and effectively in all settings and whatever their stage of activation
  - Awareness of health literacy issues and the ability to communicate clearly in a way that includes patients, family, caregivers and others in the patient’s network as appropriate
  - Enable advanced care planning and planning for palliative care and end-of-life decisions
  - Ensure that individuals understand that they are part of a care system
  - Enable a learning health system for providers and patients alike

• **Ease of Use**
  - To the extent possible, ensure appropriate geographic access to health care services across the continuum of care
  - To the extent possible, ensure that access to appointments is rapid and waiting time minimal across the continuum of care
  - To the extent possible, ensure that home visits, telehealth visits, remote monitoring and similar services are available to individuals whose health depends upon that access
  - Ensure that those with chronic or acute medical needs can promptly access medical advice or care as needed
  - Ensure that information about the quality of care and its cost is readily available and clearly presented
  - Ensure that financial barriers do not block access to appropriate services
  - Care coordination should minimize gaps in care and integrate community resources

**Overlapping Patient-Centeredness Categories (Note: overlaps with other work group areas)**

• **Governance and culture**
  - Clinical policies should promote patient-centeredness
Human resource policies should ensure that patient-centeredness is a criterion for hiring in general and for leadership in particular.

Organizational leaders should be trained in patient-centeredness principles.

The patient voice should be explicitly integrated into governance through both memberships on governing bodies and advisory councils throughout the organization.

The patient voice should be integrated into all quality and safety improvement and population health programs.

- **Health IT**
  - Portals include transparency of cost, outcomes and quality information.
  - Enable easy patient access to useful and usable data, taking into account differing health literacy abilities.
  - Patient-centered health IT implementation that includes accessibility issues such as font size and language.

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