

Assessing Progress in End-of-Life and Serious Illness Care

National Academy of Medicine

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Person-Centered, Family Oriented Care

NOTES—BREAKOUT SESSION 2

Barriers
<ul style="list-style-type: none">• Access (geographic and expertise) to skilled care providers• Teams do not have full inter-professional representation• (Lack of) Institutional commitment to honor wishes• Measurement – quality metrics not patient oriented• Lack of opportunity for improving quality (too accountability focused)• Fragmentation of the system (siloed teams)• Lack of expertise in the business/systems design piece (in building out programs into the community)• Evidence based care delivery (also culture, geographic specific)• Patients' expectations• Caregiver expectations and assessment – is the caregiver able and willing? Assuming resources that may not be there.• True informed consent (improving the process and transparency)• Do not systematically offer the opportunity to change course• Do not have a systematic way of providing care in the home that patients want and care givers are responsible for providing• Lack of cultural proficiency among providers; lack of diversity in provider workforce
Solutions/Opportunities
<ul style="list-style-type: none">• Leverage payment for quality• Telemedicine; shifting care into the home• Raise patients' expectations to be more holistic and demand care they deserve• Community based organizations and support networks• Peer mentors• Leverage other new requirements coming in and study them• Work with hospital associations and non-profits who have boots on the ground; community-institution partnerships• Institute appropriate protocols for responding to abusive situations (caregiver → person and person → caregiver); opportunity to get upstream of this and implement safeguards• Find agencies that respond to caregiver neglect• Opportunity to shore up• Concurrent care for veterans under Medicare benefit• Advance testing and acceptance of concurrent care; continue collecting evidence• Multidisciplinary learning and interaction• Population health model
Other
<ul style="list-style-type: none">•

Top Priority Action Items (limit to 3-5)		Actor(s)
1	Leverage tech to shift care into the home (telemedicine)	Foundations (for model testing); Congress and states; public-private partnerships; professional organizations
2	Expand concurrent care model	Medicare (CMS), non-profits/specialty orgs; other payers
3	Develop person-centered, quality outcome measures that capture the patient experience and well-being, and are consumer friendly	CMS; patients (representatives)
4	Raise awareness of caregiver role, responsibilities, and needs, and interventions to address these	National Alliance for Caregiving; other advocacy groups; research funders
5	Engage hospital administrators in recognizing importance of patient-centered and quality care services across the organization	Professional orgs – AHA, American health care executives; ACGME
	Every provider views primary palliative care as their responsibility	Medical specialty societies, Congress
	Ensure the safety of the person and the family in all settings	Advocacy groups, law enforcement, criminal justice system, first responders (national EMS org)
	Start the conversation early (before onset of any illness)	