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Authors
Shortell, Stephen M
Sehgal, Neil J
Bibi, Salma
et al.

An Early Assessment of Accountable Care Organizations Efforts to Engage Patients and Their Families

Stephen M. Shortell[1,2], **Neil Sehgal**[1,2], **Salma Bibi**[1,2], **Patricia P. Ramsay**[1,2], **Linda Neuhauser**[1], **Carrie H. Colla**[3,4], and **Valerie A. Lewis**[3,4]

[1]School of Public Health, University of California, Berkeley, CA

[2]Center for Healthcare Organizational and Innovation Research, Berkeley, CA

[3]Geisel School of Medicine, Dartmouth College, Lebanon, NH

[4]The Dartmouth Institute for Health Policy and Clinical Practice, Lebanon, NH

Abstract

Accountable Care Organizations (ACOs) have incentives to meet quality and expenditure targets and share in resulting savings. Achieving these goals will require ACOs to engage more actively with patients and their families. The extent to which ACOs do so is currently unknown. Using mixed-methods including a national survey, phone interviews and site-visits; we examine the extent to which ACOs actively engage patients and their families, explore challenges involved; and consider approaches for dealing with those challenges. Results indicate that greater ACO use of patient activation and engagement (PAE) activities at the point-of-care may influence more positive leadership perceptions of the impact of PAE investments on ACO costs, quality, and outcomes of care. We identify a number of important practices associated with greater PAE, including high-level leadership commitment, goal-setting supported by adequate resources, extensive provider training and use of inter-disciplinary care teams, and frequent monitoring and reporting on progress.

Keywords

Accountable Care Organizations; Patient Activation; Patient Engagement; Shared Decision Making; Mixed Methods

INTRODUCTION

A major challenge for the United States health care system is to provide greater value for invested resources. A key strategy in response to this challenge is the formation of Accountable Care Organizations (ACOs) – entities outlined in the Affordable Care Act to accept responsibility for the cost and quality of care for defined patient populations ("Social Security Act, Section 1899," 2010). ACOs have incentives to meet quality and expenditure

Corresponding Author: Stephen M. Shortell, PhD, MBA, MPH, Blue Cross of California Distinguished Professor of Health Policy and Management, Director, Center for Healthcare Organizational and Innovation Research, Dean Emeritus, School of Public Health, Professor of Organization Behavior, Haas School of Business, University of California, Berkeley, 50 University Hall, Berkeley, CA, USA 94720-7360, Phone: 510-643-5346, Shortell@berkeley.edu.

targets and share in resulting savings. There is growing recognition that it will be difficult for ACOs to achieve their goals without more active engagement of patients and their families (Cosgrove et al., 2013; Greene & Hibbard, 2012). Under the Medicare ACO programs patients can select providers outside of the ACO making it more difficult for the ACO to control costs and providing an additional incentive for the ACO to actively engage patients.

Evidence suggests that greater patient and family activation and engagement (PAE) is associated with higher quality and better outcomes of care at the same or lower cost (Cosgrove et al., 2013; Greene & Hibbard, 2012; Greene, Hibbard, Sacks, Overton, and Parrotta, 2015; Greenfield, Kaplan, Ware Jr, Yano, & Frank, 1988;. Hibbard, Greene, & Overton, 2013; Hibbard & Greene, 2013; Hibbard, Mahoney, Stock, & Tusler, 2007). However, implementing PAE activities is difficult work and presents many challenges. Among these are dealing with the traditional roles of the physician as expert and the patient as passive recipient of information, physician desires for autonomy, changes in workflow and the nature of the office visit, the rapid accumulation of new medical knowledge and advances, and variation in patient desires to be more engaged in their care. Thus, it is not surprising that adoption of PAE activities among health care delivery systems and provider organizations nationwide appears to be relatively low (Braddock III, Edwards, Hasenberg, Laidley, & Levinson, 1999; Elwyn et al., 2013).

The purpose of this paper is to assess the extent to which ACOs are making efforts to engage their patients, to identify PAE barriers and challenges, and to learn about the strategies to address these challenges

NEW CONTRIBUTION

There is currently no information on the extent to which ACOs have implemented strategies to engage patients and families in their care. Given ACOs' incentives to provide high quality, cost-effective care, PAE is expected to be a key organizational strategy. We use a combination of early assessment data from a national survey of patient activation and engagement (PAE) in ACOs, phone interviews with a sub-sample of 11 ACOs, and site visits to two additional ACOs to accomplish this objective. This mixed methods triangulation approach provides a more complete assessment and understanding of current PAE activities among ACOs than could be obtained from using one method alone. The inquiry is guided by a conceptual framework of ACO adoption and use of PAE strategies being driven by 1) external environmental factors, such as payment reform policies, 2) by ACO organizational characteristics such as size and ownership, and 3) by the operational barriers and challenges that need to be addressed when implementing PAE strategies. The resulting findings can be used by both policy makers and providers interested in accelerating the extent to which patients and families are engaged in their care. The results also provide baseline information for further research.

DIMENSIONS OF PATIENT ACTIVATION AND ENGAGMENT (PAE)

Four major dimensions of patient and family activation and engagement include: 1) patient participation in policies and practices to prevent disease through health promotion and addressing the underlying behavioral and social determinants of health; 2) patient involvement in direct care provision, 3) patient participation in organizational quality improvement and governance, and 4) patient participation in determining "end of life" preferences for care. The first three areas draw from Carman et al's patient and family engagement framework, with the second dimension —obtaining direct care— as an especially common focus of PAE activities for managing chronic conditions such as diabetes, asthma, lower back pain, and post cardiac rehabilitation (Carman et al., 2013). Chronic illness accounts for 75% of all U.S. healthcare expenditures, with two-thirds of health care costs spent on the 20% of people with multiple chronic conditions (Anderson & Horvath, 2004; LeRoy et al., 2014). We added the fourth PAE dimension —addressing "end of life" care— given the significant impact on healthcare expenditures and the frequent incongruence of end-of-life treatment with patient desires. In 2007, inpatient spending during the last six months of life per Medicare enrolled dependent averaged $14,788, 27% of Medicare-patient deaths occurred while hospitalized, and 17% of those hospitalizations included an intensive care unit admission (Wennberg & Cooper, 1996), despite a decided preference among patients to die at home (Gallup, 1997; Hays, Galanos, Palmer, McQuoid, & Flint, 2001; Karlsen & Addington-Hall, 1998; Townsend et al., 1990). This paper focuses primarily on PAE activities involving direct care and patient participation in ACO organizational quality improvement and governance, recognizing that prevention and end of life PAE activities also occur within these domains.

CONCEPTUAL FRAMEWORK

Figure 1 illustrates the conceptual framework guiding the study. As shown, the external environment involving payment reform, expansion of insurance coverage and benefit design, adoption of new information technologies and broad-based population health initiatives can influence other factors associated with PAE activities. Such factors include organizational characteristics such as size, ownership, and physician compensation which we suggest may be associated with how ACO leaders perceive the impact of engaging in PAE activities which, in turn, may be associated with actual patient point of care engagement and patient involvement in organizational policies. As shown in Figure 1, the extent to which this occurs will also be influenced by the barriers and facilitators to implementing PAE activities.

The framework is grounded in the resource dependence theory of organizations (Aldrich & Pfeffer, 1976; Salancik & Pfeffer, 1978; Zinn & Mor, 1998). ACO characteristics such as size, ownership, and physician compensation influence leaders' perception of the importance of PAE activities to their organization's success and these perceptions, can influence the success of efforts to use PAE strategies in routine practice. Organizational characteristics typically associated with greater innovation adoption include greater access to capital, slack resources, and a sufficient number of patients to spread risk and to achieve economies of scale and scope with respect to creating a "business case" for investing in PAE activities.

Organizational Size

A central tenet of Resource Dependence theory is the organizations desire to minimize uncertainty and dependence on the environment for external resources. Larger organizations are often less dependent on the environment as a result of economies of scale. Similarly, larger organizations generally have greater slack resources (Cohen, March, & Olsen, 1972; Cyert & March, 1963) at the disposal of organizational leaders or managers to be drawn upon in order to take strategic action and to invest in new initiatives (Casalino et al., 2003; Rittenhouse et al., 2011; Robinson et al., 2009; Thompson, 1967) and buffer against downside risk. Larger ACOs also care for a greater number of patients, making it worthwhile to invest in the changes needed to promote greater PAE in terms of both economies of scale and scope. Thus, *our first hypothesis: Larger ACO size will be positively associated with greater PAE activities.*

ACO Ownership

In addition to available slack resources, to engage patient and families ACOs need access to a workforce with the skills and competencies required to initiate and support PAE activities. Emerging evidence on ACOs suggests that compared to hospital-led ACOs, physician-led ACOs are less-likely to offer services outside the scope of traditional medical care, making it more difficult to coordinate care between different types of providers (Colla, Lewis, Shortell, & Fisher, 2014; Shortell, Wu, Lewis, Colla, & Fisher, 2014). Hospital-led ACOs are more likely to have the resources, staff, and connections with post-acute care providers to facilitate coordination and patient involvement in decision-making. Thus, *our second hypothesis: Hospital owned ACOs will be positively associated with greater PAE activities.*

Physician Compensation

Though size and ownership may both predispose ACO decision makers to adopt PAE strategies, internal constraints such as resistance from individuals within the organization to implement these strategies may attenuate their success and temper leaders' enthusiasm about adoption or innovation (Hannan & Freeman, 1977). Inertia in organizations impedes organizational change, though incentives – particularly those anchored in organizational policy, such as compensation – may better align individual and organizational goals, and ease barriers to the organizational implementation of innovative practices (Kaplan & Henderson, 2005). We propose that tying physician compensation to patient experience may help mitigate the impact of individual, professional, and structural inertia to engaging patients. Thus, *our third hypothesis: Greater physician compensation based on patient experience scores will be positively associated with greater PAE activities.*

In summary, ACO size may be a marker for the availability of slack resources to implement PAE programs; ACOs that are part of hospital and health systems are more likely to possess linkages and capacities that make the adoption of PAE initiatives viable; and patient experience-based compensation is a proxy for increasing the motivation of physicians to engage in PAE.

Further we expect that these relationships will be influenced by ACO leaders' perceived impact of PAE activities on achieving the ACOs performance goals related to cost, quality,

patient experience and overall success. Thus, *our fourth hypothesis: The more positive the leader's perceptions of the impact of PAE activities, the greater the actual number of PAE activities used within the organization.*

STUDY DESIGN AND METHODS

To achieve both goals of identifying what ACOs are doing in PAE and understanding the barriers, challenges and strategies to address them, we developed the mixed methods triangulation approach described earlier. This involved a national survey of all ACOs in existence at the time (2013), phone call interviews with a sub-sample of 11 of the ACOs in 2012 and again in 2013, and on-site visits to two additional ACOs in 2013 and 2014. The PAE survey provided valuable information on the extent of involvement in motivational interviewing, joint setting of treatment goals, use of decision-making aids, use of patient portals, and related areas along with the opportunity to provide examples and further comments. These then served as a basis for further examination in the phone interviews and the site visits.

Web-based surveys

Based on input from the expert advisory group who also completed a survey pilot' literature review (Cosgrove et al., 2013), and recent examination of patient engagement activities undertaken in the Aligning Forces for Quality initiative (AF4Q) (Alexander, Hearld, & Mittler, 2014); the PAE web-based survey focused on the following topics related to "patient point of care engagement": 1) the extent to which primary care physicians (PCPs) involve patients in developing treatment plans; 2) the extent to which shared decision-making tools are used (Arterburn et al., 2012; Elwyn et al., 2006; Friedberg, Van Busum, Wexler, Bowen, & Schneider, 2013); 3) the extent to which PCPs are trained in motivational interviewing to facilitate PAE; 4) the extent to which patients have access to their medical records and/or clinical notes; 5) the extent to which telehealth is used; and 6) the extent to which patient health literacy levels are formally assessed.

Three additional survey topic areas focused on "patient involvement in organizational policies" including: 1) the extent to which patients and family members are involved in quality improvement teams; 2) the extent to which they are involved in advisory councils; and 3) the extent to which they participate in governing board discussions. The survey also asked about ACO leaders' perception of the impact of PAE activities on cost, quality, and outcomes of care.

The overall data collection flow is shown in Figure 2. ACOs for the web-based PAE survey were identified based on the universe of the first wave of the National Survey of Accountable Care Organizations (NSACO) conducted by The Dartmouth Institute for Health Policy and Clinical Practice and The Center for Healthcare Organizational and Innovation Research (CHOIR) at the UC-Berkeley School of Public Health between October of 2012 and May of 2013 (Lewis, Colla, Carluzzo, Kler, & Fisher, 2013). The survey universe for NSACO wave 1 was 282 ACOs with 173 ACOs completing the NSACO. The Patient and Family Activation and Engagement Survey (PAE), the focus of this paper, was administered between September 2013 and April 2014 and completed by the ACO leader most

knowledgeable about the ACO's PAE activities across the ACO. Sixty-three (63) of the 173 wave 1 NSACO respondents also completed the PAE survey. An additional 38 ACOs completed the PAE survey but did not complete the NSACO. Thus, we analyzed a total of 101 (63 + 38) ACOs that completed the PAE survey—an overall response rate of 36 percent (AAPOR method) (American Association for Public Opinion Research, 2011). While no statistically significant differences were found on variables such as size and ownership between the respondents and non-respondents, it is highly probable that the responding ACOs were more likely to be involved in PAE activities than the non-respondents. Data from NSACO were used to validate the PAE survey questions such as patient/family participation in ACO advisory councils, quality improvement initiatives, and in decisions about care self-management.[1]

The ACO size ranged from 15 to 2,100 FTE physicians with a mean of 227 FTE physicians (SD=311). Forty five percent of the ACOs were physician led; 42 percent were hospital/health system led; and 13 percent other led. Sixty-six percent paid between 0 and 5% physician compensation based on patient experience scores; 29 percent were in the 6 to 10% range and 5 percent were in the over 10% category. Twenty-one percent of the ACOs were in the Mid-Atlantic/New England region; 30 percent were in Mountain/Pacific region and 49 percent in other regions across the country.

In-depth phone interviews

As shown in Figure 2, from the universe of 173 NSACO responding organizations we purposely sampled 11 ACOs for in-depth key-informant telephone interviews at two points in time (2012 and 2013) to learn about the challenges of implementation. Sampling criteria included organization type, number of covered lives, type of Medicare ACO, whether or not a commercial contract was also involved and geographic location. In total, four of the 11 were part of an Integrated Delivery System, three were medical groups, two were IPAs, and one each was a PHO and owned by a hospital system. Eight of the 11 had risk-based contracts with both Medicare and commercial carriers, two with Medicaid and commercial carriers; and one with Medicare only. Of those with Medicare contracts, three were in the Pioneer program, and the remaining six were in the Shared Savings program. Four were located in the west, three in the east, two in the Midwest; and two in the south. The number of covered lives ranged from 13,000 to 364,000 with most having between 25,000 and 50,000 covered lives.

In both 2012 and 2013, we asked each ACO: "In the past year, have there been any changes or new developments in how your ACO actively engages patients in their care?" The phone interviews asked each of the six areas also addressed in the national PAE survey:

- Disease prevention and health promotion outreach programs,

- Communication between clinicians and patients during office visits,

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[1]Using data from NSACO, we were able to validate similar questions from the PAE survey. For example, two-thirds of survey respondents have patient/family participation in advisory councils (equal across the PAE and NSACO surveys). Similarly, over half of ACOs reported patient involvement in quality improvement initiatives, while 70 to 80 percent indicated patient involvement in decisions about self-management of their care.

- Shared decision-making with patients regarding their care and treatment options,

- Self-management programs for patient conditions including health coaches,

- End of life or advanced serious illness care, and

- Management and governance or quality improvement activities of the ACO.

Site visits

As shown in Figure 2, we supplemented the web-based survey and in depth phone interviews with site visits to two ACOs conducted between November 2013 and March 2014: Group Health Cooperative (GHC) of Puget Sound in Seattle and UCLA Medical Center and Health System in Los Angeles. We selected these two ACOs because of their national reputation for innovation in PAE activities. The purpose of the site visits was to obtain greater understanding of some of the challenges of implementing PAE even in leading organizations and to identify some innovative approaches to engaging patients and their families.

GHC was founded in the 1940s as a cooperative owned by members and were one of the early health maintenance organizations (HMOs) created by the HMO legislation in the 1970s. They care for more than 600,000 patients in Washington State and are one of the leaders in developing and implementing patient centered medical homes. UCLA is a major academic medical center serving more than 300,000 patients. In recent years, they have expanded their patient base through developing a primary care practice network and developing linkages with community hospitals.

Under the guidance of the project's expert advisory panel, we developed a semi-structured interview protocol based on a review of literature about PAE strategies and practices. We conducted one-hour interviews on-site (and in a few cases via telephone) with a total of 27 respondents across the two sites including administrators, physicians, nurses, and other providers, as well as patients and families. The interview protocol employed largely open-ended questions to identify the types and degree of PAE practices used, processes of implementation, challenges, facilitators, and any resulting outcomes. All interviews were conducted by two to four members of the research team with experience in qualitative research, and all interviews except those with patients and family members were digitally recorded. The UC Berkeley Office for the Protection of Human Subjects approved the study protocol.

ANALYSIS

To assess the efforts that ACOs are making in PAE, we analyzed the PAE survey data in two stages. First, we examined responses to individual questions[2] (see Table 1). We then used an exploratory factor analysis (Harman, 1976) to examine the relationships among selected

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[2]Significant efforts were made including follow up calls to PAE survey respondents to minimize missing data, resulting in less than 4% missing data for two variables. Due to the small amount of missing data, mean substitution was used to replace missing values with the variable mean for the purpose of calculating descriptive statistics (See Table 1). Variables used in regression analysis did not have any missing data.

survey items to measure the core dimensions of PAE involving direct engagement in patient care and involvement in organizational quality improvement and policy participation. We also examined the items comprising the perceived impact construct to see if they formed an index as expected. Using eigenvalues above 1.0 and factor loadings of .40 and above, the results yielded three factors or indices: 1) Perceived Impact of Patient Activation and Engagement, 2) Point of Care Engagement and, 3) Quality Improvement and Policy Participation (See Table 2 for the individual items, assignment of points and measures of internal consistency reliability).

We used linear regression to explore the relationship between ACO size, ownership, physician compensation and geographic region with leader's perceived impact. We also examined the direct relationship of size, ownership, physician compensation, and region on Patient Point of Care Engagement and on Patient Involvement in Organizational Policies. We then examined the association of size, ownership, physician compensation, region and perceived impact on both Patient Point of Care Engagement and Patient Involvement in Organizational Policies. We hypothesized that greater perceived impact of PAE activities would be positively associated with both greater Patient Involvement at the Point of Care and greater Patient Involvement in Organizational Policies.

The qualitative analysis involved three components. First, responses to open-ended survey questions in the PAE survey were reviewed and categorized based on recurrent themes. A recurrent theme was defined as a common response to a single question mentioned by five or more respondents. A response could be categorized into more than one theme, if applicable, while some responses did not fit into a theme category. Responses for each identified theme were counted by theme. Illustrative quotes are presented in Table 4. Second, for the two case study sites, three members of the research team verbatim coded interview transcripts by question and domain to identify major recurring themes. Initial code-sets were reviewed for agreement, harmonized, and a focused code-set was developed to capture domains of innovative PAE strategies implemented at each site, barriers or obstacles to implementing PAE practices, and the frequency of each. All qualitative data were analyzed independently by a minimum of two reviewers, and any codes/themes resulting from analyses were examined for agreement. Third, the 11 in-depth telephone interviews were summarized and coded by two research team members using the same recurring themes method.

RESULTS

Our results are organized around three themes; 1) the extent of PAE activities undertaken by ACOs; 2) efforts to improve care coordination, communication and outreach; and 3) the challenges of competing priorities, resource constraints, and lack of time.

Extent of PAE Activities (Table 1)

The vast majority of responding ACO leaders reported implementing PAE strategies, such as sending patients follow-up and reminder notices either electronically, by mail or by phone call (100 percent) and allowing patients access to their own medical records (71 percent). But, only 24% of ACOs allowed patients to access clinical notes related to their care. We

found that ACO respondents reported that a mean of only 45% of their high-risk chronically ill patients received health coaching.

Respondents reported that approximately half of PCPs received training in PAE techniques (48 percent) and 45 percent offered decision aids to patients or families. Respondents stated that slightly more than half of clinicians were trained in shared decision-making practices (58 percent) and that 62 percent of their PCPs were working with patients and families to develop a treatment plan that sets goals for their care. Two-thirds of ACOs reported offering patients/families opportunities to engage in governing board discussions, but there was a relatively low level of participation (4.7 on a 1 to 9 scale). Approximately half of ACOs reported patient participation in quality improvement activities.

Perceptions of PAE Impact

ACO respondents felt strongly that investment in PAE would lead to improved quality of care on a 1 low to 9 high scale (7.79/9, SD 1.89), improvement in health outcomes (7.78/9, SD 1.55), retention of patients (7.37/9, SD 1.74), and reduced cost of care (7.35/9, SD 1.73). Additionally, ACO leaders felt strongly that PAE was critical to their organization's success (7.35/9, SD 1.73). Though only 26 percent of ACOs had explicitly calculated a return on investment (ROI) in PAE activities, those that did reported between a 2:1 and 4:1 ROI. Most of the ROI was attributed to reduced emergency department visits and hospitalizations.

Examination of the Hypotheses

Table 3 reveals no support for our hypotheses regarding predicted positive associations of size, ownership, and physician compensation based on patient experience scores with PAE activities at point of care or in organizational polices. But there is support for our fourth hypothesis involving the predicted positive association between the leader's perceived impact of PAE and greater use of point-of-care engagement. Perceived impact of PAE was also marginally associated ($p<.06$) with the Patient Involvement in Organizational Polices index (data not shown).

Improving Care Coordination, Patient Communication, and Outreach

A major theme that emerged from the open ended questions from the survey, the phone interviews and the site visits was the effort devoted to improving coordination of care through better communication and outreach. Open-ended comments from the survey are summarized in Table 4. Many ACOs are using interdisciplinary care teams featuring care coordinators to better manage patient needs (mentioned 41 times). Training providers in motivational interviewing, using health coaches, implementing evidence-based protocols, developing patient portals and various community outreach initiatives were also frequently mentioned as strategies to improve coordination of care and communication with patients.

The phone interviews provided more specific information and examples of coordination and communication actions that were taken. For example, six of the 11 phone interview respondents reported increased use of embedded case managers/care coordinators in primary care physician (PCP) practices. These case managers developed transition programs for patients with complex chronic conditions. Consistent with new developments in

communication technologies (Asch, Muller, and Volpp, 2012), interviewees also reported increased use of in-home monitoring devices, development of patient portals to enhance two-way communication, and expansion of medical home capabilities. One hybrid hospital-physician led ACO respondent reported: "In our program for high risk patients the patient has an iPad-like device and other monitoring devices in their home….so we respond to requests for help immediately."

A physician-led ACO network in the Northeast uses an inter-disciplinary care team to work with patients with complex needs. One was a patient "…who went 132 times in 12 months to the emergency department. She is … in a wheelchair… lives in a house with no ramp. She doesn't have much social support, doesn't have any food. A diabetic, out of control. She doesn't have a refrigerator for insulin. From one visit, we engaged our team of care management (who)… built her a ramp, donated a refrigerator, and hooked her up to an equivalent of Meals on Wheels so she has food, and arranged for transportation to get her to regular visits to her primary care physician. And in the past ten months… she's not been back (into the ER) one time."

Challenges are reflected in the comments of several other respondents, one of whom stated: "We're evaluating how to engage patients, whether it's with third party software, whether it is texting. I don't think we've cracked the code here. I think this is where we are going to spend a lot of our time."

Another Southwest ACO site is waiting for the installation of a data analytics platform that will include patient engagement and interactive modifiable care plans. This respondent noted: "Having a patient portal has shown us how much more our patients want and how much more our patients are willing to engage. And because of the patients' positive response to the portal, the docs are more willing to accept the portal than they were when they first heard about it."

The site visits further underscored the importance as well as challenges of improving patient communication and engagement. This was particularly true in developing patient portals and tailoring messages to facilitate greater communication with patients. A GHC respondent noted: "We have limited data about people to personalize information and therefore make it feel more relevant personally to them." Another challenge for both sites was providing training to new staff and "refresher" training for existing staff in patient engagement techniques and tools.

Competing Priorities, Resource Constrains, and Lack of Time

A third theme involving competing priorities, resource constraints, and lack of time emerged from the two site visits. In total, there were 43 individual instances of these issues mentioned across 22 interviewees. Among the competing organizational priorities identified was an emphasis on trying to improve scores on the Health Employer Data Information System (HEDIS) process measures such as lipids, blood pressure, and blood sugar levels (12 mentions). Tight budgets restricting investment in PAE training was mentioned 11 times, and lack of time to increase PAE training and related PAE activities was mentioned seven times. Open-ended comments from the web based survey also mentioned that it is a "struggle" to

implement interventions with busy physicians in addition to educating them in PAE activities. This was reinforced in the site visits. A GHC respondent stated: "We have the same struggles that I am sure everybody does. And that is, are we really building patient-centric care or is it just a continuation of provider-centric?" A UCLA respondent noted that: "It is hard to do this kind of work because it's got to be professionally led…but it's through the engagement of people in the trenches that you get the acceptance and the spread, but it takes time. It takes a lot of effort to do that."

Using motivational interviewing techniques to learn what matters most to patients was also perceived as time-intensive, and therefore hard to implement. As a GHC respondent shared: "Our clinicians have… so much on their plates that it's really hard for them to think about the full package that's available for their patients…there's competing priorities." Another noted: "providers are…burdened by all the things that they have to do and the short amount of time they have with patients and now even the midlevel…clinical staff… feel stressed out and overburdened for time. So, nobody feels like they have the time to really sit down and engage and do some of the tasks that would need to happen to really either activate patients or incorporate them into the kind of administrative functions where they might be able to give input."

Budget issues arose in the context of the difficulty involved in conducting ROI analyses on PAE activities to justify continued expenditures. Speaking about shared decision making, a responded at GHC said: "it was very difficult to forecast what we would get out of that investment, and then even now that we have data it's still difficult to forecast what our savings is… many of these interventions have so many effects on so many different aspects of patient care it's difficult to quantify the direct impact." As previously indicated from the web-based survey only 26 percent of responding ACOs were able to do any ROI calculations.

Common Facilitators for Addressing Challenges

At both GHC and UCLA, a number of common approaches or strategies were in place to address the challenges involved. These included strong leadership at the top of the organization, a strong emphasis on teams, widespread training, frequent monitoring and reporting, and recognizing that it takes time to spread PAE activities throughout the organization. Each site had strong leadership that clearly communicated the importance of PAE with specifically stated goals and budgets for implementation. A senior leader at UCLA noted: "We have leadership that's obsessed around patient satisfaction and patient engagement. That is our strategy. That is our focus... It is our truth. It is our true north. We do everything around what is best for our patients and where the voice of the patient is absolutely crucial in every decision we make-- every meeting we have. They're there with us."

Both organizations highly value making the patients more central in care decisions. The emphasis on teams included UCLAs involvement of patients on teams to redesign several service lines. This resulted in new discoveries as expressed by one respondent: "We gave them (patients) an initial care pathway as we saw it and had them fill in what we missed. Every single interview raised using catheters as a point of anxiety for the patient and the

urologists didn't realize that was a point of anxiety." Both sites were expanding their training programs. GHC, for example, recently began emphasizing expanded use of decision-making videos. The organization's goal is to reduce the percentage of patients who get an elective surgery without a formal shared decision-making aid to 20 percent by improving communication and coordination among primary care physicians, specialists, and patients.

Finally, both sites recognized that increasing PAE activities is an ongoing long-term commitment that would take time and continual attention. For example, one UCLA respondent noted: "When we first started putting care coordinators in the offices, we got pushback from the doctors that we were taking away some of the things they do. But after they got familiar with it and realized that these aren't things that you really need a medical degree for and it actually means that the minutes I'm in the room with the patient I can talk to the patient about their health, they were OK with it."

DISCUSSION

While the findings clearly indicate that the responding ACOs are involved in efforts to engage patients and their families, there are major barriers to doing so. These include gaining greater attention in the face of competing priorities, redesigning work flows, developing new communication skills, educating providers and committing the necessary time and resources.

PAE activities involve a paradigm shift in the historical doctor-patient relationship. While it can be argued that this shift has been occurring for some time, what is new is that the relationship is now increasingly taking place in complex organizational settings with changing economic incentives and consequences for both patients and physicians.

It is particularly important to note that PAE disrupts the workflow of physician practices as currently designed. Movement toward re-organizing practices around inter-disciplinary practice teams enabled by EHR technology may help. This facilitates the use of e-visits, in-person visits, in-home health assessments, health coaching, and related means of engagement with patients and families. The suggestion is that "PAE model of care" needs to move from vertical physician-patient dyads to horizontal and circular reciprocally interdependent teams with the patient at the center as a full partner in the process. A number of promising practices were identified including embedding care managers (often nurses or medical assistants) into the practice itself, developing patient portals, patient-to- patient peer coaching, expanding use of in-home monitoring devices, and increasing patient involvement in quality improvement and practice redesign. Adoption of these and other PAE practices also depends, in part, on creating a stronger evidence base for their use.

As shown in Figure 1, there are four external factors – payment reform, insurance coverage/ benefit design, information technologies, and broad population health interest - that might facilitate expansion of PAE activities beyond the current base of early adopters. For example, as Medicare moves shared savings ACOs toward accepting downside risk over time and as private insurers follow, there will be increased economic incentives for providers

to engage patients and families in efforts to help meet both quality and cost goals. Additional impetus may be provided by CMS' intent in 2015 to introduce a non-visit based chronic care management (CCM) payment of $40 per beneficiary for those patients with two or more chronic conditions provided the practices collaborate with the patient in creating and maintaining a comprehensive care plan (Edwards & Landon, 2014).

The supply side provider payment incentives may be reinforced by demand side insurance coverage benefit designs that contain increased deductibles and co-payments both for polices on the insurance exchanges and in employer's policies. The result may be more cost and value-conscious consumers who will want more "voice" in all of their interactions with the health care system.

New information technologies are also likely to increase PAE activities. These include health apps and decision aids. In this regard, creating a National Certifying Body for health apps and decision aids based on meeting evidence-based standards will play an important role.

The fourth external factor involves the growing interest across the U.S. in creating Accountable Care Communities or Accountable Communities for Health (ACHs) (Hester & Strange, 2014). These communities extend the features of ACOs' accountability for the cost and quality of care for their own patients to the broader, population-defined community, cutting across any single provider or insurer's current enrolled population (Casalino and Noble, 2013; Shortell, 2013). For example, CMS or commercial insurers could work together to provide a risk-adjusted global budget to an "accountable community entity" to improve outcomes for all patients with diabetes in a given area over a defined period of time (Shortell, 2013). This would involve the participation of the education, housing, transportation and other sectors in addition to the health care sector consistent with the "health in all" policies addressing the social and behavioral determinants of health. This will provide expanded opportunities for citizen participation and engagement that could give added force to individual ACOs' PAE initiatives. The goal becomes not only "engagement in care" but "engagement in health."

LIMITATIONS

The findings must be considered within the context of the study's limitations. Using NSACO data on the number of practicing full time equivalent PCPs, ACO ownership, and geographic region of the country, we found no statistically significant differences between respondents and non-respondents (Johnson and Wislar, 2012). However, as previously noted, it is highly probable that the responding ACOs were more likely to be involved in PAE activities and therefore more willing and interested in responding than those less involved. Thus, the data reported on the extent of PAE involvement should be considered as likely somewhat greater than in the overall population of ACOs. This is borne out in analysis of data from the wave 2 NSACO respondents who reported less PAE with respect to having a beneficiary advisory panel, holding town hall meetings, and fielding a beneficiary survey than those in the first wave.[3]

Second, the two case study sites were selected to participate because we felt they provided rich examples of PAE practices and initiatives that others could benefit from. This, of course, involves tradeoffs with their generalizability to other sites that may not possess the same level of motivation or resources for PAE activities. Third, our findings are based on respondents who were recommended for interview by individuals involved in and/or knowledgeable of PAE practices and strategies at each site. Other administrators, clinicians, or staff may have had different responses. Thus, the survey data largely reflects ACO leaders' assessment of the ACOs PAE activities and not those of the front line staff.

Also, the point of care engagement, involvement in quality improvement and organizational policy-making, and the perceived impact of PAE indices are new and need to be validated in further research. It may also be the case that some of the questions may have been difficult for the respondent to report on with precise knowledge. Examples include the percent of primary care physicians who involve patients in treatment plans and/or in following up on treatment plans. Further, the survey data analysis is based on a cross section at one point in time and precludes drawing any causal inferences. The analysis only reflects associations between the variables of interest. Finally, it was beyond the scope of this exploratory study to measure the impact of the external factors – payment reform, expanded insurance coverage and benefit designs, new information technology adoption, and broad based population health initiatives – shown in our conceptual framework in Figure 1. But we suggest that each of these factors may play an important role in influencing future adoption of PAE initiatives and are deserving of future research.

CONCLUSION

ACO leaders clearly recognize the importance of PAE to their organizations' success and efforts are underway to engage patients and their families through multiple means including enhanced patient interfaces with electronic health records, increased sharing of treatment plans, goals, and decision aids, and increasing involvement in quality improvement and care redesign initiatives. Given their resources and experience the responding ACOs are likely ahead of other ACOs and non-ACO delivery organizations across the U.S. in engaging patients and their families. However, research is needed on the extent to which what is reported is actually occurring in everyday practice. Research is also needed on the external factors likely to drive the pace of change. These include a more rapid adoption of payment models that reward providers for keeping patients well, greater patient awareness of the potential financial consequences to themselves and their families of not being more actively engaged in their care, the availability of tools and interventions to make it easier for such engagement, and increased participation of providers, patients and the wider community in addressing the underlying physical and social determinants of health through the development of Accountable Communities for Health. Learning more about what matters to patients and their families as opposed to focusing only on "what is the matter with you" will

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[3]We also used a second wave (September, 2013 to March, 2014) of the NSACO survey of 97 new ACOs to examine changes between the wave 1 ACOs and the wave 2 ACOs in the development of beneficiary advisory panels, town hall meetings, and use of beneficiary surveys. Sixty one (61%) percent of wave 1 vs. 42% wave 2 respondents reported having a beneficiary advisory panel (p=0.0074); 26% wave 1 vs. 12% wave 2 respondents reported having town hall meetings (p=0.0242); 72% wave 1 vs. 41% wave 2 respondents reported having a beneficiary survey (p=0.0023).

increasingly matter to physicians and other members of the health care team, as they are increasingly held accountable for the quality and cost of care that they provide.

Acknowledgments

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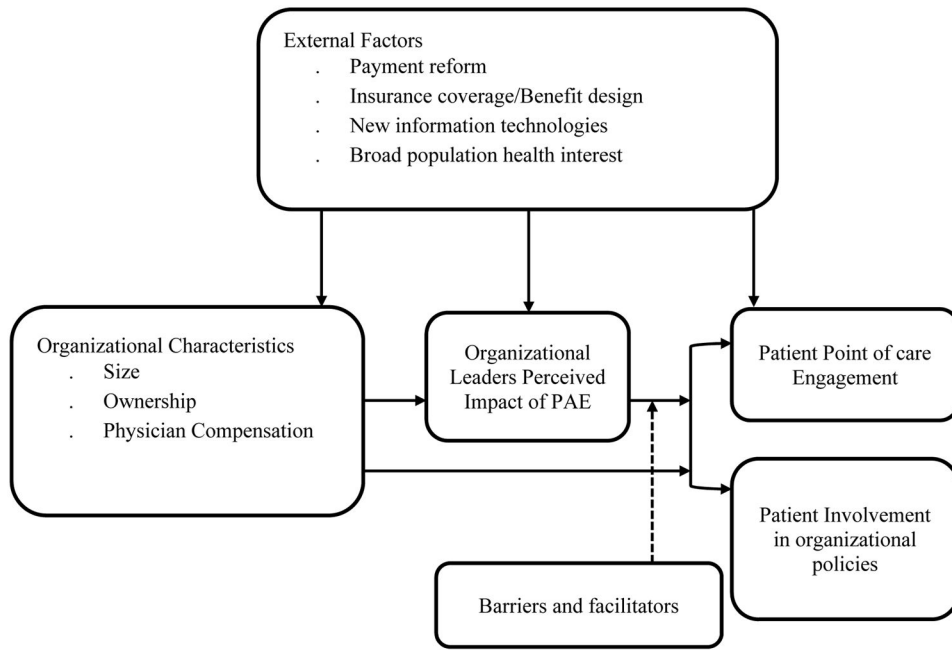
Figure 1.
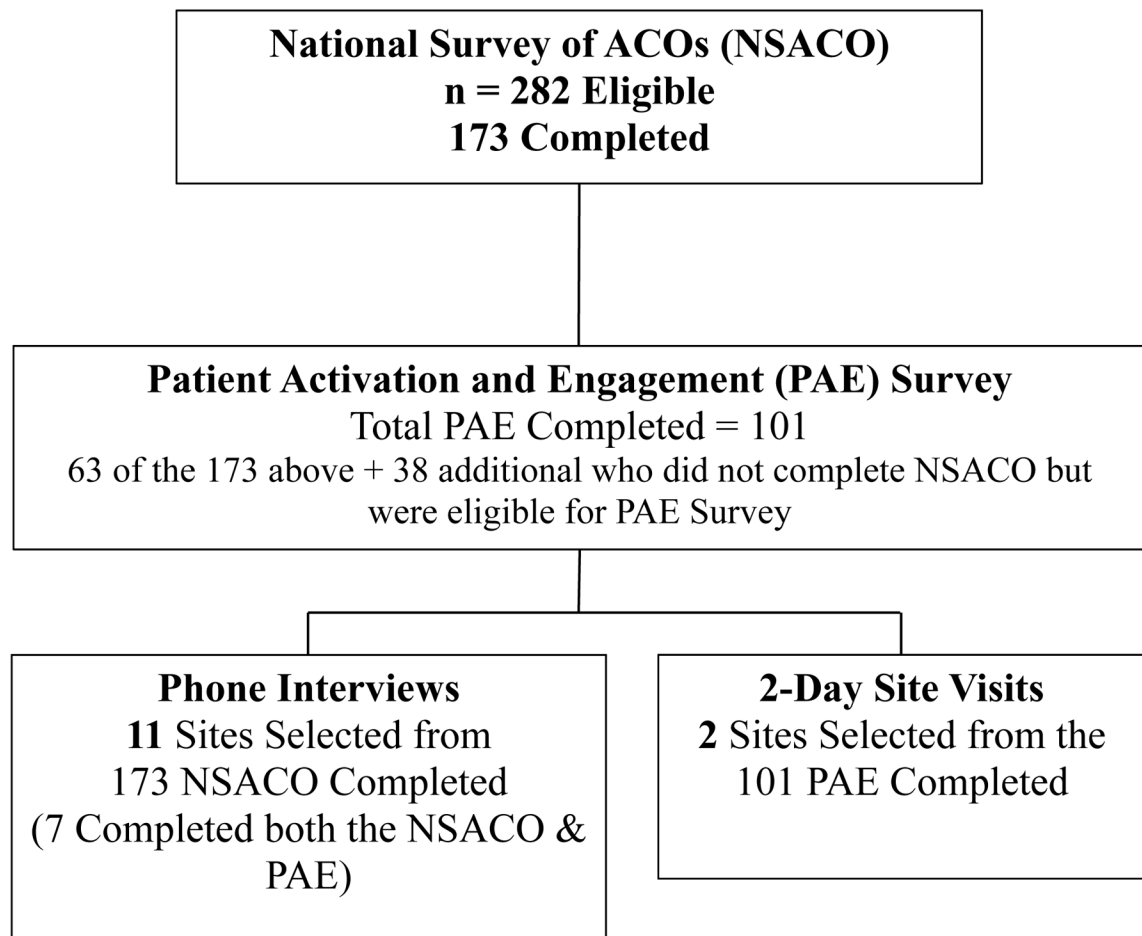Conceptual Framework for Patient Activation and Engagement

Figure 2.
Triangulated Data Collection Flow

Table 1

Summary Statistics for each PAE Survey Question

Question	N	Mean (SD) or %[†]
Patient and Family Direct Engagement in their Care		
% of PCPs that have received training in PAE	101	48.54 (30.67)
% of PCPs that work with patients/families to develop a treatment plan that sets goals for their care	101	61.56 (29.02)
% of PCPs that follow-up with patients/families to assess and monitor the treatment plan	101	57.31 (28.46)
ACO sends patients reminder notices using a computerized system (yes/no)	101	55.45% [†]
ACO sends patients mail or phone call reminders (yes/no)	101	81.19% [†]
ACO provides patients access to their medical records AND to clinical notes (yes/no)	101	23.76% [†]
ACO provides patients access to their medical records, but NOT to clinical notes (yes/no)	101	47.52% [†]
ACO currently assesses chronic illness patients' ability to manage their own care (yes/no)	101	83.17% [†]
% of ACO's high-risk chronic illness patients that receive health coaching	101	45.39 (27.53)
% of ACO's high-risk chronic illness patients that participate in peer support groups or group visits	101	18.47 (17.77)
% of ACO's high-risk chronic illness patients that participate in a care-transition program	101	60.72 (31.21)
ACO uses telehealth	101	52.53% [†]
If YES, % of patients with whom ACO uses telehealth	53	20.37 (26.40)
ACO formally assesses literacy levels	100	30.0% [†]
If YES, % of PCPs that use health literacy information in working with patients/families	23	53.35 (34.94)
% of PCPs that offer patients families evidence-based decision aids	101	45.54 (30.80)
ACO offers training or support to clinicians for adopting shared decision-making practices (yes/no)	101	57.42% [†]
Patient and Family Engagement in Practice Improvement		
ACO recruits patients/families to participate in quality improvement activities (yes/no)	101	50.50% [†]
ACO recruits patients/families to participate in patient/family advisory councils (yes/no)	101	67.33% [†]
Level of participation of patients in ACO governing board discussions (1 to 9 scale)	101	4.7 (3.5)
ACO provides PCPs data on quality of care based on patient surveys or experiences (yes/no)	101	87.13% [†]
0% to 5% of physician compensation is based on patient experience data (yes/no)	101	66.34% [†]
6% to 10% of physician compensation is based on patient experience data (yes/no)	101	28.71% [†]
Greater than 10% of physician compensation is based on patient experience data (yes/no)	101	5.0% [†]
Beliefs about Patient Activation and Engagement Efforts		
Extent of ACO leadership's belief that having activated and engaged patients will lead to improved quality of care (1 not at all to 9 very high)	101	7.79 (1.90)
Extent of ACO leadership's belief that PAE will lead to improved health outcomes (1 to 9 scale)	101	7.78 (1.55)
Extent of ACO leadership's belief that PAE will result in patient retention within ACO system (1 to 9 scale)	101	7.37 (1.74)
Extent of ACO leadership's belief that PAE will lead to reduced costs of care (1 to 9 scale)	101	7.35 (1.73)
ACO has calculated ROI (yes/no)	96	26.04% [†]
Extent of ACO's belief that PAE is critical to success of ACO (1 to 9 scale)	101	7.35 (1.73)

SOURCE: National Accountable Care Organization Patient Activation and Engagement Survey.

NOTES:

[†] represents % of "yes" responses.

Table 2

Means, Standard Deviations, Cronbach Alphas, and Scoring Algorithm for Each Index

Index Components	Criteria	Mean (SD)
Perceived Impact of Patient Activation and Engagement Index ($\alpha = 0.85$)		
Extent of ACO leadership's belief that having activated and engaged patients will lead to improved quality of care (1–9 scale)	1 point if >= to 7	3.72 (1.72)
Extent of ACO leadership's belief that PAE will lead to improved health outcomes (1–9 scale)	1 point if >= to 7	
Extent of ACO leadership's belief that PAE will result in patient retention within ACO system (1–9 scale)	1 point if >= to 7	
Extent of ACO leadership's belief that PAE will lead to reduced costs of care (1–9 scale)	1 point if >= to 7	
Extent of ACO's belief that PAE is critical to success of ACO (1–9 scale)	1 point if >= to 7	
Point of Care Engagement Index ($\alpha = 0.76$)		
% of PCPs that have received training in PAE	1 point if >= 50	2.79 (1.86)
% of PCPs that work with patients/families to develop a treatment plan that sets goals for their care	1point if >=50	
% of PCPs that follow-up with patients/families to assess and monitor the treatment plan	1point if >=50	
% of ACO's high-risk chronic illness patients that receive health coaching	1point if >=50	
% of PCPs that offer patients families evidence-based decision aids	1point if >=50	
% of ACO's high-risk chronic illness patients that participate in peer support groups or group visits	1point if >=50	
Quality Improvement and Policy Participation Index ($\alpha = 0.66$)		
ACO recruits patients/families to participate in quality improvement activities	1 point if "yes"	1.58 (1.12)
ACO recruits patients/families to participate in patient/family advisory councils	1 point if "yes"	
Level of participation of patients in ACO governing board discussions (1–9 scale)	1 point if >= to 5	

SOURCE: National Accountable Care Organization Patient Activation and Engagement Survey.

Table 3

Factors associated with Point of Care Engagement Index (0–6) (N=101)

Factor	Estimate	95% Confidence Interval	p-value
Intercept	1.5	(0.3, 2.8)	<0.02[*]
ACO size (PCP + Specialty clinicians)	0.0	(0.0, 0.1)	0.87
Physician-owned[1]	0.5	(−0.3, 1.3)	0.25
Other-owned[1]	0.4	(−0.7, 1.6)	0.45
Physician compensation based on patient experience data (0% to 5%)[2]	−0.5	(−1.3, 0.3)	0.25
Physician compensation based on patient experience data (Greater than 10%)[2]	0.7	(−1.3, 1.4)	0.48
Mid-Atlantic/New England Region[3]	0.5	(−0.5, 1.4)	0.33
Mountain/Pacific Region[3]	0.0	(−1.0, 0.8)	0.85
Perceived Impact of Patient Activation and Engagement Index score (0–5)	0.3	(0.1, 0.5)	0.003[*]
R^2	0.16		
F value	2.09		
p-value	0.05		

SOURCE: National Accountable Care Organization Patient Activation and Engagement Survey, National Survey of Accountable Care Organizations.

NOTES:

[*] $p < 0.05$;

[1] Reference group is hospital-owned;

[2] Reference group is 6%–10% of physician compensation based on patient experience data;

[3] Reference group Other category.

Table 4

Commonly-Reported Comments from PAE Survey Open-ended Questions

Question (n) [†]	Common Themes [††]	# responses per theme	Key Quotes
What does your ACO do to work with patients and families to develop a treatment plan that sets goals for their care? (42)	Interdisciplinary care teams: PCP's, care managers, nurses, social workers, health coaches etc.	17	"We provide a full interdisciplinary team to each patient identified at risk and work with them to develop a very individualized plan of care to include medical, behavioral, and social issues" "We have a care team approach. Nurses and coordinators work with the patient and provider to develop a treatment plan and set goals" "We have Health Coaches who have been trained in motivational interviewing and self-management support who work with our patients after they have seen their PCP to establish self-management goals"
	Additional measures taken for high-risk and chronic disease patients: individually-assigned care managers etc.	10	
	Care plans or goals are part of the medical record/copy accessible to patients	7	
What does your ACO do to assess your chronic disease patients' ability to manage their own care? (74)	Use of care coordinators or case managers for patient assessment	41	"RN Care Coordinators work one on one with patients and their family members to understand patient limitations" "Care coordinators work with patients with chronic conditions to assess their knowledge of their condition, ability to identify red flags, medication compliance, etc."
	Conducts patient outreach, follow-up, or monitoring/tele-monitoring of care management	15	
	Motivational interviewing used to assess patients' understanding of their condition	6	
What training or support does your ACO offer clinicians for adopting shared decision-making practices or other PAE practices? (46)	ACO uses evidence-based care protocols, patient-aids, and access to other resources that support SDM efforts	19	"We have formal training programs and dedicated staff resources available to help spread the adoption of SDM" "Video coaching for improved patient communication techniques, utilization of evidence-based treatment programs, proactive office strategies to help close care gaps of patients, and patient education"
	ACO provides computer-based training services on shared decision making	10	
What are recent examples during the past 3 to 6 months of patient activation and engagement initiatives that your ACO has tried?(71)	Increased utilization of patient care coordinators or coaches and motivational interviewing techniques	21	"Patient portal enrollment and utilization" "High risk RN Case Managers engage high risk patients" "We have engaged a community organization to train patients and their neighbors as Community Health Workers"
	Community outreach efforts including health fairs, group disease-management or exercise programs, and training of community health workers	19	
	Contact patients with gaps in care and outreach to high risk/ chronic care patients	16	
	Increased investment in and promotion of online patient portals	11	
What results have been achieved to date in each of these areas? (62)	Too early in implementation of patient activation and engagement initiatives to have concrete data	19	"Reduction in ED visits and admissions (too early in program to have population-specific data)" "Reduced ER utilization and hospitalizations for the high-risk patients with chronic disease that have intensive care management/health coaching"
	Reduced ED/ER utilization/ hospitalization for patients involved in patient activation and engagement efforts	9	
Do you have any other comments that you wish to make about your ACO's patient activation and engagement efforts? (24)	Many ACO's just beginning to ramp up patient activation and engagement initiatives	6	"We are in the early stages of a complete system redesign of care delivery, which includes patient engagement tactics" "This has been a difficult process to implement, and the lack of education of the physicians has been a barrier"

Question (n) [†]	Common Themes [††]	# responses per theme	Key Quotes
	The work is challenging and difficult to build momentum for increased PAE efforts within ACO	6	"Patient engagement will determine whether or not an ACO will be successful" "It is a struggle but worth it in the end"

SOURCE: National Accountable Care Organization Patient Activation and Engagement Survey.

NOTES:

[†]represents # open-ended responses received for the question.

[††]Themes reported by 5 or more respondents presented in this table.