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Meaningfully Engaging Patients in ACO Decision Making

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Accountable care organizations (ACOs) aim to improve quality and slow the growth of healthcare costs by making clinicians, hospitals, and other healthcare providers jointly accountable for the health outcomes and expenditures of their patients.[1,2] When ACOs meet quality and cost benchmarks, they can share in the cost savings accrued. ACOs are forming rapidly in the public and private sectors; more than 400 ACOs already cover more than 7 million beneficiaries in Medicare alone.[3]

Engaging patients (ie, incorporating patients' needs, values, and preferences into healthcare decision making) is considered necessary for ACOs to succeed[4,5] and is an ethical obligation of healthcare organizations.[6] Patient engagement is important in 3 distinct domains: individual patient-clinician interactions, organizational or "system-level" governance, and the broader community (ie, patients and organizations beyond the ACO).[7] Engaging patients in their individual care interactions is crucial for empowering patients to achieve better health in ways that are consistent with their values; here, ACOs are no exception.[8,9] Engaging with the broader community beyond the ACO is also considered necessary for ACOs to improve population health.[10,11]

However, despite a regulatory requirement for involving patients in the governance of Medicare ACOs, what constitutes effective engagement in this regard has received relatively little attention.[12] We describe how ACOs can achieve *meaningful* system-level patient engagement.

The Importance of System-Level Engagement

System-level engagement can serve both practical and ethical aims for ACOs. Practically, as shown for patient safety and quality programs,[13] system-level engagement should help ACOs design care programs and set priorities (eg, about which quality or cost areas to

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target) in ways that help them meet quality and cost goals. It also has the potential to improve trust in the organization and create a more positive organizational culture.

System-level engagement helps fulfill the ethical requirement to respect persons affected by ACO decision making, and helps ensure that these individuals or their representatives contribute to these decisions.[6] Accomplishing this should enhance ACOs' ability to meet their ethical obligations of beneficence: programming that is tailored in such a way is more likely to improve health outcomes. Meeting this obligation intersects with an ACO's practical goals; informing policies, procedures, and care management programs with patient-level input could make these programs more effective and therefore help ACOs succeed. Moreover, system-level engagement creates opportunities to fulfill justice-based ethical obligations by implementing fair processes in ACO decision making and/or by explicitly including vulnerable or marginalized groups in ACO governance. System-level engagement that is attentive to these interrelated practical and ethical aims might reasonably be considered meaningful system-level engagement.

Toward Meaningful Engagement

Accomplishing meaningful engagement may nevertheless be challenging. Unlike engagement activities in individual clinics or hospitals, ACOs can involve numerous combinations of individual providers, clinician groups, and hospitals. These may be geographically diverse or include groups and hospitals with little prior association or relationship, which may impede patients perceiving the ACO as a unit. Because an essential part of the ACO concept incorporates payment reform (via complex analytics, benchmark expenditures, quality and cost metrics, etc), knowledge barriers may get in the way of involving patients in decision making. Finally, because patients may not enroll in the ACO per se (eg, in a Medicare ACO) but instead become involved in the ACO by virtue of where they receive primary care, patients may not associate or identify with "their" ACO itself.

Regulations governing the Medicare Shared Savings Program (MSSP) recognize the importance of system-level engagement. All MSSP ACOs must have a governing board that includes a Medicare beneficiary representative "to advocate for the local community, patient safety issues, provide a strong, independent voice and be part of ACO decision making."[5] This implies that meaningful system-level engagement goes beyond merely having a patient present during board meetings. Instead, system-level engagement intends to actively incorporate the preferences of a particular ACO's patients into specific organizational decisions.

The requirement for a single beneficiary representative received significant attention during MSSP rule making. Some questioned whether a single individual could adequately represent an ACO's patients, while others expressed concern that even with a single individual it might be entirely infeasible.[5] Acknowledging such comments, final MSSP rules attempted to strike a balance by requiring a single representative, at a minimum, while allowing ACOs to "seek innovative ways to involve beneficiaries in ACO governance."[5]

However, all ACOs can implement innovative beneficiary representation and/or the complementary strategies that support it. Resources exist for them to begin doing so. First, because similar issues arose for managed care organizations, they can heed previously learned lessons, including those that highlighted the importance of ethics for effective organizational engagement.[14,15] Second, practical tool kits have recently been developed to aid in the implementation of engagement strategies. For example, the Agency for Healthcare Research and Quality developed a handbook for engagement within hospital-level patient safety and quality improvement.[13] The Gordon and Betty Moore Foundation and the American Institutes for Research recently developed a road map for engagement that includes a number of practical strategies for engagement at the organizational level.[16] By adapting and simplifying engagement frameworks from these and other contexts,[17] an ACO's activities could be structured according to 3 basic steps of engagement:

1. Identifying Beneficiary Representatives

How an ACO identifies its beneficiary representative raises ethical issues of justice in terms of appropriate representation and the use of fair processes to select a representative. For example, MSSP regulations require that a beneficiary representative be served by the ACO, have no conflicts of interest, and not be a provider within the ACO's network. Beyond these requirements, ACOs have significant latitude in choosing a representative.

The intuitive concept of patients electing their representative is appealing, but several factors make this impractical, and the remainder of the board is unlikely to be selected this way. For example, Medicare ACOs must identify a beneficiary representative (or an alternative means of representation) during the application process, before its assigned patients are known. Moreover, due to patient flux in and out of ACOs,[18] there may be no stable "electorate" of patients from which to choose a representative.

Nevertheless, ACOs can employ principles of procedural justice to identify appropriate representatives. First, whatever process an ACO uses should be transparent, publicly justified to its patients, and open to revision (eg, an ACO might need to modify its engagement strategy over time because of changing clinical priorities and circumstances). Second, the process used— which may involve board choice, an application process, or other means—should be guided by how well the individual can represent patients' values and how they are likely to be perceived by the ACO's patients. In some cases, such as when an ACO forms from an existing health system, a choice could build upon ongoing patient/family engagement representatives within that health system. In others, an ACO concerned with serving particular vulnerable or minority groups could select someone who clearly represents these groups.

Except in ACOs that are small or serve homogenous patient populations, the final choice of a representative has additional ethical implications. For instance, when ACOs include diverse patient groups (eg, race/ethnicity, socioeconomic status), a single Medicare beneficiary could not reasonably be expected to be able to represent all patients or their needs, values, and preferences. ACOs in these circumstances should consider novel forms of representation, including multi-patient advisory boards, rotating representatives, or identifying specific representatives, to assist with developing particular interventions (eg, ensuring that a patient with heart failure informs decision making about heart failure care programs).

Some ACOs are doing this. For example, recognizing that ACOs may include organizations, hospitals, physician groups, and patient communities with unique characteristics, Bellin Theda-Care includes 1 patient representative from each of the 2 geographic markets (anchored by Bellin Health and Theda-Care) involved in their partnership. Both Arizona Connected Care and the Johns Hopkins Medicine Alliance for Patients involve a beneficiary representative on the board and have a separate beneficiary advisory council. Duke Connected Care formed a Beneficiary Representative Committee in lieu of a single representative. These and other models of beneficiary representation attempt to accomplish meaningful engagement by ensuring that more (and more diverse) patients' voices are heard. Over time, different models for beneficiary representation should be studied to determine if they result in improved patient engagement or achieve more patient-focused care.

2. Cultivating Relationships

Making engagement meaningful also requires cultivating productive relationships with beneficiary representatives, and among representatives and the patients they represent.

Because beneficiary representation on an ACO governing board is somewhat analogous to community representation on institutional review boards,[19] community engagement in research,[20] hospital patient/family advisory boards,[13,16,21] and public deliberation about health priorities,[22] lessons from all of these contexts could be translated to the ACO setting. For example, dedicating time on the meeting agenda for patient-level input, or having the board chair regularly solicit the views of patient beneficiary members, could empower representatives to express their opinions. Providing beneficiary representatives with background knowledge and accessible informational materials about ACOs (along with adequate time to review materials and ask questions about them) could help inform their input into decision making. Finally, offering financial support—even for small expenses, like parking—could ease potential obstacles to beneficiaries getting involved. At the same time, efforts should be made to preserve representatives' distinct roles as "patients" on the board.

Meaningful engagement also requires ACOs to create an environment where relationships among representatives and the ACO's broader patient population can be cultivated. For example, regularly scheduled "town hall" meetings could update patients about ACO activities and encourage feedback among patients, beneficiary representatives, other board members, and ACO leadership. Because not all patients can attend such meetings, direct outreach, interactive Web sites, and social media (eg, electronic, virtual "comment boxes") could facilitate their involvement. As a matter of justice, special attention could be given to fostering connections with ACOs' most vulnerable patients or acknowledging that in some populations (eg, elderly, low literacy, low income), there may be fewer electronic communication tools that readily support beneficiary engagement.

3. Evaluating Engagement

Meaningful system-level engagement requires knowing whether objectives are being met; in other words, evaluating engagement is itself an ethical obligation. At present, there are few widely accepted outcomes related to system-level engagement.[21] Although quality and cost are outcomes of interest, it may be difficult (given ACOs' diverse activities) to associate these outcomes causally with system-level engagement. Process measures, such as numbers of patients or families involved in system-level engagement or numbers of meetings or town halls per year,[23] are easily gathered but may not fully capture meaningful engagement.

Importantly, other aspects of engagement may be amenable to evaluation. ACOs could regularly assess whether beneficiary representatives' and governing board members' expectations of the relationship are being met. To make sure that engagement is fairly representing all patients' views, ACOs could also survey patients broadly about whether they perceive that their preferences are being incorporated in organizational decision making. Patient focus groups could also provide rich information about how to connect patients with their representative(s) and extend system-level engagement directly to more of an ACO's patients. Specific attention should be given to documenting the impact of engagement on how ACOs craft policies and care programs, including those areas where engagement is needed or could be improved. A comprehensive, iterative evaluation process could build trust in the ACO and facilitate dissemination of effective strategies among ACOs.

Conclusions

The 3-step framework we propose can help ACOs conceptualize a plan for meaningfully engaging patients in ACO governance. ACOs operating in diverse contexts may need to apply a wide range of approaches unique to their needs to achieve meaningful system-level engagement. This may necessitate adapting a number of practical strategies from the tool kits and resources we have highlighted. ACOs outside of Medicare may not have the same regulatory requirements, but they too can employ these approaches to improve system-level engagement activities. Whether strategies from other contexts (eg, hospital safety) will be effective for ACOs is unknown. Therefore, an opportunity exists to implement and study system-level engagement in the ACO context, define outcomes relevant for effective system-level engagement, and disseminate successful strategies. The lessons learned from ACOs could then be applied more broadly to help ensure truly patient-centered delivery system reform.

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