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## Patients' Views about Patient Engagement and Representation in Healthcare Governance

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### Executive Summary

Health systems increasingly engage with patient representatives on their governance boards or with patient and family advisory councils to improve care delivery. Little is known about how general patients regard those engagement activities. The objective of this study was to assess the importance of patient representation. We mailed a survey to 31,687 Medicare beneficiaries attributed to a Medicare accountable care organization. We examined relationships between respondents' views and their health characteristics and performed thematic analysis on free-text responses. Among 3,061 respondents, the majority believed that having a patient representative (74.1%) or a patient council (74.0%) mattered “some” or “a lot.” The main factors respondents considered in answering were that “patients deserve a voice” (64%) and “having a patient on the [governance] board increases my trust” in this organization (46%). Our analysis of free-text responses illuminated why patient representatives are important, keys to successful engagement, and reasons behind the skepticism. This study indicates that most patients believe representation in

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health system governance is important, and that realizing its potential requires engagement activities that improve general patients' awareness of, and interaction with, their representatives.

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## Introduction

Involving patients and families in the design and implementation of healthcare programs and practices is widely regarded as part of patient-centered care (Carman et al., 2013; National Committee for Quality Assurance, 2017; Sharma & Grumbach, 2017). Whether as individual advisers or as part of patient and family advisory councils (PFACs), engaging patients in this way has the potential to help improve healthcare quality, patient safety, and organizational culture.

Involving patients and families is not only beneficial and ethically necessary, but also frequently a policy requirement. Powerful case studies highlight the potential of patient councils to catalyze positive changes in healthcare delivery (Agency for Healthcare Research and Quality, 2013; Niehaus et al., 2017), and evidence suggests that, when done well, patient advisory councils can help improve healthcare quality and reduce costs (Lewis, 2015). Ethically, a case can be made for patient involvement in organizational decision-making independent of its effect on quality and costs (Conway et al., 2006; Berwick, 2009). Engaging patients in governance could demonstrate respect for patients (Danis & Solomon, 2013) and be part of fair and inclusive decision-making processes (DeCamp, Sugarman, & Berkowitz, 2015).

From a policy standpoint in the United States, federally qualified health centers (FQHCs) have long required patient involvement in governance (Wright & Ricketts, 2013). More recently, healthcare reforms have required patient representation on governance boards (e.g., in the Centers for Medicare & Medicaid Services (CMS) Medicare Shared Savings Program (Centers for Medicare & Medicaid Services, 2015)) or establishment of PFACs (e.g., in the Comprehensive Primary Care Plus (CPC+) model). State laws may also require PFACs for individual hospitals (Health Care for All, 2018a) or for state Medicaid programs (Wiitala, Metzger, & Hwang, 2016).

Despite an increasing number of toolkits aimed at facilitating meaningful patient representation, evaluation (Cene et al., 2016; Coulter, 2012; Crawford et al., 2002; McGreevey, 2006; Institute for Patient- and Family-Centered Care, 2013; Health Care for All, 2018b); Sharma, Knox, Mleczo, & Olayiwola, 2017; Agency for Healthcare Research and Quality, 2013) and evaluation tools (Dukhanin, Topazian, & DeCamp, 2018) remain limited. Most studies of patient representatives and patient councils have focused on the patients, healthcare professionals, and administrators directly involved in patient engagement activities (Caplan et al., 2014; Johnson et al., 2016; Luxford, Safran, & Delbanco, 2011; Peikes et al., 2016). Although increasing transparency and connecting patient representatives or councils with patients more generally are recognized as necessary (Peikes et al., 2016), to our knowledge, few studies have directly examined what general patients expect of those who represent them on governance boards and advisory councils. Understanding this may be helpful in achieving certain benefits of patient and family engagement. For instance, only when patients are aware of patient and family engagement

activities, and when their expectations are met, could these activities increase patient satisfaction or patient trust in healthcare systems.

In this article, we describe results of a survey, designed and conducted in collaboration with a patient advisory council, of patients' views on patient representation and patient councils. We sought to assess the importance patients attach to this type of engagement, the factors they consider in assessing that importance, and whether or how they prefer to connect with their patient representatives. Additionally, we sought to determine whether these views were associated with patients' health status or healthcare utilization.

## Methods

### Study Setting

This study was conducted within Johns Hopkins Medicine Alliance for Patients (JMAP), an accountable care organization (ACO) in the CMS Medicare Shared Savings Program. JMAP includes nearly 3,000 physicians and healthcare providers in the greater Maryland and Washington, D.C., region. The ACO is responsible for the care of approximately 40,000 Medicare fee-for-service beneficiaries. JMAP has been an ACO in the Medicare Shared Savings Program since 2014.

Like all ACOs in the Medicare Shared Savings Program, JMAP is required to include a patient representative on its governance board. JMAP, in collaboration with its first patient representative, created a model whereby the patient on the board represents the perspective of the broader Beneficiary Advisory Council (BAC). The BAC is a volunteer group of JMAP patients that reflects the diversity of JMAP's Medicare patient population and assists in meeting JMAP's goals of improving the quality and value of healthcare. In this role, the BAC reviews policies, advises on educational materials, and contributes patients' views at regular JMAP meetings.

As part of its ongoing efforts, in 2017, JMAP created a mailed outreach to all JMAP patients to increase patient awareness of JMAP and the services available to them. This mailer included an informational brochure about JMAP and the BAC. We took advantage of this operational effort and designed a brief survey to accompany it.

### Study Participants and Data Collection

In May 2017, we mailed a self-administered, two-page survey to 31,687 Medicare fee-for-service beneficiaries attributed to JMAP based on the December 2016 attribution file. We included only individuals for whom we had a valid mailing address, who had not opted out of ACO data sharing, and who were not deceased. We provided an addressed, stamped envelope for respondents to send completed surveys to a third-party survey vendor. Survey data were collected through August 2017.

### Survey Instrument and Variables

To develop the survey, we drew from our systematic review of the literature (Dukhanin, Topazian, & DeCamp, 2018) and worked with the BAC as well as the marketing and communications team of Johns Hopkins Medicine to ensure the survey's appropriate content

and readability. The BAC provided critical feedback on two iterations of the survey drafts regarding content and clarity, and we incorporated those suggestions into the final version.

We hypothesized that self-reported health status, healthcare utilization, or awareness of the ACO (JMAP) might affect respondents' views about patient representation. Therefore, we used the relevant item from the Consumer Assessment of Healthcare Providers and Systems (CAHPS) Clinician and Group Survey (version 3.0) regarding self-reported health status and adapted an item for self-reported healthcare utilization. At the BAC's suggestion, we did not collect other variables, such as age, race, or income, out of concern that these might be perceived as intrusive. We assessed awareness by asking respondents whether and how they had heard about JMAP.

Our main outcomes of interest were the importance of having a patient representative on the board or of having a patient council in addition to a representative (which we assessed with 4-point Likert scales ranging from "not at all" to "a lot," with an option for "not sure"). We inquired about the factors respondents considered when thinking about the importance of patient representation. These factors were identified from our knowledge of the literature (Dukhanin, Topazian, & DeCamp, 2018), from our separate ongoing national qualitative study of ACO leaders and patient representatives, and from discussions with the BAC. This allowed us to present six postulated factors to respondents, but we also allowed respondents to write in their own factors.

Finally, we were interested in whether or how patients might be interested in connecting with their patient representatives. To assess this, we again reviewed the literature and worked with the BAC to identify seven putative ways of interacting with patient representatives (which were evaluated via a 5-point Likert scale, from "very likely to use" to "very unlikely to use").

A full version of the survey is provided as Appendix A to this article, published online as Supplemental Digital Content at <http://links.lww.com/JHM/A32>

### Data Management and Analyses

A third-party survey vendor collected mailed responses and entered data into Microsoft Excel. For statistical tests of association, data were imported into Stata (version 14.2). Response rate was calculated using the RR2 definition of the American Association for Public Opinion Research (2016).

We used Pearson's chi-squared test to establish the statistical associations between variables. We further used logistic regressions to examine the direction and strength of those associations. For the latter analysis, we grouped some variables. We dichotomized perceived importance of patient representation into two categories by grouping "some" and "a lot" into one outcome variable and "not at all" and "just a little" into another. Self-reported healthcare utilization, for which respondents indicated how many times they obtained care for a physical or mental healthcare need in the past six months, was grouped into none, one time, two to four times and five times and more (on the basis that these would be meaningful categories of difference). Respondents' awareness of JMAP was dichotomized into "never

heard about” or “have heard about” regardless of how that awareness came about (e.g., via mailings, signage, or being informed by members of the medical team). Lastly, for respondents’ reported likelihood of using a particular means of communication with patient representatives, we dichotomized by grouping “very likely” and “likely” into one outcome variable and “very unlikely,” “unlikely,” and “neutral” into another. Survey records with missing variables were dropped out of regressions.

For free-text responses, we employed an emergent thematic qualitative content analysis (Hsieh & Shannon, 2005). First, a preliminary codebook that categorized responses by thematic relatedness was developed by a member of the BAC by reviewing all responses. Next, a research team member/coauthor (VD) used this codebook to reanalyze the data, iteratively modifying primary codes and adding secondary codes. At this stage, for example, the preliminary primary code “the patient representative is important” was expanded with several secondary codes covering reasons why the representative was viewed as important. Additional primary codes were added, such as “things patients want to know,” and other codes were modified. This codebook was used by another member of the research team (MD) to independently code all the responses. Disagreements between codes at this point were resolved by consensus (between VD and MD) and codes were rearranged thematically into a final codebook.

## Results

### Characteristics of Respondents

We received 3,061 surveys for a response rate of 9.6%. Survey respondents’ characteristics are presented in Table 1. Compared to the general Medicare population, respondents were similar in terms of the range of reported healthcare utilization, but included fewer individuals with self-reported “poor” or “fair” health status. By comparison, in an observational study of data collected between 1998 and 2010, about 25% of Medicare fee-for-service beneficiaries reported “fair” health and 9% reported “poor” health (Chawla et al., 2015). About half of respondents (51%) reported awareness of JMAP. Of those, 719 (47%) reported learning of JMAP via mailings or signs in clinical settings (or both), and 642 (42%) reported learning via their medical care team (Table 1).

### Importance of Patient Representation

About half of the respondents believed it mattered “a lot” that there was a patient representative on the ACO governance board (1,591/3,001, 53%) and that there was a patient council in addition to the representative (1,391/2,943, 47.3%). When including those for whom it mattered “some,” nearly three-quarters of respondents (2,225/3,001 or 74.1% regarding the patient representative and 2,177/2,943 or 74.0% regarding a council) expressed that such engagement was important. By comparison, a minority of respondents reported that it did not matter at all that the patient representative (310/3,001, 10.3%) or council (257/2,942, 8.7%) existed (Table 2).

## Factors Considered Regarding Patient Representation

Respondents could select one or more of our hypothesized factors (or add their own free-text response) regarding what they considered when answering about the importance of having a patient representative (Table 2). The most common factor considered was the general statement that “patients deserve a voice in the organization where they receive care,” and the second most common was that “having a patient on the [governance] board increases my trust that the organization puts my needs first.” A number of respondents appeared to want to learn more, either about the board itself (1,121/2,958, 38%) or about the patient representative (681/2,958, 23%). Moreover, a minority (416/2,958, 14.1%) selected the option that “a patient on the board is probably unable to influence decisions”; 326 respondents left free-text responses (analyzed later).

## Health Status, Healthcare Utilization, and Perceptions about Patient Representation

We found no consistent statistical association between awareness of the ACO and respondents’ perceived importance of patient representatives or a council. However, there was a statistically significant association between health status and importance of having a patient representative on the board ( $p = 0.015$ ). Respondents who rated their health as “excellent” were more likely to believe having a patient on the board mattered “some” or “a lot” compared to beneficiaries who rated their health as “poor” (OR = 3.0, 95% CI = 1.6–5.7,  $p$ -value = 0.001).

We also found a statistically significant association between self-reported healthcare utilization and the importance of having a patient on the board ( $p = 0.025$ ). Respondents who reported having received care five or more times in the past six months were more likely to believe having a patient on the board matters “some” or “a lot” compared to those who have not obtained any care (OR = 1.7, 95% CI = 1.2–2.4,  $p$ -value = 0.004).

Regarding the importance of having a patient council in addition to a representative, we found no statistical association with health status but did find a statistically significant association with self-reported healthcare utilization ( $p = 0.001$ ). Respondents who reported having received care five or more times in the past six months were more likely to believe having patient council in addition to a patient representative mattered “some” or “a lot” compared to those who have not obtained any care (OR = 2.2, 95% CI = 1.5–3.2,  $p$ -value < 0.001).

We examined, but did not find, statistically significant evidence that health status and healthcare utilization interacted. That is, the effect of respondents’ health status on the perceived importance of patient representation did not depend upon their healthcare utilization.

## Importance of Patient Representation and Factors Considered

We found no statistical association between self-reported health status or healthcare utilization and the factors respondents considered when assessing the importance of patient representation. However as Table 2 shows, respondents who selected options that suggested a desire for more information (either about the board’s decisions or about the representative)

or that were skeptical (because the representative would be unable to influence the board) appeared less likely to report that having a patient representative or a council matters “a lot.”

### Interacting with Patient Representatives

Most (80%) of respondents reported that they were “very likely” or “likely” to use at least one way of learning about or interacting with a patient council. Less enthusiasm was evident for more “active” means of interaction (e.g., small group meetings, town halls, or individual meetings with members of a patient council) than for more “passive” means, such as newsletters or websites (Table 3). We found a statistically significant association between self-reported health status and the response that an individual would be very likely or likely to use e-mail ( $p = 0.001$ ) or a website ( $p = 0.004$ ) to communicate with the council. We found no other statistically significant associations between health status or healthcare utilization and preferred ways of learning about the council.

### Qualitative Findings

Overall, 326 of 3,061 (11%) respondents provided free-text responses to the question about what factors they considered when assessing how much it matters to them that JMAP has a patient on the board. We determined that 242 of 326 statements were related to our topic of interest; the others were either unrelated to patient representation or could not be definitively determined as related. Table 4 summarizes these findings and includes coding frequencies while recognizing that coding frequencies may not correlate with importance. (A comprehensive summary with example quotations is provided as Appendix B to this article, published online as Supplemental Digital Content at <http://links.lww.com/JHM/A32>) These qualitative findings supplemented our survey findings in several important ways.

First, respondents offered additional rationales behind patient representation not captured in our original hypothesized list, suggesting ways ACOs’ required patient engagement can be successful. They also strengthened the rationale behind JMAP’s decision to have a beneficiary advisory council. One respondent also noted that the patient voice could “help you market the program,” perhaps suggesting how patient representatives could increase awareness of the ACO and help it achieve its goals.

Second, respondents shed light on our observed relationship that those reporting worse health status were less likely to consider patient representation as important. As one respondent succinctly noted, “When your [sic] sick, these stuff is meaningless to you.”

Third, respondents offered insights into what the broader patient population wants to know about patient representation and ACO board decision-making. Many respondents wanted additional information, for example, about who is on the governance board, how decisions made by the board affect them, how representatives were chosen, and how to connect with patient representatives.

Fourth, some respondents expressed skepticism about either the concept or practice of patient representation, with a number using the word “token” to reference a patient being chosen for public relations purposes, unable to influence board decisions, or unable to

represent the broader patient population. These respondents' comments stand in contrast to others, but they are nevertheless important.

Fifth, several of observed themes may appear to be in tension with each other. For example, several respondents included free-text responses along the lines of "It just makes sense to have a patient on the board. Of course she needs to be someone who is also knowledgeable about healthcare systems," or "Unless the patient is a doctor that understands medical terms and decisions, it makes no difference." We analyzed as possible keys to success. Yet the idea that a representative needs to have these characteristics to succeed can be in tension with another major theme in our analysis, which is that the representative should reflect diversity or be explicitly naïve about healthcare (as one respondent said, "Have an amateur on the board to ask questions doctors take for granted.").

Likewise, several respondents expressed sentiments that patient representatives should offer "general patient input" and avoid being "overly self-focused" (Table 4). Yet others thought that this was not possible ("one patient cannot represent all patients," Table 4), and some free-text and discrete survey items related the idea that a patient representative should represent an individual patient's own particular needs. These two conceptions—one of a general patient versus another expressing specific individual needs—may not always be consistent.

## Discussion

Our survey revealed that a vast majority of patients believe patient representation in healthcare organizations is important, for various reasons. Our findings offer lessons for the practice of patient representation in healthcare organization governance by suggesting tangible ways to improve the practice and policy of patient, family, and caregiver engagement in healthcare organizations.

Simultaneously, this study can be viewed as evaluating Medicare policy requirements. For instance, although Medicare requires patient notification regarding ACO participation (e.g., via clinic signage related to the ability to opt out of data sharing and publicly reported data), we found that only about half of respondents indicated that they were aware of the ACO. While this could partly reflect the effectiveness of mail outreach, it is also possible that some beneficiaries were attributed to the ACO after the initial start date; as notification requirements changed, they might not have had the opportunity to receive an initial outreach letter. Alternatively, a patient may be aware of ACO-related services but may view them as associated with their physician or the practice, rather than being linked to an ACO or other entity.

More germane to the primary objective of our study, Medicare requires its ACOs to have, at a minimum, one beneficiary on the ACO governance board. We were able to evaluate patients' beliefs about the importance of this minimum requirement as well as about having a patient council in addition to it.

We found that having patient representation mattered more to patients who reported higher healthcare utilization and who reported being healthier. Intuitively, those who interact more



with the health system might be expected to care more about patient representatives, and those who experience ill health may be more concerned about their own illness rather than patient representation. Intriguing as these findings are, and despite their statistical significance, we emphasize that differences between groups were small. For instance, about 50% of respondents reporting poor or fair health stated that it matters “a lot” that they had a patient on the board compared to about 55% of respondents reporting very good or excellent health.

Interestingly, the minority of respondents to whom patient representations did not seem to matter appeared more likely to express skepticism about the concept or practice of patient representation (e.g., about the power of patient representatives to influence decisions) or to express wanting to know more about the board and patient representation. This is an important opportunity for ACOs and other healthcare organizations. By making patient engagement via patient representatives, advisers, or PFACs more visible, and by providing those representatives with the time and resources necessary to empower that visibility (Health Research and Educational Trust, 2015; Jeppson & Thomas, 1995; Niehaus et al., 2017; Institute for Patient- and Family-Centered Care, 2013; Agency for Healthcare Research and Quality, 2013), skeptical beliefs about patient engagement could be changed.

Our findings also identified important possible tensions experienced in the practice of engaging patients in healthcare governance. One is the possible tension between having an authentic patient voice and ensuring that a patient representative is both comfortable in the board setting and knowledgeable about health systems. Fortunately, this tension is not inexorable; it can be mitigated by training all board members. A second possible tension is between whether patient representatives might be overly “self focused” rather than representing patients in general (Williamson, 2014). This tension may reflect disagreement about the fundamental role of the patient representative.

We highlight two potential improvements to the practice of patient representation evident from our findings. First, patients in general believe that there should be more voices, rather than fewer, involved in healthcare organization governance; second, these voices should be diverse. This was reflected in our qualitative findings, where respondents expressed that more than one patient should be involved (or more negatively expressed that one patient cannot possibly represent all patients). Moreover, respondents offered recommendations regarding rotating representatives, ensuring diversity, or creating a council in addition to a board representative (in line with what JMAP already does). Such recommendations support the idea of including more patient voices.

Second, the vast majority of respondents wanted a way to connect with, or learn about, their patient representatives. Although most preferred more passive methods (e.g., newsletters or websites), some desired more active interactions in small group settings. These could be pursued as means to aid the goals of transparency and to increase patient awareness of how their voices can be heard.

Lastly, we propose a hypothesis for future research. About half of our respondents believed that having patient representatives could improve trust in the healthcare organization.

Because distrust of healthcare systems and organizations can be associated with poor health outcomes (independently of distrust in healthcare professionals) (Armstrong, 2018; Armstrong et al., 2006; Boulware, Cooper, Ratner, LaVeist, & Powe, 2003; Ozawa & Sripad, 2013), meaningful and trustworthy engagement of patients in healthcare organizations could address this problem. However, the exact characteristics that make this type of engagement truly trustworthy remain understudied, and deserve greater attention.

### Study Limitations

Our study has limitations. It was conducted in a single ACO, so its findings may not apply to others. However, little reason exists to think that the broad concepts here cannot be generalized to other ACOs, healthcare organizations, or other patient populations, thereby informing PFACs and patient engagement practices broadly. Our response rate was low and budgetary limitations prevented multiple contact attempts, creating a potential for response bias. Individuals who responded, for example, might care more about patient representation than other patients. Because we deliberately did not collect other demographic or socioeconomic variables, we cannot compare respondents to the broader patient population. Finally, we relied on self-reported health status and health utilization and could not verify these with claims or other objective data.

### Conclusion

By working with the Beneficiary Advisory Council of an ACO, our study demonstrates that most patients believe engagement via patient representatives and councils is important. For patient engagement via organizational representation to be meaningful, asking key questions about what it means to be a representative and determining the optimal number of representatives, how best to identify them, how to achieve diversity (and along what dimensions), among many other questions, must be answered. To achieve important, patient-desired outcomes such as improved trust in the healthcare system, patients broadly need the opportunity to be aware of and—if they choose—to interact with their representatives.

### Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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**Table 1.**

## Characteristics of Survey Respondents and Views Regarding Representation

Characteristics	<i>n</i> (%) <i>N</i> = 3,061
Self-rated overall health	<i>N</i> = 3,014
Poor	81 (2.7%)
Fair	475 (15.8%)
Good	1,163 (38.6%)
Very good	1,008 (33.4%)
Excellent	287 (9.5%)
Use of care for physical or mental healthcare needs in past 6 months	<i>N</i> = 2,994
10 or more times	303 (10.1%)
5–9 times	582 (19.4%)
4 times	392 (13.1%)
3 times	381 (12.7%)
2 times	570 (19.1%)
1 time	460 (15.4%)
None	306 (10.2%)
Awareness about JMAP	<i>N</i> = 3,014
Yes	1,537 (51.0%)
No	1,477 (49.0%)
Means of awareness about JMAP	<i>N</i> = 3,014
Via mailing or signage or both	719 (23.9%)
From a member or several members of the medical team	642 (21.3%)
From mailing or signage and from a member or several members of the medical team	146 (4.8%)
Other	30 (1%)
How much it matters that JMAP has a patient on the board	<i>N</i> = 3,001
A lot	1,591 (53%)
Some	634 (21.1%)
Just a little	125 (4.2%)
Not at all	310 (10.3%)
Not sure	341 (11.4%)
How much it matters that JMAP has a beneficiary advisory council in addition to a patient on the board	<i>N</i> = 2,943
A lot	1,391 (47.3%)
Some	786 (26.7%)
Just a little	116 (3.9%)
Not at all	257 (8.7%)
Not sure	393 (13.4%)
Factors considered when answering how much it matters that JMAP has a patient on the board. *	<i>N</i> = 6,853
-Patients deserve a voice in the organization where they receive care	1,883 (64%)
-Having a patient on the board increases my trust that the organization put my needs first	1,361 (46%)
-I do not know enough about how the board's decision affect me to decide	1,121 (38%)
-I want to be sure my individual needs are represented on the board	957 (32.4%)

Characteristics	<i>n</i> (%) <i>N</i> = 3,061
-I need to learn more about the beneficiary who represents me to decide	681 (23%)
-A patient on the board is probably unable to influence decisions	416 (14.1%)
-Other statement	331 (1.2%)

*Note.* JMAP = Johns Hopkins Medicine Alliance for Patients.

\* Respondents could choose multiple factors.

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**Table 2.**

## Importance of Patient Representation and Factors Respondents Considered Regarding Patient Representation

Factors Considered Regarding Patient Representation	Importance of Patient Representation			
	How much it matters that JMAP has a patient on the board:		How much it matters that JMAP has a BAC in addition to a patient on the board:	
	A lot	Not at all	A lot	Not at all
Among respondents who considered the following statements:				
Patients deserve a voice	69% ***	5% ***	58% ***	4% ***
Patient on board increases my trust	76% ***	4% ***	65% ***	3% ***
I do not know enough about board decision-making	22% ***	15% ***	24% ***	13% ***
My individual needs must be represented	70% ***	5% ***	61% ***	4% ***
I need to learn about the representative.	41% ***	8%	39% ***	7%
The representative is probably powerless	31% ***	15% **	31% ***	10%
Other statement ( <i>see text for qualitative analysis</i> )	55%	15% **	52%	12%
<b>All respondents</b>	53%	10%	47%	9%

Note. JMAP = Johns Hopkins Medicine Alliance for Patients; BAC = Beneficiary Advisory Council

\*\*  
 $p < 0.05$ , in comparison with all respondents

\*\*\*  
 $p < 0.001$ , in comparison with all respondents

**Table 3.**

Likelihood Survey Respondents Would Use the Following Ways of Learning About Patient Representatives on a Council

Ways of Learning About BAC ( <i>N</i> = 3,061)	Very Likely or Likely	Neutral	Unlikely or Very Unlikely
Any way	80% ( <i>n</i> = 2,461)	10% ( <i>n</i> = 294)	6% ( <i>n</i> = 188)
Newsletter from the council	61% ( <i>n</i> = 1,871)	14%	14%
E-mail	49% ( <i>n</i> = 1,506)	14%	21%
Website	39% ( <i>n</i> = 1,187)	16%	22%
Suggestion box in doctor's office	29% ( <i>n</i> = 885)	22%	30%
Small group with council members and patients (e.g., over coffee)	22% ( <i>n</i> = 666)	20%	39%
Town hall meeting	15% ( <i>n</i> = 455)	20%	44%
Meeting with members of the council	15% ( <i>n</i> = 451)	22%	42%

*Note.* BAC = Beneficiary Advisory Council.



**Table 4.**

Summary of Qualitative Findings Related to Factors Respondents Considered When Assessing Patient Representation

Coded Theme	Coding Frequency
Things patients want to know	33
What are the representative's qualifications?*	12
I would like more information in general	7
What does the board do?*	6
Who is on the board?*	3
How can I connect with the representatives?	2
How was the representative selected?*	3
Keys to success	79
There should be more than one patient representative	39
Success depends on who the patient representative is	20
Patient representatives should be representative of the population served	3
Patient representatives should reflect diversity	2
Transparency	5
Ensure the patient representative connects with patients	3
Ensure full participation of the representatives	2
Rotate patient representatives after a fixed term	4
Patients should choose their patient representative	1
A patient representative is important	66
Offers general patient input	60
Is critical to the success of the ACO	3
Having some representation is better than none	1
Helps represent my needs*	1
Improves trust*	1
Expressing skepticism about patient representation, in concept or in practice	64
Representatives may be unable to influence the board*	16
One patient cannot represent all patients	13
Being on a board is not something for a patient to do	8
A patient representative may be overly self-focused	4
As an individual, I do not need this	9
It would be better to spend resources elsewhere	10
The representative may be chosen for public relations purposes	4
Not coded	84
Total	326

*Note.* Rows with \* relate to the six postulated factors reported in Table 1; rows without \* therefore represent additional insights. ACO = accountable care organization.