Update on Patient Engagement in Healthcare System-level Decision-making: Commentaries from Scholars and Patients’ Perspectives

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Acknowledgments/Gratitude

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• Johns Hopkins Medicine Alliance for Patients, LLC (JMAP), an ACO participating in the CMS Medicare Shared Savings Program

• Anonymous reviewers and those provided public commentaries

• JMAP Beneficiary Advisory Council (BAC): 8 JMAP patient-volunteers

• JMAP patients and their caregivers participated in the survey and the focus groups

• Center for Health Services and Outcomes Research
Outline

• Recapitulation: measuring P2C2 engagement in healthcare system-level decision-making
• Overview of 5 scholarly commentaries
• Results of JMAP general patient survey on P2C2 engagement
• Results of 5 focus patient group interviews: P2C2 engagement model
• Next Steps: Practice, Policy & Research Implications
Recapitulation
Recapitulation


Vadim Dukhanin¹, Rachel Topazian²,³, Matthew DeCamp³,⁴*
Recapitulation

We defined patient, public, consumer, and community (P2C2) engagement\[^1\] as a continuous systematic effort to incorporate the needs, values, and preferences of the P2C2 engagement participants into decision-making.

In those activities, P2C2 engagement participants are involved as stakeholder representatives of their constituents, rather than as individuals. No episodic or one-off engagement.

P2C2 engagement in organization- or system-level healthcare decision-making not engagement in patients’ personal medical decisions.

Setting: clinical care delivery, healthcare administration, (NOT) research, public health, or health promotion.
Recapitulation

Developed a comprehensive Taxonomy of 116 possible engagement metrics grouped into distinct domains and subdomains (44 outcomes metrics in three domains, 72 process metrics in four domains).

Identified 23 tools that could be used to evaluate P2C2 engagement.

There was no perfect tool: they varied in their coverage of Taxonomy, in the method used and intended evaluators.

Parts of Taxonomy were absent from all tools.
Recapitulation

We suggested (in Discussion) what might be essential components of evaluation and how to advance evaluation. These suggestions were tailored to a health care system level of maturity for P2C2 engagement, inspired by the Arnstein’s “ladder of participation.”[2]

Noted a need for a consensus-building process to identify and disseminate core metrics. Stated that the taxonomy provides a starting point for that process that itself must include P2C2 participants.

Called for:

- comparative evaluation of the metrics (e.g., to find the best way to measure representativeness)
- additional research to better understand the validity and reliability of tools and metrics in different contexts
- development of new tools
Commentary 1

**Shoshanna Sofaer**: American Institutes for Research, Washington, DC & Graduate School of Public Health and Health Policy, City University of New York, NYC.

“To begin, it is important to recognize that at the core of this study [Dukhanin et al.] is a commitment by the authors to the idea of meaningful participation in decision-making by individuals who are served by healthcare organizations.”[3]

“Typically, however, whoever funds the evaluation calls that tune, which in turn heavily impacts the choice of metrics.”[3]

“Furthermore, it is important that these metrics not be reduced to a “check the box” approach...”[3]

“... if a healthcare organization did not in fact implement patient engagement in a genuine and complete way, then it is not fair to say patient engagement is useless...”[3]
Sofaer helpfully reframes our taxonomy into a logic model that is attentive to realistic timelines and the stage of maturation of a particular healthcare organization or engagement strategy.
Commentary 2

Antoine Boivin: Center of Excellence on Partnership with Patients and the Public, University of Montreal Hospital Research Center, Montreal, Canada & Canada Research Chair in Patient and Public Partnership.

“An original contribution of Dukhanin’s review is its proposed taxonomy of evaluation metrics.”[4]

“In order to fully contribute to the “art and science” of engagement, greater collaboration is required between engagement practitioners and scientists, while keeping in mind the ethical, epistemological and political tensions that are inherent to patient engagement.”[4]

Boivin suggests re-structuring of the taxonomy into structures, processes and outcomes and recommends adapting it to different P2C2 engagement methods.
Commentary 3

Samira Rahimi, Hervé Zomahoun, France Légaré: McGill University, Montreal, Canada, Université Laval, Quebec, Canada & Canada Research Chair in Shared Decision Making and Knowledge Translation.

“We used this review as a launchpad to further evaluate the psychometric properties of the identified tools, and as the authors themselves pointed out, the psychometric reporting was poor."[5]

“the taxonomy of possible engagement evaluation metrics developed by Dukhanin and colleagues could be validated with international experts, including with patient evaluators and public representatives, using group-based approaches such as a Delphi-type exercise to produce a consensually agreed structured taxonomy.”[5]
Commentary 4

Zackary Berger: Division of General Internal Medicine, Johns Hopkins School of Medicine and Johns Hopkins Berman Institute of Bioethics.

“Whether SDM at the systems level means merely encouraging SDM at the patient-provider level, or if – in addition – this implies sharing of systems-level decisions with patients, is a question that does not yet have a clear answer.”[6]

Berger asks us to consider the connection between organizational- or system-level engagement and the engagement of individual patients with their clinicians and their healthcare. More research is required to address this question.
Commentary 5

Marion Danis: Head of the Section on Ethics and Health Policy in the Department of Bioethics at the Clinical Center of the National Institutes of Health, Bethesda, MD.

“Theyir taxonomy offers a useful, systematic evaluation framework that can be applied to the various types of public engagement …”[7]

Danis introduces an important additional dimension to P2C2 engagement evaluation: its timing. Danis is correct in noting that the results of any evaluation can be affected by when either the evaluation or the engagement itself occurs. The need to consider the political context of any engagement is critically important; if significant parts of organizations’ goals are determined by policy requirements, then the potential of P2C2 engagement participants to exert control and influence may be limited. In our view, this is an argument for engaging public in the creation of these policies.
Our Response

http://ijhpm.com
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Our Response

Correspondence


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Our Response

All 5 commentaries emphasized that any P2C2 engagement evaluation should be guided by its fundamental goals or underlying theory. We agreed\[8\], however, our more recent research indicates that general patient population are just as concerned about “who” their representatives are and how they can interact with them as they are about the “why” of engagement.

Agreed regarding the need for those working in engagement to reach across engagement contexts.

The vibrant discussion motivated by our systematic review is exactly what it is needed to generate and maintain momentum that will ensure successes of both theory and practice of P2C2 engagement.
JMAP General Patient Survey
Objective & Setting

Most studies of patient representatives and patient councils have focused on the patients, health care professionals, and administrators who are directly involved.

Objective\cite{9}: to assess the importance of patient representation in a general patient population; to seek patients’ views of patient representation and patient councils; to determine whether these views were associated with patients’ health or care utilization.

Conducted within the Johns Hopkins Medicine Alliance for Patients, LLC (JMAP), an ACO in the CMS Medicare Shared Savings Program. JMAP includes nearly 3000 physicians and health care providers in the greater Baltimore and Washington, DC region; JMAP is responsible for the care of approximately 40,000 Medicare fee-for-service beneficiaries.
Objective & Setting

Regional characteristic

- Greater Washington Region: 1088
- Greater Baltimore Region: 866
- Mid-Maryland Region: 862
- Unknown Region: 245
- Unknown Region: 1475

JMAP Physician groups

- **JHCP** | Johns Hopkins Community Physicians
- **PPA** | Potomac Physician Associates
- **JHU** | Johns Hopkins University School of Medicine
- **CMP** | Columbia Medical Practice
- **CSCM** | Johns Hopkins Regional Physicians (Cardiovascular Specialists of Central Maryland)
Objective & Setting

As a Medicare Shared Savings Program ACO, JMAP must include a patient representative on its governance board. JMAP in collaboration with its first patient representative created a model where this patient on the board represents the perspective of a 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 health care. In this role, the BAC reviews policies, advises on educational materials, and contributes patients’ views at regular JMAP meetings.

JMAP created a mailed outreach to all JMAP patients in 2017 to increase awareness of JMAP and the services available. This mailer included a colored informational brochure about JMAP and about the BAC. We took advantage of this and enclosed an accompanying survey.
Methods

A 2-page survey to 31,687 Medicare beneficiaries attributed to JMAP using the mailing address in EHRs. Some households received more than one survey. Provided a stamped envelope to send to a survey vendor. Respondents chose to be anonymous or include contacts. May-August 2017.

Survey was developed based on the systematic literature review[1] and closely working with the BAC.

CAHPS item on self-reported health status and adapted item for self-reported health care utilization.

Awareness: whether and how they had heard about JMAP.

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 demanding and/or intrusive.
Methods

Main outcomes: importance of (I) having a patient representative on the board; (II) having a patient council in addition to a representative (4-point Likert scale).

Inquired about the factors respondents considered when thinking about this importance (6 postulated factors + free-text box).

Whether or how patients might be interested in connecting with their patient representatives choosing among 7 putative ways of interacting with patient representatives (5-point Likert scale, from “very likely to use” to “very unlikely to use”).

[JMAP survey part] elicited patients’ perspectives on which health care services they would be likely to use within JMAP.
Methods

Mixed-methods.

Pearson’s chi-squared tests and logistic regressions.

For open-ended questions, an emergent thematic qualitative content analysis. A preliminary code book developed by a BAC member. A second research team member (MD) used this codebook to re-analyze the data, iteratively modifying primary codes and adding secondary codes. This codebook was used independently by a third member of the research team (VD) to code all the responses. Disagreements between codes at this point were resolved by consensus and codes were rearranged thematically into a final codebook.
Results

We received 3,061 surveys yielding a response rate of 9.6%.

Compared to the general Medicare population, respondents were similar in terms of the range of reported health care utilization, but included fewer individuals with self-reported “poor” or “fair” health status.

51% of the respondents reported awareness of JMAP.

53% of the respondents believed it matter “a lot” that there was a patient representative on the JMAP governance board (74% + it mattered “some”).

47% believed it matter “a lot” that there was a patient council in addition to the representative (74% + it mattered “some”).
Results

The factors considered when thinking about the importance a patient representative on the JMAP governance board:

“patients deserve a voice in the organization where they receive care” (64%).

“having a patient on the [governance] board increases my trust that the organization puts my needs first” (46%).

Respondents wanted to learn more, either about the board itself (38%) or about the patient representative (23%).

“wanted to be sure their individual needs are represented on the board” (32%).

“a patient on the board is probably unable to influence decisions” (14%).
## Results

### Characteristics

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>n</th>
<th>N = 3,061</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Self-rated overall health</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor</td>
<td>81 (2.7%)</td>
<td>N = 3,014</td>
</tr>
<tr>
<td>Fair</td>
<td>475 (15.8%)</td>
<td></td>
</tr>
<tr>
<td>Good</td>
<td>1,163 (38.6%)</td>
<td></td>
</tr>
<tr>
<td>Very good</td>
<td>1,008 (33.4%)</td>
<td></td>
</tr>
<tr>
<td>Excellent</td>
<td>287 (9.5%)</td>
<td></td>
</tr>
</tbody>
</table>

### Utilization of care for physical or mental health care needs in past 6 months

<table>
<thead>
<tr>
<th>Frequency</th>
<th>n</th>
<th>N = 2,994</th>
</tr>
</thead>
<tbody>
<tr>
<td>10 or more times</td>
<td>303 (10.1%)</td>
<td></td>
</tr>
<tr>
<td>5-9 times</td>
<td>582 (19.4%)</td>
<td></td>
</tr>
<tr>
<td>4 times</td>
<td>392 (13.1%)</td>
<td></td>
</tr>
<tr>
<td>3 times</td>
<td>381 (12.7%)</td>
<td></td>
</tr>
<tr>
<td>2 times</td>
<td>570 (19.1%)</td>
<td></td>
</tr>
<tr>
<td>1 time</td>
<td>460 (15.4%)</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>306 (10.2%)</td>
<td></td>
</tr>
</tbody>
</table>

### Awareness about JMAP

<table>
<thead>
<tr>
<th>Awareness</th>
<th>n</th>
<th>N = 3,014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>1,537 (51.0%)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>1,477 (49.0%)</td>
<td></td>
</tr>
</tbody>
</table>

### Importance of Patient Representation

<table>
<thead>
<tr>
<th>Importance of Patient Representation</th>
<th>n</th>
<th>N = 3,061</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>How much it matters to the respondents that JMAP has a patient on the board</strong></td>
<td></td>
<td>N = 3,001</td>
</tr>
<tr>
<td>A lot</td>
<td>1,591 (53%)</td>
<td></td>
</tr>
<tr>
<td>Some</td>
<td>634 (21.1%)</td>
<td></td>
</tr>
<tr>
<td>Just a little</td>
<td>125 (4.2%)</td>
<td></td>
</tr>
<tr>
<td>Not at all</td>
<td>310 (10.3%)</td>
<td></td>
</tr>
<tr>
<td>Not sure</td>
<td>341 (11.4%)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Importance of Patient Representation</th>
<th>n</th>
<th>N = 2,943</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>How much it matters to the respondents that JMAP has a Beneficiary Advisory Council in addition to a patient on the board</strong></td>
<td></td>
<td>N = 2,943</td>
</tr>
<tr>
<td>A lot</td>
<td>1,391 (47.3%)</td>
<td></td>
</tr>
<tr>
<td>Some</td>
<td>786 (26.7%)</td>
<td></td>
</tr>
<tr>
<td>Just a little</td>
<td>116 (3.9%)</td>
<td></td>
</tr>
<tr>
<td>Not at all</td>
<td>257 (8.7%)</td>
<td></td>
</tr>
<tr>
<td>Not sure</td>
<td>393 (13.4%)</td>
<td></td>
</tr>
</tbody>
</table>

### Factors considered when answering how much it matters to the respondents that JMAP has a patient on the board

- 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%)
- 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 (11.2%)
Results

No statistical association between awareness of JMAP and perceived importance of patient representatives or a council.

Heathier respondents and those who received care five or more times in the past six months were more likely to believe having a patient on the board mattered “some” or “a lot”.

As for importance of having a patient council in addition to a representative, we found no statistical association with health status but it mattered more for those with higher utilization.

No health status and health care utilization interaction.

No statistical association between self-reported health status or utilization and the factors respondents considered when assessing the importance of patient representation.

For those desiring more information or skeptical, having a patient representative or a council mattered less (Table).
## Results

<table>
<thead>
<tr>
<th>Factors considered regarding patient representation [Patients’ views]</th>
<th>Importance of patient representation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Among respondents who considered the following statements:</td>
<td>How much it matters that JMAP has a patient on the board:</td>
</tr>
<tr>
<td>Patients deserve a voice.</td>
<td><strong>A lot</strong></td>
</tr>
<tr>
<td>Patient on board increases my trust.</td>
<td>69%***</td>
</tr>
<tr>
<td>I do not know enough about board decision making.</td>
<td>76%***</td>
</tr>
<tr>
<td>My individual needs must be represented.</td>
<td>22%***</td>
</tr>
<tr>
<td>I need to learn about the representative.</td>
<td>70%***</td>
</tr>
<tr>
<td>The representative is probably powerless.</td>
<td>41%***</td>
</tr>
<tr>
<td>Other statement (see qualitative analysis)</td>
<td>31%***</td>
</tr>
<tr>
<td>All respondents</td>
<td>55%</td>
</tr>
</tbody>
</table>

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Results

Qualitative analysis - 1

326 (out of 3,061, 11%) free-texts about what factors they considered when assessing how much it matters that JMAP has a patient on the board; 242 were related to the topic.

Offered additional rationales behind patient representation and strengthened the rationale behind having a beneficiary advisory council, e.g., “help you market the program”

Shed light on the finding that for those reporting worse health patient on the board was less important. “When your sick, these stuff is meaningless to you.” [sic]

Respondents wanted information 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.
Results

Qualitative analysis - 2

Skepticism about either the concept or practice of patient representation, with a number using the word "token"/"PR".

“... needs to be someone who is also knowledgeable about health care” / “Unless the patient is a doctor that understands medical terms and decisions, it makes no difference”

vs. [Tension 1]

“Have an amateur on the board to ask questions doctors take for granted”.

Patient representative should offer “general patient input” and avoid being “overly self-focused”

vs. [Tension 2]

a patient should represent their own particular needs / “one patient cannot represent all patients”
## Results

<table>
<thead>
<tr>
<th>Coded theme</th>
<th>Coding frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Things patients want to know</strong></td>
<td></td>
</tr>
<tr>
<td>What are the representative’s qualifications?*</td>
<td>12</td>
</tr>
<tr>
<td>I would like more information in general</td>
<td>7</td>
</tr>
<tr>
<td>What does the board do?*</td>
<td>6</td>
</tr>
<tr>
<td>Who is on the board?*</td>
<td>3</td>
</tr>
<tr>
<td>How can I connect with the representatives?</td>
<td>2</td>
</tr>
<tr>
<td>How was the representative selected?*</td>
<td>3</td>
</tr>
<tr>
<td><strong>Keys to Success</strong></td>
<td></td>
</tr>
<tr>
<td>There should be more than one patient representative</td>
<td>39</td>
</tr>
<tr>
<td>Success depends on who the patient representative is</td>
<td>20</td>
</tr>
<tr>
<td><strong>Transparency</strong></td>
<td></td>
</tr>
<tr>
<td>Ensure full participation of the representatives</td>
<td>2</td>
</tr>
<tr>
<td>Rotate patient representatives after a fixed term</td>
<td>4</td>
</tr>
<tr>
<td><strong>A patient representative is important</strong></td>
<td></td>
</tr>
<tr>
<td>Offers general patient input</td>
<td>66</td>
</tr>
<tr>
<td><strong>Expressing skepticism about patient representation, in concept or in practice</strong></td>
<td></td>
</tr>
<tr>
<td>Representatives may be unable to influence the board*</td>
<td>16</td>
</tr>
<tr>
<td>One patient cannot represent all patients</td>
<td>13</td>
</tr>
<tr>
<td>Being on a board is not something for a patient to do</td>
<td>8</td>
</tr>
<tr>
<td>A patient representative may be overly self-focused</td>
<td>4</td>
</tr>
<tr>
<td>As an individual, I do not need this</td>
<td>9</td>
</tr>
<tr>
<td>It would be better to spend resources elsewhere</td>
<td>10</td>
</tr>
<tr>
<td>The representative may be chosen for public relations purposes</td>
<td>4</td>
</tr>
<tr>
<td><strong>Not Coded</strong></td>
<td></td>
</tr>
<tr>
<td>TOTAL</td>
<td>326</td>
</tr>
</tbody>
</table>
## Results

Among our Medicare surveyed population, 80% 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>
<thead>
<tr>
<th>Ways of learning about BAC (N = 3061)</th>
<th>Very Likely or Likely</th>
<th>Neutral</th>
<th>Unlikely or Very unlikely</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any way of learning</td>
<td>80% (n = 2461)</td>
<td>10% (n=294)</td>
<td>6% (n = 188)</td>
</tr>
<tr>
<td>Newsletter from the council</td>
<td>61% (n = 1871)</td>
<td>14%</td>
<td>14%</td>
</tr>
<tr>
<td>By email</td>
<td>49% (n = 1506)</td>
<td>14%</td>
<td>21%</td>
</tr>
<tr>
<td>By a website</td>
<td>39% ( n = 1187)</td>
<td>16%</td>
<td>22%</td>
</tr>
<tr>
<td>A suggestion box in my doctor's office</td>
<td>29% (n = 885)</td>
<td>22%</td>
<td>30%</td>
</tr>
<tr>
<td>In a small group with council members and patients, such as over coffee</td>
<td>22% (n = 666)</td>
<td>20%</td>
<td>39%</td>
</tr>
<tr>
<td>In a town hall meeting</td>
<td>15% (n = 455)</td>
<td>20%</td>
<td>44%</td>
</tr>
<tr>
<td>By meeting with members of the council</td>
<td>15% (n = 451)</td>
<td>22%</td>
<td>42%</td>
</tr>
</tbody>
</table>
Status


Patients’ Views About Patient Engagement and Representation in Healthcare Governance

Matthew DeCamp, MD, PhD, assistant professor, Johns Hopkins Berman Institute of Bioethics and Division of General Internal Medicine, Johns Hopkins University, Baltimore, Maryland; Vedim Dukhanin, MD, research associate, Center for Health Services & Outcomes Research, Department of Health Policy and Management, Johns Hopkins Bloomberg School of Public Health; Lindsay C. Hebert, manager, population health program administration, Johns Hopkins HealthCare; Sarah Himmelrich, director, accountable care operations, Office of Johns Hopkins Physicians; Scott Feeser, MD, office medical director, Johns Hopkins Community Physicians, Remington Internal Medicine, and medical director, Johns Hopkins Medical Alliance for Patients (JMAP); and Scott A. Berkowitz, MD, senior medical director, accountable care, Office of Johns Hopkins Physicians, executive director, JMAP, and associate professor, Division of Cardiology, Johns Hopkins School of Medicine

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

For more information regarding the concepts in this article, contact Dr. DeCamp, now at the University of Colorado, at matthew.decamp@ucdenver.edu. Supplemental digital content is available for this article. The direct URL citation appears in the printed text and is provided in the HTML and PDF versions of this article on the journal’s website (www.jhmonline.com).

The authors declare no conflicts of interest.

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Other Results

[JMAP survey part] elicited patients’ perspectives on which health care services they would be likely to use within JMAP.


The survey revealed:
(I) Opportunities to increase awareness of JMAP and available services;
(II) Low survey response rate and heterogeneity in patient’s perspectives warrants a more continuous approach to incorporating patients’ views in value-based quality improvement priority-setting;
(III) conducting surveys and other outreach projects that inform patient advisory councils (e.g., the JMAP BAC) has a vast potential to bring patients’ voices into prioritizing quality improvement activities.
BACKGROUND
Accountable care organizations (ACOs) and other recent health care reforms seek to improve the value of health care delivery by rewarding the provision of high quality care at reduced cost. Value in health care can be defined from different perspectives, including those of society, payers, health care organizations, and patients. Value-based quality improvement (QI) activities are likely to be more successful and patient-centered when they align with expressed needs and preferences of patients.

One way to assess these needs and preferences is via patient surveys that inform patient advisory bodies in QI priority-setting.

Johns Hopkins Medicine Alliance for Patients, LLC (JMAP) is Johns Hopkins Medicine’s (JHM) Medicare Shared Savings Program Accountable Care Organization (ACO). JMAP represents a collaboration of participating providers, including all JHM physicians, 5 JHM hospitals in DC and Maryland, and 3 independent practices in Howard and Montgomery Counties, MD. JMAP leverages existing infrastructure and population health analytics, in collaboration with Johns Hopkins HealthCare LLC, a managed care organization.

OBJECTIVE
As a part of continuous patient-centered value-based QI, we sought to elicit patients’ perspectives on which health care services they would be likely to use within a Medicare accountable care organization, JMAP.

METHODS
From May-July 2017, we conducted a mail-based survey of 31,687 Medicare beneficiaries attributed to JMAP with a valid mailing address. Respondents were provided an addressed, stamped envelope to mail surveys to a 3rd party survey vendor.

The 2-page survey included:
• Previously validated survey items
• De novo items developed in collaboration with JMAP’s Beneficiary Advisory Council (BAC), a volunteer group of JMAP patients that advises JMAP on its activities.

We hypothesized that self-reported health status, health care utilization, and awareness of JMAP might affect respondents’ preferences to which health care services they would likely use. For statistical tests of association, Pearson’s chi-squared test was used. Response rate (RR) was calculated using the RR2 definition of the American Association for Public Opinion Research.

This study was reviewed and declared exempt by the Johns Hopkins Medicine Institutional Review Board.

RESULTS
3,061 beneficiaries responded (RR, 9.6%). Respondents’ self-reported health care utilization was consistent with the general Medicare population, but respondents reporting “poor” or “fair” overall health status were underrepresented (see Table).

Characteristics of JMAP survey respondents

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-rated overall health</td>
<td></td>
</tr>
<tr>
<td>Poor</td>
<td>2.7%</td>
</tr>
<tr>
<td>Fair</td>
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</tr>
<tr>
<td>Good</td>
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</tr>
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<td>Excellent</td>
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</tr>
<tr>
<td>Utilization of care for physical or mental health care needs in past 6 months #1</td>
<td></td>
</tr>
<tr>
<td>5 or more times</td>
<td>29.5%</td>
</tr>
<tr>
<td>1-4 times</td>
<td>60.3%</td>
</tr>
<tr>
<td>None</td>
<td>10.2%</td>
</tr>
<tr>
<td>Awareness about JMAP</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>51.0%</td>
</tr>
<tr>
<td>Primary care provider has talked with a respondent about available services</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>23.9%</td>
</tr>
</tbody>
</table>

Over half of respondents (51%) were aware of JMAP. Among these:
• 47% reported learning of JMAP through mailings or clinic signage
• 42% reported learning via their medical care team.

The top two proposed services/value-based QI respondents would be “likely” or “very likely” to use were (see Table, next panel):
• Access to urgent appointments with specialists (81%)
• Care coordination services (72%)

For some queried services, respondents held split opinions:
• While nearly half (44%) of respondents were “unlikely” or “very unlikely” to use video visits with providers (the least preferred potential service), 30% would be “likely” or “very likely” to use those video visits.
• Similar bimodal distributions were observed regarding home-based self-monitoring devices, behavioral therapy in primary care offices, and pharmacist support.

Bivariate analysis revealed the following statistically significant findings:
• Those who had talked with their primary care provider about available services more often reported being “likely” or “very likely” to use care coordination services (76% vs. 71%), behavioral therapy in primary care offices (57% vs. 45%), and pharmacist support services (62% vs. 52%).
• Those whose health status was fair or poor more often reported being “likely” or “very likely” to use care coordination services (74.9% vs. 70.6%) and behavioral therapy in primary care offices (54.1% vs. 44.7%).
• Those who had received health care services 5 or more times in the past 6 months more often reported being “likely” or “very likely” to use care coordination (74.5% vs. 67.6%) and urgent appointment with specialists (83.2% vs. 76.4%).

CONCLUSIONS
Eliciting patients’ direct preferences regarding the types of health care programs they would be likely to use is feasible and can help ensure that value-based QI are consistent with patients’ values. Our survey revealed:
• Opportunities to increase awareness of JMAP and available services
• Broad support for some commonly used QI activities, such as care coordination and urgent access to specialty care
• Mixed opinions regarding certain QI activities, such as video visits and behavioral therapy in primary care offices

Low survey RR, consistent with other studies, and revealed heterogeneity in patient’s perspectives warrants a more continuous approach to incorporate patients’ views in value-based QI priority-setting.

CLINICAL IMPLICATIONS
Our findings have several clinical and programmatic implications:
• Working collaboratively to conduct surveys and other outreach projects that inform patient advisory councils (e.g., the JMAP BAC) has a vast potential to bring patients’ voices into prioritizing QI activities.
• More in-depth patients’ perspectives examination is needed to understand which patients may be eager to use some new programs (while others may not) and why patients hold these differing opinions.

Background
Accountable care organizations (ACOs) and other recent health care reforms seek to improve the value of health care delivery by rewarding the provision of high quality care at reduced cost. Value in health care can be defined from different perspectives, including those of society, payers, health care organizations, and patients. Value-based quality improvement (QI) activities are likely to be more successful and patient-centered when they align with expressed needs and preferences of patients. One way to assess these needs and preferences is via patient surveys that inform patient advisory bodies in QI priority-setting.

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• More in-depth patients’ perspectives examination is needed to understand which patients may be eager to use some new programs (while others may not) and why patients hold these differing opinions.
Takeaways

• There are indications that P2C2 engagement practice by a health system may be important to general patient population (P2C2)
• That importance might stem from patients views/beliefs regardless the context of a particular health system
• If patients are more informed about how P2C2 engagement is done, they might consider P2C2 engagement as even more important to them
• Patents might be very [individually] patient-centered when it comes to P2C2 engagement
• Unclear if the P2C2 engagement representatives should be self-focused or advocate for others and what is needed from them for that
JMAP General Patient Focus Groups
Objective & Setting

Uncertainty not only about the best ways to involve a broader patient body in P2C2 engagement but also about what exactly it means for patients to have their representative or advisor.

Objective: to obtain rich qualitative insights regarding what patients expect from P2C2 representatives in the context of patient and family advisory councils (PFAC).

Focus group participants were recruited from a sample of 429 JMAP patients (out of 3061, 14%) who had indicated their willingness to participate via the prior survey. Of these 429, 169 were identified as receiving their care within JMAP’s Greater Baltimore region.
Methods

Focused on Greater Baltimore region (focus groups were in Berman Institute of Bioethics’ building) as defined by provider location not patients’ addresses.

Participants were from Baltimore City, Baltimore and neighboring counties, and other outlying regions (e.g., individuals living in Pennsylvania who nevertheless receive care in Baltimore City).

Of 169 called in random order, 33 agreed to participate, 26 refused to participate, and 110 were not immediately reachable.

In addition, 9 informal caregivers (7 family members and 2 friends of participants) were recruited.

This recruitment yielded 42 participants.
Methods

5 focus groups, 8-9 participants each, July-September 2018, 120 minutes (2/3 P2C2 and 1/3 JMAP services).

Interview Guide: Example prompts

• Now that I’ve given you some background about JMAP BAC, can you tell me what your first impression or “gut reaction” is to this Council?
  • What do you want to know about this Council?
  • What do you think the purpose of the Council should be?
• Describe to me the ideal Council member.
  • How should Council members be chosen?
• What should the BAC do?
  • What should beneficiaries, like you all, expect of this group of patients?
Methods

Constant comparative technique of grounded theory. Open coding: transcripts and field notes to write research memos and potential themes. One researcher (VD) reviewed the transcript text line-by-line and developed a comprehensive set of codes using both descriptive and evaluative coding approaches.

Related codes were grouped based on the *a priori* research questions and emergent patterns in the data. A second researcher (MD) used this preliminary codebook to code transcripts independently.

Two researchers met and discussed code interpretation and reviewed half of the transcripts line-by-line, for coding accuracy.
Methods

Axial coding to begin postulating relationships among codes. Group-to-group validation, where a topic seemed important or of interest to all groups, was specifically sought.

The goal of this approach was to allow a core category and a theoretical model that connects the categories to emerge from the data.

To further ensure reliability, the researchers employed reflexivity techniques and engaged in member checking by sharing the full code book and the model with 20 focus group participants and with the BAC. Received comments were used to update and finalize the model.
## Results: Participants Characteristics

<table>
<thead>
<tr>
<th>Demographics</th>
<th>N = 42</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>35-44</td>
<td>1 (2%)</td>
</tr>
<tr>
<td>45-54</td>
<td>1 (2%)</td>
</tr>
<tr>
<td>55-64</td>
<td>6 (15%)</td>
</tr>
<tr>
<td>65-74</td>
<td>16 (38%)</td>
</tr>
<tr>
<td>75-84</td>
<td>16 (38%)</td>
</tr>
<tr>
<td>84-95</td>
<td>2 (5%)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>19 (45%)</td>
</tr>
<tr>
<td><strong>Race/ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td>11 (26%)</td>
</tr>
<tr>
<td>Caucasian</td>
<td>26 (62%)</td>
</tr>
<tr>
<td>Native American</td>
<td>1 (2%)</td>
</tr>
<tr>
<td>Other</td>
<td>4 (10%)</td>
</tr>
<tr>
<td><strong>Hispanic/Latino</strong></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>42 (100%)</td>
</tr>
<tr>
<td><strong>Educational attainment</strong></td>
<td></td>
</tr>
<tr>
<td>8th grade or less</td>
<td>1 (2%)</td>
</tr>
<tr>
<td>Some high school, not graduated</td>
<td>2 (5%)</td>
</tr>
<tr>
<td>High school graduate or GED</td>
<td>8 (19%)</td>
</tr>
<tr>
<td>Some college or 2-year degree</td>
<td>4 (10%)</td>
</tr>
<tr>
<td>4-year college graduate</td>
<td>11 (26%)</td>
</tr>
<tr>
<td>More than 4-year college degree</td>
<td>16 (38%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Demographics</th>
<th>N = 42</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Yearly personal income</strong></td>
<td></td>
</tr>
<tr>
<td>&lt;$25,000</td>
<td>13 (32%)</td>
</tr>
<tr>
<td>Between $25,000 and $50,000</td>
<td>9 (21%)</td>
</tr>
<tr>
<td>Between $50,000 - $100,000</td>
<td>10 (24%)</td>
</tr>
<tr>
<td>More than $100,000</td>
<td>9 (21%)</td>
</tr>
<tr>
<td>Not disclosed</td>
<td>1 (2%)</td>
</tr>
<tr>
<td><strong>Overall self-reported health</strong></td>
<td></td>
</tr>
<tr>
<td>Excellent</td>
<td>5 (12%)</td>
</tr>
<tr>
<td>Very good</td>
<td>11 (26%)</td>
</tr>
<tr>
<td>Good</td>
<td>17 (40%)</td>
</tr>
<tr>
<td>Fair</td>
<td>6 (15%)</td>
</tr>
<tr>
<td>Poor</td>
<td>2 (5%)</td>
</tr>
<tr>
<td>Not disclosed</td>
<td>1 (2%)</td>
</tr>
<tr>
<td><strong>Beneficiary reported being a Caregiver</strong></td>
<td></td>
</tr>
<tr>
<td>Yes, currently</td>
<td>11 (26%)</td>
</tr>
<tr>
<td>Yes, in the past</td>
<td>3 (7%)</td>
</tr>
<tr>
<td>No</td>
<td>28 (67%)</td>
</tr>
<tr>
<td><strong>Beneficiary reported Difficulty doing errands alone</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>6 (15%)</td>
</tr>
</tbody>
</table>
## Results: Participants Characteristics

### How much it matters to you that JMAP has a patient on the board

<table>
<thead>
<tr>
<th></th>
<th>All surveyed</th>
<th>Focus groups</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>A lot</strong></td>
<td>1,591 (53%)</td>
<td>23 (70%)</td>
</tr>
<tr>
<td><strong>Some</strong></td>
<td>634 (21.1%)</td>
<td>4 (12%)</td>
</tr>
<tr>
<td><strong>Just a little</strong></td>
<td>125 (4.2%)</td>
<td>-</td>
</tr>
<tr>
<td><strong>Not at all</strong></td>
<td>310 (10.3%)</td>
<td>3 (9%)</td>
</tr>
<tr>
<td><strong>Not sure</strong></td>
<td>341 (11.4%)</td>
<td>3 (9%)</td>
</tr>
</tbody>
</table>

**N = 3,001**

### How much it matters to you that JMAP has the BAC in addition to a patient on the board

<table>
<thead>
<tr>
<th></th>
<th>All surveyed</th>
<th>Focus groups</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>A lot</strong></td>
<td>1,391 (47.3%)</td>
<td>22 (71%)</td>
</tr>
<tr>
<td><strong>Some</strong></td>
<td>786 (26.7%)</td>
<td>1 (3%)</td>
</tr>
<tr>
<td><strong>Just a little</strong></td>
<td>116 (3.9%)</td>
<td>1 (3%)</td>
</tr>
<tr>
<td><strong>Not at all</strong></td>
<td>257 (8.7%)</td>
<td>2 (6%)</td>
</tr>
<tr>
<td><strong>Not sure</strong></td>
<td>393 (13.4%)</td>
<td>5 (16%)</td>
</tr>
</tbody>
</table>

**N = 2,943**

### Awareness about JMAP

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<tr>
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<tbody>
<tr>
<td><strong>Yes</strong></td>
<td>1,537 (51.0%)</td>
<td>18 (56%)</td>
</tr>
<tr>
<td><strong>No</strong></td>
<td>1,477 (49.0%)</td>
<td>14 (44%)</td>
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**N = 3,014**

### Factors considered (when answering how much it matters to you that JMAP has a patient on the board)

1. **Patients deserve a voice in the organization where they receive care**
   - **N = 1,883 (64%)**
   - **Focus groups: 23 (72%)**

2. **Having a patient on the board increases my trust that the organization put my needs first**
   - **N = 1,361 (46%)**
   - **Focus groups: 19 (59%)**

3. **I do not know enough about how the board’s decision affect me to decide**
   - **N = 1,121 (38%)**
   - **Focus groups: 10 (31%)**

4. **I want to be sure my individual needs are represented on the board**
   - **N = 957 (32.4%)**
   - **Focus groups: 17 (53%)**

5. **I need to learn more about the beneficiary who represents me to decide**
   - **N = 681 (23%)**
   - **Focus groups: 11 (34%)**

6. **A patient on the board is probably unable to influence decisions**
   - **N = 416 (14.1%)**
   - **Focus groups: 7 (22%)**
Results: Model

The primary product of this analysis is the model.

Because participants were largely unaware of the particular patient and family advisory council representing them (JMAP BAC), the model should be seen as an idealized conception of what patients might expect of a PFAC (a form of P2C2 engagement).

This model places a PFAC at the interface between a broader patient population and a health care organization, emphasizing the clear expectation expressed by participants that a PFAC should be communicating bidirectionally with both.
Patient and Family Advisory Council (PFAC)

**WHO?**

- **INDIVIDUAL PFAC MEMBER TRAITS**
  - Communication skills ("listener")
  - Advocate
  - Open-minded

- **GROUP COMPOSITION**
  - Demographic diversity
  - Medical & non-medical
  - Sick & healthy

**WHAT**

- Resolving individual patient issues
- Advising on policy & practice

**EFFECTING CHANGE**

- Improving individual patient experience
- Patient-centered policies and care programs
- Changing patients’ opinions about the health system

Open recruitment
Selection

Issues solicited or raised by the patient population

Communicating activities to patients (e.g., via newsletters, websites, brochures)

Involving the broader patient population empowers

Training, support, and organizational commitment

Communicating back changes made

Measurable impact on the health system

Open recruitment
Selection

Organizationally identified issues and assigned roles
Participants wanted to and felt they should know “who” represents them

“And I think patients should know who that patient advocate is …”

“I think it's pretty bad that none of us knew anything about it. If we’re having somebody that's representing us and we didn't even know they’re around it seems like pretty poor, like [Person 2] was saying, communication is lacking immensely …”

“I think first how do you find out about that the council even exists?”

“Most people here, I don't think knew about the board to start with. So how would they ever get any requests to look into anything?”

“But the average patient doesn't know about that, that should be publicized that there is such a thing, I think it's a great idea. But unless you're aware of it …”
Participants strongly believed that patients should be able to connect to the council.

“So if I go back and Google … I'll be looking for how would you contact them?“

“I think I would just call Hopkins and say, ‘I'm a patient, I have an issue, who do I talk to?’ and they should be able to refer me, but I'd probably do it with a phone call.”

“Like a stockholders’ meeting… there's got to be interaction with the patient body or at least the opportunity to do that.”

“I should be able to contact a person on the council, the council shouldn't be something that's like it is now sort of off in the clouds, I mean it's nothing right now that as a patient can go to and say, "I have this problem…” the council ought to be there for people to go to.”
Participants offered ideas for who an ideal council member should be.

(1) AN ABILITY TO LISTEN, COMMUNICATE AND ADVOCATE
“Be a good listener.” “Open-minded.” “Understanding.” “Compassion.”
“They definitely would have to be a person that goes around and asks other people.”
“They'd be able to speak for other folks, yeah”
“Converse with doctors and administrators as equals.”
“They should have a passion for helping. It's like belonging to any of board of directors you've got to be interested in doing it.”

(2) OBJECTIVE
“I think you have to go into it willing to look at the data available and make unbiased recommendations rather than this bad thing happened to me in the past that I need to get the system to correct it.”
“How do you inform yourself so that you could speak for the grassroots, the person who is out there the trenches?”

(3) FAMILIARITY WITH HOPKINS
“And I think they should also have familiarity with Johns Hopkins and the services that are provided now. And, in fact, really understand today's environment.”
Participants believed the ideal council was diverse, very broadly construed.

“When somebody's going to answer my problem, will they understand what the condition is, my ethnic group, my age, my gender, will they understand, will all that be considered…”

“The eight would be a select group of all the patients, okay, and it might represent each problem area if you will, okay?”

“Well if you go to try to help people you've got to get a wide diversity are the types of people”

“Do you deal with geographic distribution in the council?”

Yet some knew there might be limits to how much diversity could be practical.

“Well then I would think, like I'm Native American, I can't expect a Native American to serve on the board…”
Council Recruitment and Membership

There were suggestions to have council candidates nominated by their physicians or to have an open call. The finalists would have been selected either via interviewing or randomly. Alternatively, elections could be held. The membership on the council was seen as limited by terms with the member rotation.

“A suggestion I might make that you might think about would be to have your primary care physicians nominate candidates because they know their patients well. They know who's been around for a while”

“Perhaps there also could be, on the website there could be a listing of that board, of that volunteer board and information on it could be given, "This is basically what it is and what it does and if you're interested in serving with this group, call so and so."

“And having a rotation, too, is valuable. I know with most boards you’re elected to a board of directors for two years or three years.”
“Who” affects “what.” So does a Health System.

“So I think there's an interaction between who sits on the board and what kind of issues the board deals with, I think there's an interaction between the two and one affects the other.”

“Personally, I would volunteer only if I had access top to bottom. To all of the different committees and how the decisions are made. I think myself to be more of the whole thing, not a part of it.”

“I think to be effective it has to be part of the institutional structure. Otherwise, it just becomes a place where we vent our disagreements.”
Participants believed that adequate institutional support is needed.

“Probably it would require some type of Hopkins staff support.“

“it could be a paid coordinator who is called by a patient and then they would refer it to this committee of eight.” “… someone [who] could compile the views.”

“So maybe it would be good if the patient council could have access to even some MD, PhD graduate students.”

“a place or a room like an office, like a little office where we could meet each other… If you’re doing a job you have to have access to the environment you’re working in.”

“A very good orientation to work on the advisory council before I came on it. Have the hospital or ACO has used that advisory board, what the connections have been just a very good orientation program.”

“Well, I’d want to see the metrics that the hospital uses to evaluate themselves.“
Participants were very interested in what the council was doing.

“What are they doing?”

“What issues to they deal with, yeah.”

“I'd like to see what the council has done since 2014.”

“Tell us exactly what they're doing.”

“First, I'd want to know how active, do they show up all the time?”

“And how often do they meet. What do they hear? What are they interested in hearing?”

“What decisions are made? And where is some information about those decisions?”

“What do they do? I know, it's still not clear to me, you said they're currently in operation right now, so what do they do, I mean you said they advise JMAP but what do they advise on or about?”
Uncertainty if the council should be dealing with individual complaints or with policies.

“We still haven't determined whether this is going to be an advocacy group or if they try to influence policy.”

“I should be able to contact a person on the council, the council shouldn't be something that's like it is now sort of off in the clouds, I mean it's nothing right now that as a patient can go to and say, "I have this problem," whether it's with a doctor or whether it's with a lab or whether it's the cleanliness of a room, the council out to be there for people to go to.”

“And are they dealing strictly with complaints? Or with suggestions?”

“I thought that the kinds of cases that they might deal with were really complicated things … that would make it difficult to be able to resolve whatever issue they had with either the doctor or the hospital.” “So it was much more focused, not just generic, anybody, any case, anytime but important cases that might fall through the cracks I guess. “

“Well if they actually do advise, if there's some venue for understanding patients' concerns, whatever they might be, then they could be a source of information.”
Reporting back to patients on actions made by the council.

This included having newsletters, websites, having council meetings open to the public or allowing visitors, and so on.

“Well, I'd like to find out is the meetings is it public record, these quarterly meetings, so that I could see, yeah, this organization, this board does do something.”

“If you had a newsletter, let's say somebody called into a councilmember, they had a complaint, it ran its little course and the complaint was solved, the question was solved then in a newsletter you could have the complaint and the solution and over time people would be educated in what the problem was, how it was solved and how the problem was voiced in the first place.”

“You got to open up to the public to really know their concerns and, you know, just grievances or whatever it is, versus, okay, the panel will meet every three months and it's just them, you know what I mean, where are they getting the input from?”
Participants cared about connecting because with connecting comes influence.

“Because I think the people that are on the border, 8 of them have 8 perspectives and they don't know the 5 million-- 5,000 others out there without listening to it...And I also think that the wider spread the exposure of the council, the more seriously the institution will take it. Because that's the way things work. If it's just eight people and nobody knows about them...”
Making a Difference, depends on: Who, How, What, and If Patients were involved.

“How they’re functioning? Is it pro forma? Or is it a real group? Because I've seen too many organizational boards not to be functional groups. I mean they can have a board and everything but if they're not taking any input from them or trying to change anything what good are they?”

“… what is going to happen with the input from that one meeting, as to what is it going to do to change anything? Or is it just something that's a requirements of Medicare and they just present a paper … [OR] eight people showed up and they all thought everything was good except for two things here. We got those two things and we've changed our procedures.”

“Well, then you made a difference.”

“unless there's a line of communication like the top of the hospital. If the president of Johns Hopkins Medicine goes to the patient council and says, "If you don't get the reaction that you want come to me. Let me know. And I'll lay the law down."

“do they [BAC] feel as though any of what they’re saying is being heard? And if it's being heard is there action as a result of that?”
Perceived Benefits of a Council

“But I think it's a consensus of opinion that opening more channels of communication directly from the patients to the hospital would be a good thing.”

“I also think that you would be able to identify patterns. If the patient advisory council is receiving information that there's a pattern of problems just being able to enable the hospital to address the pattern would be successful.”

“I don't feel like I'm lost in this huge system because here is something that is representing me.”

“… knowing that there is a beneficiary advisory council. And that they have access to that if they have issues.”

“The perception that your voice is being hard would be a plus. There is some feedback. I have an issue but I passed it on and hopefully something will be done with it.”
Participants were (semi)sensitive to the idea that council members are volunteers.

“I think they would be overwhelmed when people realized …”

“It would depend upon how many issues are flying at one time.”

“That would be a lot of meetings for someone.” [when discussing the format of the meetings with the council].

“We don't know how much work they’re going to have to do. If they've got 20 reasons, questions out there from patients is meeting every three months enough?”

“But you also have to be, I think, realistic. Both the doctors and a patient advocate all have lives.”

In the 5th group we probed, “But [suppose] I'm one of the eight…and I'm a patient and I'm a volunteer…and we don't have time to be fielding complaints.“

“Then you shouldn't be there.”

“Yeah, then why be there?”
**Patient and Family Advisory Council (PFAC)**

**WHO?**
- **INDIVIDUAL PFAC MEMBER TRAITS**
  - Communication skills (“listener”)
  - Advocate
  - Open-minded
- **GROUP COMPOSITION**
  - Demographic diversity
  - Medical & non-medical
  - Sick & healthy

**WHAT**
- Resolving individual patient issues
- Advising on policy & practice

**EFFECTING CHANGE**
- Improving individual patient experience
- Patient-centered policies and care programs
- Changing patients’ opinions about the health system

**Open recruitment Selection**

**Issues solicited or raised by the patient population**

**Organizational support, training, and organizational commitment**

**Communicating activities to patients (e.g., via newsletters, websites, brochures)**

**Involving the broader patient population empowers**

**Communicating back changes made**

**Measurable impact on the health system**

**Broader Patient Population**

**Health Care Organization or System**
Takeaways

• P2C2 engagement practice can provide benefits to a health care system, but first patients’ expectations on how the P2C2 engagement is organized should be met
• Patients have high expectations for their P2C2 engagement representatives and a health system’s commitment to this engagement
• The distinction between P2C2 engagement on organization-(system-)level and individual-level (shared decision making?) might be not be that clear and needed(?). Some patients see their P2C2 engagement representatives as those addressing their personal needs or individuals’ problems.
Who represents me? A patient-derived model of patient engagement via patient and family advisory councils (PFACs)

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Next Steps: Practice, Policy and Research Implications
Next Steps

Potential projects:

• Consensus-building around P2C2 engagement measurements: cross-sectional, P2C2 involved, aligning with policy guidance

• Development and validation of a P2C2 engagement evaluation tool(s)

• Investigation around the interplay of shared decision-making and P2C2 engagement in system-level healthcare decision-making

• Exploration of benefits of engaging general patient population in interactions with their representatives (PFACs) versus the efforts
Questions?

Thank You!
References


