

A Study of Public Deliberation about Diagnostic Error: Analyses of Two Events with Healthcare Professionals in 2016-2017*

March 2017

Report prepared by

Tina Nabatchi**
Associate Professor

Suyeon Jo
Doctoral Student

Program for the Advancement of Research on Conflict and Collaboration
Maxwell School of Citizenship and Public Affairs
Syracuse University

*This report was made possible by grant number R21HS023562-01 from the Agency for Healthcare Research and Quality/DHHS. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of AHRQ.

**Correspondence should be sent to Tina Nabatchi, Maxwell School of Citizenship and Public Affairs, Syracuse University (tnabatch@syr.edu).

A Study of Public Deliberation about Diagnostic Error: Analysis of Two Events with Healthcare Professionals in 2016-2017

Executive Summary

This report presents the results from the analysis of data collected as part of a research study, *Using Public Deliberation to Define Patient Roles in Reducing Diagnostic Error*. Specifically, this report summarizes the analyses from surveys collected at two events with healthcare professionals. The first took place prior to the Diagnostic Error in Medicine Conference in November 2016 (DEM group), and the second took place at Crouse Hospital in Syracuse, New York in February 2017 (Crouse group). Both events used a focus-group style format, during which the participants learned about and discussed diagnostic error and the recommendations developed by a consumer group in 2015 as part of the overall research study.^{1,2}

This report focuses draws on data collected from three surveys at both events, including (1) a pre-event survey, (2) a post-event survey, and (3) a survey about the quality of recommendations.

We present the results in four broad categories: (1) demographics, (2) participants' perceptions of and experiences with the diagnostic processes, (3) the individual-level impacts of participation, and (4) assessments of the quality of recommendations for reducing diagnostic error. Overall, the results show that:

- The participants were diverse across a number of indicators.
- The two groups of professionals differed slightly on a number of issues related to diagnostic error and patient engagement. In general, the DEM group was more interested and positive about these issues than the Crouse group.
- The participants experienced positive, but insignificant changes, for most of individual-level indicators, including: Clinician Support for Patient Activation (CS-PAM), perceptions about patient roles in the diagnostic process, and perceptions about citizen participation in health policy and diagnosis.
- The DEM participants experienced significant and positive changes in their willingness to use the recommendations developed by healthcare consumers and to encourage other healthcare professionals to use them.
- Participants' knowledge about diagnostic error increased after the events.
- Participants gave both positive and negative reviews of the deliberative recommendations developed by healthcare consumers as part of this project. However, as compared to recommendations developed by the Institute of Medicine and another set of laypeople, they evaluated the deliberative recommendations as being the most likely to reduce diagnostic error and the most likely to improve diagnostic quality.

¹ The participant recommendations are available at: <http://jefferson-center.org/patient-prescriptions/>.

² Information about the consumer events can be found in previous reports. For copies of those reports, please contact Tina Nabatchi (tnabatch@syrr.edu).

A Study of Public Deliberation about Diagnostic Error: Analysis of Two Events with Healthcare Professionals in 2016-2017

Overview

This report presents the results from the analysis of data collected as part of the research study, *Using Public Deliberation to Define Patient Roles in Reducing Diagnostic Error*, which was funded by the Agency for Healthcare Research and Quality (AHRQ) and implemented collaboratively by researchers and practitioners from the Program for the Advancement of Research on Conflict and Collaboration (PARCC) at the Syracuse University Maxwell School of Citizenship and Public Affairs, the Jefferson Center, and the Society to Improve Diagnosis in Medicine (SIDM). The overarching goal of the project was to use deliberative approaches to develop informed and practical patient-focused recommendations for reducing diagnostic error, which SIDM will transform into whitepapers, toolkits, and other materials that patients and providers can use to improve diagnostic quality in various healthcare settings. Subsidiary goals were to examine the use of deliberation for healthcare issues, test the efficacy of deliberation as compared to two other participatory interventions (education and feedback), and assess the perceived quality of recommendations developed through a deliberative process with healthcare consumers.

To achieve these goals, the project utilized a randomized and controlled experimental design that involved participants from two populations (healthcare consumers and healthcare professionals). Healthcare consumers were randomly assigned to participate in (1) an education group that only received information about diagnostic error, (2) a deliberation group that received the same information as the education group and engaged in deliberation to develop a set of practical, patient-focused recommendations for reducing diagnostic error, (3) a participatory feedback group that assessed the quality of the recommendations, and (4) a control group that did not participate in any activities.³

In addition, two groups of healthcare professionals were engaged in two separate participatory sessions. The first group was convened in November 2016 at the SIDM Diagnostic Error in Medicine (DEM) Conference in Los Angeles, California. A total of 18 professionals participated in the DEM group.⁴ The second group was convened in February 2017 at Crouse Hospital in Syracuse, New York. A total of 17 professionals participated in the Crouse group.⁵ Both events opened with an informational session about diagnostic error, followed by questions and answers with an expert. Next, the events used a participatory focus group format, during which the participants discussed diagnostic error and the recommendations developed by consumers. Participants completed three surveys during the events: (1) a pre-survey, (2) a survey about the consumer (and other) recommendations, and (3) a post-survey.

³ For information about the activities of the healthcare consumer groups, contact Tina Nabatchi (tnabatch@syr.edu).

⁴ Participants for the DEM group were recruited through an invitation distributed by SIDM to DEM attendees and by Kaiser Permanente to its Los Angeles staff. Attendees received a complimentary breakfast and some took advantage of an offer for complimentary registration to a professional development session at the DEM conference.

⁵ Participants for the Crouse group were recruited through an invitation distributed by Crouse Hospital to medical staff. Attendees received 3 continuing medical education credits (CMEs) and a complimentary dinner.

This report focuses on the data obtained from surveys administered at these events. We present the results in four broad categories: (1) demographics, (2) perceptions of and experiences with the diagnostic process, (3) the individual-level impacts of participation, and (4) assessments of the quality of the recommendations.

Demographics

Table 1 provides demographic information for all 34 participants,⁶ as well as for the participants in the event at the Diagnostic Error in Medicine Conference (DEM group) and the participants in the event at Crouse Hospital (Crouse group). The table shows that the participants were fairly diverse on a number of indicators, including gender, age, profession, and years of practice.

Of the 34 total participants, 23 were male and 11 were female. The participants were also diverse in terms of age, though almost half of the professionals were in their 50s. Most of the participants were physicians, 11 worked as primary care doctors, and 13 were specialists. In addition, 5 participants were nurses, and 5 had other professional roles such as surgical quality control director and risk/patient safety director. Their years of medical practice ranged from 1-3 years to more than 20 years, with about 70 percent of the participants having been in medical practice for more than 20 years. Finally, all of the physicians indicated that they use electronic medical records.

Table 1: Demographic Information of Participants

		All (N=34)	DEM (N=17)	Crouse (N=17)
Gender	Male	23	14	9
	Female	11	3	8
Age	18-29	0	0	0
	30-39	2	1	1
	40-49	9	5	4
	50-59	16	8	8
	60-69	5	3	2
	70-79	2	0	2
	Over 80	0	0	0
Medical Profession	Physician – Primary Care	11	5	6
	Physician – Specialist	13	10	3
	Physician Assistant	0	0	0
	Nurse	5	1	4
	Other	5	1	4
Years of Medical Practice	Less than 1 Year	0	0	0
	1-3 Years	2	1	1
	3-5 Years	0	0	0
	5-10 Years	1	0	1
	10-20 Years	7	3	4
	More than 20 Years	24	13	11
Records Used (if physician)	Electronic medical record	27	16	11
	Paper record	0	0	0

⁶ One participant at the DEM conference did not complete pre- and post-surveys, but only completed the recommendation assessment survey. The demographic questions were only included in pre-survey; thus, the data reported here includes only 34 participants.

Professionals' Perceptions of and Experiences with the Diagnostic Process

This section reports on the professionals' responses to a number of questions about their perceptions of and experiences with the diagnostic process. These questions appeared in the pre-event survey only, as the research team assumed that perceptions about these issues were unlikely to change as a result of participation in these short events. We report the results of the responses based on four broad categories: (1) perceptions about diagnostic error, (2) experiences with diagnostic error, (3) current practices with regard to diagnostic error, and (4) challenges of patient engagement. All items were measured on a 5-point Likert scale, where 1 = strongly disagree to 5 = strongly agree. Table 2 reports the average of the participants' responses to survey items.

Table 2: Participants' Perceptions and Experiences with the Diagnostic Process

	DEM	Crouse
<i>Perceptions about Diagnostic Error</i>		
Diagnostic error is an under-recognized and under-studied problem.	4.82	3.76
Diagnostic error is the sole responsibility of physicians.	1.53	1.71
I find diagnostic error to be an interesting issue.	4.88	4.06
<i>Experiences with Diagnostic Error</i>		
I have experienced diagnostic error in my own medical practice.	4.79	3.59
I am able to recognize when my clinical judgment was incorrect.	3.35	3.74
<i>Current Practices with regard Diagnostic Error</i>		
I participate in incident reporting systems.	4.76	4.06
For a patient with a new complaint, I list a differential diagnosis at least half of the time.	3.50	3.65
In the past month, I used DXplain, ISABEL, or another web-based tool to assist in formulating a comprehensive differential diagnosis.	1.82	2.06
I encourage my patients to get a second opinion about a new problem.	3.53	3.16
I make a conscious effort to make the patient my partner in the diagnostic process.	4.19	4.16
<i>Challenges of Patient Engagement</i>		
The policies of health care organizations make it challenging to engage effectively with patients.	3.59	3.76
There are more standard practices, educational tools, and support systems to engage patients on treatment than on diagnosis.	4.18	3.09

There are interesting similarities and differences among the responses of the two groups to the questions. First, with regard to perceptions about diagnostic error, the DEM group seemed to be more concerned about the issue of diagnostic error than the Crouse group. On average, the DEM group strongly believed that diagnostic error is an under-recognized and under-studied problem (4.82/5.00), whereas the Crouse group was more neutral on the statement, though the average response approached agreement (3.76/5.00). Moreover, while both groups found diagnostic error to be an interesting issue, the DEM group (4.88/5.00) more strongly agreed with this statement than the Crouse group (4.06/5.00). Finally, both groups indicated

that diagnostic error is not the sole responsibility of physicians, with the DEM group (1.53/5.00) disagreeing slightly more strongly than the Crouse group (1.71/5.00). These results are perhaps not surprising given that the participants at the DEM group self-selected into both a conference on the issue and this particular session, while the Crouse group self-selected into a free CME opportunity.

In terms of experiences with diagnostic error, the DEM group (4.79/5.00) more strongly agreed that they have experienced diagnostic error in their own practices than the Crouse group (3.59/5.00). Moreover, though both groups offered neutral responses (that approached agreement) to the question of whether they are able to recognize when their clinical judgment was incorrect, the DEM group (3.35/5.00) felt less secure about their abilities to do so than the Crouse group (3.74/5.00). This makes sense given that the DEM group disagreed more strongly with the statement that diagnostic error is the sole responsibility of physicians.

The results on current practices with regard diagnostic error are also noteworthy. The DEM group (4.76/5.00) reported that they participate more frequently in incident reporting systems than the Crouse group (4.06/5.00), but the Crouse group (2.06/5.00) reported using web-based tools in the past month more frequently than the DEM group (1.82/5.00), although neither group reported using such tools often. Their practices with regard to treating patients are similar. Both the DEM and Crouse groups were neutral with the statements that they list a differential diagnosis at least half of the time for a patient with a new complaint (3.50/5.00 and 3.65/5.00, respectively) and that they encourage patients to get a second opinion about a new problem (3.53/5.00 and 3.16/5.00, respectively). Participants in both the DEM and Crouse groups also reported that they make a conscious effort to engage patients as equal partners in the diagnostic process (4.19/5.00 and 4.16/5.00, respectively).

Participants' perceptions of patient engagement generally align with the observations presented above. The DEM group was more neutral on the statement that the policies of healthcare organizations make it challenging to engage with patients (3.59/5.00), but was quite positive about the tools and practices used to support patient engagement on treatment (4.18/5.00). In contrast, the Crouse Hospital group found patient engagement to be more challenging due to the policies of healthcare organizations (3.76/5.00) and was less optimistic about the using tools to engage patients on treatment (3.09/5.00).

In sum, we found slight differences between the DEM and Crouse groups on a number of issues related to diagnostic error and patient engagement. Generally speaking, the DEM group was more interested in these issues and regarded patient engagement as being more challenging, but also more feasible. In contrast, the Crouse group had more conservative perceptions about engaging patients in the diagnostic processes and has less interest in diagnostic error.

Individual-Level Impacts

This section reports on the impacts of the sessions on various individual-level outcomes, including clinician support for patient activation, perceptions about patient roles in the diagnostic process, willingness to use recommendations produced by patients, perceptions about citizen participation in health policy making, and knowledge about diagnostic error. To measure clinicians' belief about the importance of patient activation, we use the Clinician Support for Patient Activation Measure (CS-PAM), an empirically validated scale used frequently in health research and practice. The remaining individual-level outcomes are

measured with 5-point Likert scale items. T-tests were used for statistical analyses and the results are reported in a series of tables that include before-after comparisons for the two groups.

CS-PAM Clinician Support for the Patient Activation

The Clinician Support for Patient Activation Measure (PAM),⁷ licensed by Insignia Health, aims to assess “clinicians’ beliefs in the importance of patient activation in self-management behaviors and competencies.”⁸ Specifically, the 13-item measure (see Appendix 1) places individuals on a 0-100 scale, where higher scores indicate greater support for patient activation and empowerment. The scores can be further segmented into three levels – low, medium, and high – each of which represents the degree to which clinicians believe in patients’ self-management abilities.

As seen in Table 3, the mean CS-PAM scores of both DEM and Crouse group increased after our sessions by 2.08 and 5.92, respectively; however, neither difference is statistically significant. This is not surprising – it is unlikely that a short, one-time meeting centered on information and brief discussions would yield significant changes in professionals’ perceptions about patient activation. This suggests that longer, more in-depth, and perhaps deliberative sessions, are needed to change CS-PAM scores. It is, however, interesting to note that Crouse group experienced larger changes in their support for patient activation than did the DEM group. Thus, engagement might be more effective for those who have less interest in the issues of patient activation and diagnostic error.

Table 3: Changes in CS-PAM Scores by Group

	DEM	Crouse
N	17	17
Before	66.69	66.06
After	68.78	71.98
Difference	2.08	5.92

Note: *p < .10, **p < .05, ***p < .01; two-tailed test of significance

As noted above, the CS-PAM segments people into low, medium, and high levels. Figures 1 and 2 show the cumulative changes in CS-PAM levels among the DEM and Crouse groups, respectively. The figures show few changes, which is consistent with the results reported above. Specifically, before the event, 13 of 17 DEM participants had a high CS-PAM level, while 3 had a medium level, and 1 had a low level. After the event, 14 participants had a high CS-PAM level, 2 had a medium level, and 1 had a low level. The results for the Crouse group are similar. Specifically, before the event, 12 participants had a high CS-PAM level, 3 had a medium level, and 1 had a low level. After the event, 13 had a high CS-PAM level, 3 had a medium level, and none had a low level.

⁷ Patient Activation Measure (PAM) assesses patients’ knowledge, skills and confidence for managing their own health. This measure is also licensed by Insignia Health.

⁸ Hibbard, J. H., Collins, P. A., Mahoney, E., & Baker, L. H. (2010). The development and testing of a measure assessing clinician beliefs about patient self-management. *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy*, 13(1): 65–72.

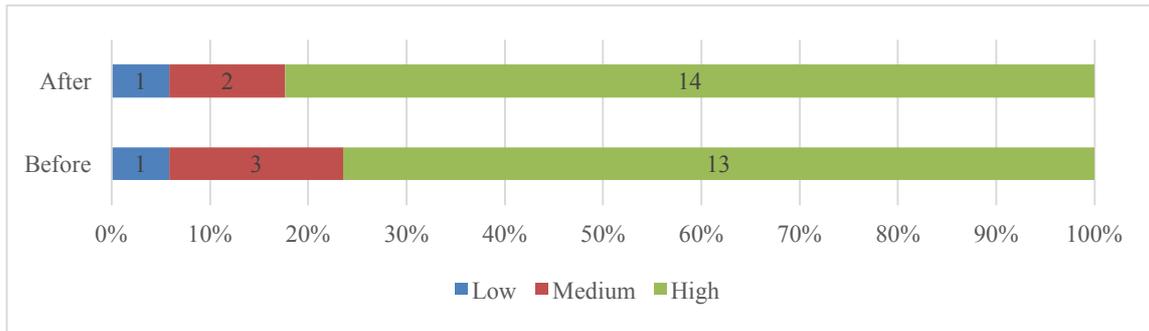


Figure 1: DEM CS-PAM Levels Before/After the Event

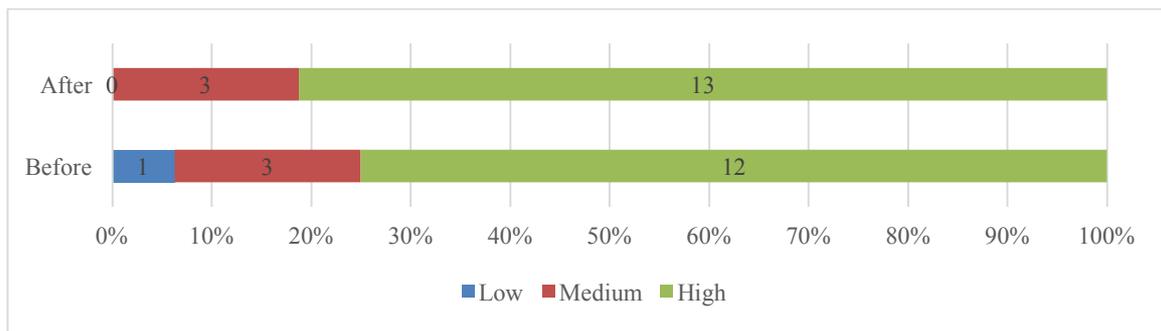


Figure 2: Crouse CS-PAM Levels Before/After the Event

An assessment of the individual results among the two groups provides a more nuanced analysis of the changes in CS-PAM levels. In Tables 4 and 5, participants' pre- and post-responses are linked, which allows for the assessment of how a person's individual PAM score changed (or did not) by the end of the event. The rows indicate the number of individuals at each CS-PAM level on the pre-survey, and the columns indicate the number of individuals at each CS-PAM level on the post-survey. The shaded cells show those participants whose CS-PAM levels did not change after the event. The cells below the shaded ones show the number of participants whose CS-PAM levels decreased, while the cells above show the number of participants whose CS-PAM levels increased.

Several points from these tables are worth noting. First, the CS-PAM levels did not change for most participants in both groups. Specifically, in DEM group, one person began and ended at the Low level, two began and ended at the Medium level, and 13 began and ended at the High level. In the Crouse group, three people began and ended at the Medium level, and 12 began and ended at the High level. Second, no participants in either group experienced a decrease in their CS-PAM levels. Third, one person in each group had an increase in their CS-PAM levels. Specifically, one DEM participant moved from the Medium to the High level, and one Crouse participant moved from the Low to the High level.

Table 4: Individual CS-PAM Level Changes Before/After the Event (DEM group)

CS-PAM Level (Before)	CS-PAM Level (After)			Total
	Low	Medium	High	
Low	1	0	0	1
Medium	0	2	1	3
High	0	0	13	13
Total	1	2	14	17

Table 5: Individual CS-PAM Level Changes Before/After the Event (Crouse group)

CS-PAM Level (Before)	CS-PAM Level (After)			Total
	Low	Medium	High	
Low	0	0	1	1
Medium	0	3	0	3
High	0	0	12	12
Total	0	3	13	16

Perceptions about Patient Roles in the Diagnostic Process

To measure professionals' perceptions about patient roles in the diagnostic process, we used an additive index ($\alpha = 0.84$) consisting of four 5-point Likert scale items, where 1 = strongly disagree to 5 = strongly agree:

1. Patients can play a critical role in the diagnostic process.
2. Patients can play a critical role in improving diagnostic quality.
3. Patients can provide valuable inputs in addressing the problem of diagnostic error.
4. Patients can take actions that reduce diagnostic error.

As seen in Table 6, the DEM and Crouse groups experienced small, but positive changes (0.06 and 0.09, respectively) in their perceptions about patient roles in the diagnostic process. However, neither change is statistically significant.

Table 6: Changes in Perception about Patient Roles in the Diagnostic Process

	DEM	Crouse
N	17	17
Before	4.66	4.22
After	4.72	4.31
Difference	0.06	0.09

Note: * $p < .10$, ** $p < .05$, *** $p < .01$; two-tailed test of significance

Willingness to Use Recommendations Developed by Healthcare Consumers

In this section, we report on two 5-point Likert scale items (where 1 = strongly disagree and 5 = strongly agree) that assess the professionals' willingness to use the recommendations developed by healthcare consumers.

As seen in Table 7, both groups' willingness to make use of the patients' recommendations increased after the events; however, only the changes for the DEM group were statistically significant. Specifically, the Crouse group saw a 0.03 increase in their willingness to use the recommendations in their own practice and a 0.08 increase in their willingness to encourage fellow professionals to use the recommendations. The DEM group saw a 0.75 ($p < .01$) increase in their willingness to use the recommendations in their own practice, and a 0.41 ($p < .10$) increase in their willingness to encourage fellow professionals to use the recommendations. The differences between the groups may be a function of participant characteristics.

Table 7: Willingness to Use the Recommendations Developed by Patients

		DEM	Crouse
I am willing to use the recommendations produced by patients in my own medical practice.	N	16	16
	Before	3.75	3.81
	After	4.5	3.84
	Difference	0.75***	0.03
I am willing to encourage fellow healthcare professionals to use recommendations produced by patients.	N	17	17
	Before	4.00	3.76
	After	4.41	3.84
	Difference	0.41*	0.08

Note: *p < .10, **p < .05, ***p < .01; two-tailed test of significance

Perceptions about Citizen Participation in Health Policy

Beyond looking at issues of patient engagement, we also wanted to get a sense of how medical professionals think about citizen participation in health policy more broadly. To do so, we used four individual survey items, all of which were on a 5-point Likert scale, where 1 = strongly disagree to 5 = strongly agree.⁹ Table 8 shows the average response from the before and after surveys, as well as the difference, for both the DEM and Crouse groups.

Table 8: Perception about Citizen Participation in Health Policy and Diagnosis

		DEM (N=17)	Crouse (N=17)
Health policy decisions should be left to professionals and experts	Before	2.75	3.12
	After	1.94	3.13
	Difference	-0.81	0.01
Citizens are able to craft effective health policy.	Before	2.88	2.88
	After	3.06	3.00
	Difference	0.18	0.12
Citizens can produce effective recommendations for reducing diagnostic error.	Before	3.94	3.41
	After	4.06	3.66
	Difference	0.12	0.24
Citizens can understand problems related to healthcare systems.	Before	3.76	3.59
	After	4.12	3.75
	Difference	0.35	0.16

Note: *p < .10, **p < .05, ***p < .01; two-tailed test of significance

The first item is: “Health policy decisions should be left to professionals and experts.” As Table 8 shows, the DEM group experienced decreases in the belief that the experts should make health policy decisions, acknowledging some room for patients to be engaged in health policy decision-making. However, this change is not statistically significant. There was virtually no difference (0.01) in the responses for the Crouse group.

⁹ A factor analysis revealed that the three items measure different aspects of participation in health policy and did not combine into a single index.

The results for the second item, “Citizens are able to craft effective health policy,” are similar. The opinions of both the DEM and Crouse groups increased by 0.18 and 0.12 respectively, moving from slight disagreement toward a more neutral position. Neither change, however, is significant, and both sets of responses reveal professionals’ doubt about the ability of average citizens to participate in health policy making.

With regard to the issue of citizens’ ability to “produce effective recommendations for reducing diagnostic error,” both the DEM and Crouse groups saw increases (0.12 and 0.35, respectively). Moreover, after participation, the DEM leaned toward agreement, while the Crouse group remained neutral.

Finally, the last item concerns citizens’ ability to “understand problems related to healthcare systems.” Once again, both groups saw increases (0.35 for DEM and 0.16 for Crouse) that were not statistically significant, with the DEM group leaning toward and the Crouse group remaining more neutral.

Together, the results presented above show that participants became slightly more positive about the abilities of citizens to participate in health policy making, but neither group witnessed statistically significant changes on any measure. These results suggest that medical professionals are skeptical about the abilities of citizens to understand and participate effectively in health policy making, even after learning about the recommendations developed in 2015 by healthcare consumers.

Knowledge about Diagnostic Error

We also attempted to measure the changes in the knowledge about diagnostic error. To do so, we used a multiple choice question: “On average, what fraction of patients seen in clinics every year will be subject to a diagnosis that is wrong, missed, or delayed?” Table 9 shows the percentage of people who selected the correct answer (“1 in 10”) before and after our sessions. Although we cannot calculate statistical significance, the results are noteworthy. Prior to the events, approximately 35% of participants in the DEM group and 25% of the Crouse group answered the question correctly. After our events, approximately 53% of participants in DEM group and 38% of people in the Crouse group chose the right answer. This shows that our sessions had a small, but potentially meaningful impact on improving professionals’ knowledge about diagnostic error.

Table 9: Knowledge about Diagnostic Error

	DEM	Crouse
Before the Event	6 out of 17 (35.29%)	4 out of 16 (25.00%)
After the Event	9 out of 17 (52.94%)	5 out of 16 (38.46%)

Taken together, there were generally positive, but insignificant individual-level impacts on participants’ perceptions about a variety of diagnostic error and health-related issues. These results are not surprising given that the events were short, and involved less intensive discussion about the issues. The only significant changes occurred in the DEM group who reported being both more willing to use and more willing to encourage others to use the recommendations developed by consumers. This might be due to the nature of the group; participants in DEM event were generally more interested in issues related to diagnostic error and patient engagement and empowerment.

Assessments of Recommendations

This section reports on the professionals' assessments of the recommendations for improving the diagnostic process and reducing diagnostic error. Three sets of evaluations were included in this assessment activity: (1) an assessment of the general quality of the recommendations produced by healthcare consumers in 2015; (2) an assessment of the quality of the consumers' recommendations as compared to recommendations developed in other fora; and (3) an assessment of the best overall set of recommendations. We discuss each assessment activity below.

General Quality of the Recommendations

First, professionals in both the DEM and Crouse groups were presented with the 5 categories of recommendations and asked to complete a survey that assessed various facets of their quality. Specifically, the participants were asked to answer the following six questions for each recommendation category:

1. Will patients understand this recommendation? (Yes or No)
2. How likely is it that patients will use this recommendation? (5-point scale: Extremely Unlikely, Unlikely, Neutral, Likely, Extremely Likely)
3. How difficult would it be for patients to use this recommendation? (5-point scale: Very Difficult, Difficult, Neutral, Easy, Very Easy)
4. If used, how much would this recommendation improve diagnostic quality? (5-point scale: No Improvement, Minor Improvement, Neutral, Moderate Improvement, Major Improvement)
5. How appropriate do you believe it is for patients to follow through on this recommendation? (5-point scale: Absolutely Inappropriate, Slightly Inappropriate, Neutral, Slightly Appropriate, Absolutely Appropriate)
6. How appropriate would other medical professionals find it if patients were to follow through on this recommendation? (5-point scale: Absolutely Inappropriate, Slightly Inappropriate, Neutral, Slightly Appropriate, Absolutely Appropriate)

The results of this assessment activity are presented in Table 10, which shows the responses to each question about the recommendations, including frequencies and percentages. Unlike the previous sections, we do not present the results separately for the DEM and Crouse groups. Instead, we report the cumulative results (N=35). Following the table, we show each recommendation in a box and discuss the results.

Table 10: Assessment on Recommendations by Healthcare Consumers (Deliberation Recs)¹⁰

		Rec 1	Rec 2	Rec 3	Rec 4	Rec 5
<i>Will patients understand this recommendation?</i>	Yes	24 (73%)	25 (74%)	31 (91%)	32 (91%)	32 (94%)
	No	9 (27%)	9 (26%)	3 (9%)	3 (9%)	2 (6%)
<i>How likely is it that patients will use this recommendation?</i>	Extremely Unlikely	0 (0%)	0 (0%)	0 (0%)	4 (11%)	1 (3%)
	Unlikely	7 (20%)	10 (29%)	13 (37%)	15 (43%)	11 (31%)
	Neutral ¹¹	14 (40%)	14 (40%)	12 (34%)	10 (29%)	15 (43%)
	Likely	14 (40%)	11 (31%)	8 (23%)	6 (17%)	7 (20%)
	Extremely Likely	0 (0%)	0 (0%)	2 (6%)	0 (0%)	1 (3%)
<i>How difficult would it be for patients to use this recommendation?</i>	Very Difficult	0 (0%)	2 (6%)	4 (11%)	8 (23%)	2 (6%)
	Difficult	18 (51%)	14 (40%)	21 (60%)	14 (40%)	11 (31%)
	Neutral ¹²	9 (26%)	14 (40%)	7 (20%)	10 (29%)	15 (43%)
	Easy	7 (20%)	5 (14%)	2 (6%)	3 (9%)	7 (20%)
	Very Easy	1 (3%)	0 (0%)	1 (3%)	0 (0%)	0 (0%)
<i>If used, how much would this recommendation improve diagnostic quality?</i>	No Improvement	1 (3%)	0 (0%)	1 (3%)	2 (6%)	0 (0%)
	Minor Improvement	2 (6%)	1 (3%)	1 (3%)	4 (11%)	0 (0%)
	Neutral	1 (3%)	3 (9%)	1 (3%)	3 (9%)	3 (9%)
	Moderate Improvement ¹³	22 (63%)	22 (63%)	18 (51%)	18 (51%)	24 (68%)
	Major Improvement	9 (26%)	9 (26%)	14 (40%)	8 (23%)	8 (23%)
<i>How appropriate do you believe it is for patients to follow through on this recommendation?</i>	Absolutely Inappropriate	0 (0%)	0 (0%)	1 (3%)	1 (3%)	0 (0%)
	Slightly Inappropriate	0 (0%)	0 (0%)	2 (6%)	2 (6%)	0 (0%)
	Neutral	3 (9%)	3 (9%)	0 (0%)	4 (11%)	1 (3%)
	Slightly Appropriate	7 (20%)	10 (29%)	9 (26%)	14 (40%)	11 (31%)
	Absolutely Appropriate	25 (71%)	22 (63%)	23 (66%)	14 (40%)	23 (66%)
<i>How appropriate would other medical professionals find it if patients were to follow through on this recommendation?</i>	Absolutely Inappropriate	0 (0%)	0 (0%)	1 (3%)	1 (3%)	0 (0%)
	Slightly Inappropriate	0 (0%)	0 (0%)	1 (3%)	3 (9%)	1 (3%)
	Neutral	4 (11%)	5 (14%)	1 (3%)	5 (14%)	3 (9%)
	Slightly Appropriate ¹⁴	8 (23%)	14 (40%)	10 (29%)	17 (49%)	11 (31%)
	Absolutely Appropriate	23 (66%)	16 (46%)	22 (63%)	9 (26%)	20 (57%)

¹⁰ Due to rounding, some totals may not equal 100%.

¹¹ One respondent chose both “neutral” and “likely.” We included the response in the neutral category.

¹² One respondent chose both “neutral” and “easy.” We included the response in the neutral category.

¹³ One respondent chose both “moderate improvement” and “major improvement.” We included this person in the moderate improvement category.

¹⁴ One respondent chose both “slightly appropriate” and “absolutely appropriate.” We included this person in the slightly appropriate category.

Deliberation Recommendation 1 – *Present symptoms clearly and completely*

- Be truthful about your symptoms and other behaviors when telling your doctor about your history to ensure information is accurate.
- Be prepared to discuss your symptoms. For example, 8 characteristics of symptoms are quantity, quality, aggravating factors, alleviating factors, setting, associated symptoms, location, and timing.

Overall, the results for Recommendation 1 are mixed. About 73% of respondents thought that patients would understand this recommendation; however, only 40% believed patients were likely to use it, and about 23% believed it would be easy for patients to use. Nevertheless, 89% thought this recommendation would result in a moderate or major improvement on diagnostic quality. Moreover, 91% thought it was appropriate for patients to follow through on this recommendation, and 89% believed that other medical professionals would find it to be appropriate.

Deliberation Recommendation 2 – *Assert yourself in the relationship*

- Be clear, concise, and persistent in communicating your symptoms and concerns.
- Ask detailed questions of your doctor, including a plan to arrive at a diagnosis so the doctor remains engaged and focused on your concerns. For example, “could these symptoms indicate something else or an additional issue?”
- Notify your healthcare provider if your condition worsens, does or doesn’t improve, or if new symptoms develop.
 - The treatment plan could change based on new information and potentially a new diagnosis.
 - Potential new urgency could affect the healthcare provider’s level of attention.
- If you’re concerned about the accuracy of the diagnosis, seek a second opinion.

The results for Recommendation 2 are similar. About 74% of professionals thought that patients would understand this recommendation, but only 31% thought patients were likely to use it, and 14% believed it would be easy for patients to use. Still, 89% of participants believed it would improve diagnostic quality, 92% thought it was appropriate for patients to use, and 86% believed other professionals would regard it as appropriate.

Deliberation Recommendation 3 – *Coordinate your care*

- Find a primary care provider/family doctor so that they can better coordinate and manage your healthcare.
- Enlist a patient advocate, as needed, to assist you in coordinating care.
- Have your primary care provider manage all your records to ensure they are accessible to other providers.
- Seek out a health system where different doctors work together frequently, share consistent information, and coordinate services effectively.

Recommendation 3 also received mixed reviews. About 91% thought patients would understand the recommendation, but only 29% believed that patients were likely to use it, and only 9% thought it would be easy to use. Nevertheless, 91% reported that the

recommendation would make moderate or major improvement on diagnostic quality. About 92% believed the recommendation was appropriate and about 92% believed other medical professionals would find it appropriate.

Deliberation Recommendation 4 – *Ensure accurate records and tests*

- Maintain and update your own medical record, which includes test results, doctor notes, images, communication with providers, and other information pertinent to your medical history.
- If you have access to your electronic medical records or a patient portal, use that. If you don't have access, ask for a physical copy of your records and/or any recent updates.
- If you notice a factual inaccuracy with your medical record, advocate and insist to have the error corrected.

Recommendation 4 was also assessed both positively and negatively. Although 91% thought patients would understand the recommendation, only 17% thought patients were likely to use it, and only 9% thought it would be easy to use. About 74% believed that it would have a positive impact on diagnostic quality. About 80% believed that it was appropriate for patients to use this recommendation, and about 75% thought that other professionals would also regard the recommendation as appropriate.

Deliberation Recommendation 5 – *Manage your care*

- Ensure communications and expectations are clear between you and your healthcare provider.
- Throughout the relationship, follow through on your health care provider's recommendations regarding the course of action to reach an accurate diagnosis. For example, completing lab tests, going to appointments with specialists, taking medications as prescribed.
- Follow up with your healthcare provider after appointments to obtain test results to ensure proper testing was conducted. Thus, both patient and healthcare provider are accountable.

Recommendation 5 has similar results. About 94% of participants thought patients would understand this recommendation, yet only 23% believed that patients were likely to use it, and only 20% thought it would be easy to use. Despite these negative reviews, 91% believed it would make moderate or major improvement on diagnostic quality, 97% perceived it as appropriate for patients to use, and 88% thought other professionals would consider it appropriate.

In sum, professionals generally believed that the five recommendations developed by healthcare consumers in our deliberative sessions were understandable and appropriate, and would improve diagnostic quality. However, the professionals generally did not believe that patients were likely to use the recommendations or that they would be particularly easy for patients to use.

Comparative Assessments of Recommendations

We also wanted to assess whether the recommendations produced by consumers during our deliberative process were better than (or as good as) recommendations developed in other fora. Thus, in the assessment survey, we added two other sets of recommendations. One set was adapted from the Institute of Medicine's (IOM) *Recommendations for Improving Diagnosis in Health*, which were released in September 2015.¹⁵ The second set was adapted from survey responses of participants in the 2015 consumer education group.¹⁶ The three sets of recommendations (Set A: Deliberative Recommendations; Set B: IOM Recommendations; Set C: Education Recommendations) are presented in Appendix 2.

Table 11 presents the results on the assessments of the 3 sets of recommendations from the Institution of Medicine (IOM) and the three sets from the education group (ED). (The results for the deliberative recommendations are discussed above and presented in Table 10).

Appendix 3 shows the results for all three sets of recommendations in one table. In addition, we show each recommendation in a box and discuss the results. It is important to note that the recommendations were presented in random order on the assessment survey, but are covered in order here.

IOM Recommendation 1 – Facilitate more effective teamwork in the diagnostic process among health care professionals, patients, and their families.

- Health care organizations should recognize that the diagnostic process is a dynamic team-based activity.
- Health care organizations should ensure that health care professionals have the appropriate knowledge, skills, resources, and support to engage in teamwork in the diagnostic process.

All participants reported that patients would understand IOM Recommendation 1; however, only 55% thought patients would use the recommendation, and only 11% believed it would be easy to use. About 97% believed that this recommendation would improve diagnostic quality. Moreover, all the participants found the recommendation appropriate, and 94% thought that other professionals would find it appropriate.

IOM Recommendation 2 – To improve the diagnostic process, health care organizations facilitate and support

- Inter-professional and intra-professional teamwork in the diagnostic process.
- Collaboration among pathologists, radiologists, other diagnosticians, and treating health care professionals to improve diagnostic testing processes.

¹⁵ To create the IOM recommendations, the research team adapted the points under Goal 1: Facilitate more effective teamwork in the diagnostic process among health care professionals, patients, and their families. The full set of IOM recommendations can be found at http://www.nationalacademies.org/hmd/~media/Files/Report%20Files/2015/Improving-Diagnosis/Diagnosis_Recommendations.pdf.

¹⁶ To create the Education recommendations, the research team used survey responses to the question, "What ideas do you have for how patients can help improve the diagnostic process?" The research team compiled the qualitative answers of all participants, organized them into categories, and developed recommendations.

Again, all the participants thought that patients would understand IOM Recommendation 2, but only about 66% believed that patients would use the recommendation, and only 20% thought it would be easy to use. Still, 95% believed it would improve diagnostic quality, 97% thought it was appropriate, and 95% thought other professionals would find it appropriate.

IOM Recommendation 3 – *Health care professionals and organizations should partner with patients and their families as diagnostic team members and facilitate patient and family engagement in the diagnostic process, aligned with their needs, values and preferences. To do this, they should:*

- Provide patients with opportunities to learn about the diagnostic process.
- Create environments in which patients and their families are comfortable engaging in the diagnostic process and sharing feedback and concerns about diagnostic errors and near misses.
- Ensure patient access to electronic health records (EHRs), including clinical notes and diagnostic testing results, to facilitate patient engagement in the diagnostic process and patient review of health records for accuracy.
- Identify opportunities to include patients and their families in efforts to improve diagnostic process by learning from diagnostic errors and near misses.

The assessments of IOM Recommendation 3 are similar: 94% believed that patients would understand the recommendation, but only 23% thought patients were likely to use it, and only 17% thought it would be easy to use. About 74% reported that the recommendation would improve diagnostic quality, 86% believed it was appropriate, and 77% thought other professionals would find it appropriate.

Education Recommendation 1 – *Communicate clearly and efficiently*

- Listen carefully to your health care providers and present your symptoms clearly.
- Be honest and give full information to your health care providers.
- Come prepared to the visit. Bring a list of questions, concerns, or issues to share with your health care provider.

The assessments of Education Recommendation 1 show that about 94% of the participants thought patients would understand the recommendation, 80% believed patients would use it, and 42% thought it would be easy to use. About 94% thought it would improve diagnostic quality, 94% believed it was appropriate for patients to use, and 86% thought that other professionals would also find it appropriate.

Education Recommendation 2 – *Advocate for yourself actively*

- Be confident about your rights in the relationship with healthcare providers.
- If you disagree with your diagnosis, seek a second opinion.
- Get support from your advocates (family members or friends) during the visits

The assessments of Education Recommendation 2 were not as positive. Only 89% thought patients would understand the recommendation. Only 49% believed patients would use the recommendation, and only 29% thought it would be easy to use. Moreover, 63% thought the recommendation would improve diagnostic quality, 80% believed it was appropriate, and 72% thought other medical professionals would find it to be appropriate.

Education Recommendation 3 – *Be informed about your health, symptoms, diagnosis, and treatment.*

- Know your family history about health-related problems.
- Do your own research on your symptoms and the diagnoses you have received.
- Have information about each medicine you take and its possible side effects.
- Keep records of your own health and behaviors.

The assessments of Education Recommendation 3 were mixed. Although 97% of professionals reported that patients would understand the recommendation, only 31% thought patients would use it, and only 29% thought it would be easy to use. Furthermore, only 62% thought it would improve diagnostic quality. About 80% believed it was appropriate for patients to use, and about 77% believed that other professionals would find it appropriate.

In sum, the recommendations created by the deliberative group, the IOM, and the education group received both positive and negative reviews. In general, the professionals believed that patients would be most likely to understand the IOM recommendations. However, they thought that patients were most likely to use, and find easy to use, the Education group's recommendations. The recommendations from the Deliberation group and the IOM were judged as being most likely to improve diagnostic quality. The professionals' judgment about how they perceived the appropriateness of patient use was roughly the same for the Deliberation group and IOM recommendations. Their judgements about how others would perceived appropriateness was roughly the same for all sets of recommendations.

Table 11: Assessment on Recommendations by IOM and Edu-Only group¹⁷

		IOM 1	IOM 2	IOM 3	ED 1	ED 2	ED 3
<i>Will patients understand this recommendation?</i>	Yes	34 (100%)	33 (100%)	33 (94%)	33 (94%)	31 (89%)	34 (97%)
	No	0 (0%)	0 (0%)	2 (6%)	2 (6%)	4 (11%)	1 (3%)
<i>How likely is it that patients will use this recommendation?</i>	Extremely Unlikely	1 (3%)	0 (0%)	4 (11%)	0 (0%)	1 (3%)	5 (14%)
	Unlikely	5 (14%)	6 (17%)	14 (40%)	4 (11%)	9 (26%)	9 (26%)
	Neutral ¹⁸	10 (29%)	6 (17%)	9 (26%)	3 (9%)	8 (23%)	10 (29%)
	Likely	16 (46%)	20 (57%)	7 (20%)	26 (74%)	15 (43%)	11 (31%)
	Extremely Likely	3 (9%)	3 (9%)	1 (3%)	2 (6%)	2 (6%)	0 (0%)
<i>How difficult would it be for patients to use this recommendation?</i>	Very Difficult	2 (6%)	2 (6%)	4 (11%)	0 (0%)	1 (3%)	3 (9%)
	Difficult	21 (60%)	17 (49%)	21 (60%)	8 (23%)	14 (40%)	16 (46%)
	Neutral ¹⁹	8 (23%)	9 (26%)	4 (12%)	12 (34%)	10 (29%)	6 (17%)
	Easy	4 (11%)	7 (20%)	6 (17%)	11 (31%)	8 (23%)	9 (26%)
	Very Easy	0 (0%)	0 (0%)	0 (0%)	4 (11%)	2 (6%)	1 (3%)
<i>If used, how much would this recommendation improve diagnostic quality?</i>	No Improvement	0 (0%)	0 (0%)	1 (3%)	0 (0%)	1 (3%)	1 (3%)
	Minor Improvement	1 (3%)	0 (0%)	3 (9%)	0 (0%)	3 (9%)	7 (20%)
	Neutral ²⁰	0 (0%)	2 (6%)	5 (14%)	2 (6%)	9 (26%)	5 (14%)
	Moderate Improvement	20 (57%)	17 (49%)	20 (57%)	22 (63%)	19 (54%)	18 (51%)
	Major Improvement	14 (40%)	16 (46%)	6 (17%)	11 (31%)	3 (9%)	4 (11%)
<i>How appropriate do you believe it is for patients to follow through on this recommendation?</i>	Absolutely Inappropriate	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
	Slightly Inappropriate	0 (0%)	0 (0%)	2 (6%)	0 (0%)	1 (3%)	1 (3%)
	Neutral	0 (0%)	1 (3%)	3 (9%)	2 (6%)	6 (17%)	6 (17%)
	Slightly Appropriate	8 (23%)	7 (20%)	15 (43%)	7 (20%)	17 (49%)	11 (31%)
	Absolutely Appropriate	27 (77%)	27 (77%)	15 (43%)	26 (74%)	11 (31%)	17 (49%)
<i>How appropriate would other medical professionals find it if patients followed through on this recommendation?</i>	Absolutely Inappropriate	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (3%)	0 (0%)
	Slightly Inappropriate	0 (0%)	0 (0%)	2 (6%)	1 (3%)	2 (6%)	2 (6%)
	Neutral	2 (6%)	2 (6%)	6 (17%)	4 (11%)	7 (20%)	6 (17%)
	Slightly Appropriate ²¹	12 (34%)	10 (29%)	15 (43%)	7 (20%)	16 (46%)	13 (37%)
	Absolutely Appropriate	21 (60%)	23 (66%)	12 (34%)	23 (66%)	9 (26%)	14 (40%)

¹⁷ Due to rounding, some totals may not equal 100%.

¹⁸ One respondent chose both “neutral” and “likely.” We included the response in the neutral category.

¹⁹ One respondent chose both “neutral” and “easy.” We included the response in the neutral category.

²⁰ One respondent chose both “neutral” and “moderate improvement.” We included the response in the neutral category.

²¹ One respondent chose both “slightly appropriate” and “absolutely appropriate.” We included this person in the slightly appropriate category.

Assessment of the Best Overall Set of Recommendations

As a final step in our assessment, we asked the participants in both groups to look at the three sets of recommendations (Deliberation, IOM, and Education) as a whole, select the set that was best overall, and explain their choice. To assist this effort, we asked the participants to evaluate the recommendation set as a whole using four 10-point scale questions:

1. How user-friendly is the recommendation set as a whole? (1 = Least User-Friendly to 10 = Most User-Friendly)
2. How appropriate for guiding behaviors and activities is the recommendation set as a whole? (1 = Most Inappropriate to 10 = Most Appropriate)
3. If utilized, how likely is it that the recommendation set as a whole would reduce diagnostic errors? (1 = Least Likely to 10 = Most Likely)
4. If utilized, how likely is it that the recommendation set as a whole would improve diagnostic quality? (1 = Least Likely to 10 = Most Likely)

The results of the assessments of these recommendations as a whole set are presented in Table 12. Specifically, this table shows the average response (on a 10-point scale) for each of the four criteria, and indicates the number and percentage of participants that chose each set as “best.”

Table 12: Assessment of Recommendations as a Whole Set

	Deliberation Rec Set	IOM Rec Set	Edu Rec Set
User-friendly	5.88	5.26	7.52
Appropriate for guiding behaviors and activities	6.67	6.64	7.24
Likely to reduce diagnostic errors	7.58	7.00	6.69
Likely to improve diagnostic quality	7.85	7.39	6.88
<i>The Best Set</i>	10 (31%)	8 (25%)	14 (44%)

As seen in the Table 12, the recommendations developed by the Education group were seen as being the most user-friendly (7.52) and appropriate for guiding patient behaviors and activities (7.24). The Deliberation group’s recommendations were ranked second on both items (5.88 and 6.67 respectively), and the IOM Recommendations ranked third (5.26 and 6.64 respectively). However, the Deliberation Recommendations scored the highest in terms of being likely to reduce diagnostic errors (7.58) and improve diagnostic quality (7.85). The IOM Recommendations ranked second on these items (7.00 and 7.39 respectively) and the Education Recommendations ranked third (6.69 and 6.88 respectively). In terms of their overall quality (i.e., the “best” set), the Education Recommendation received the most votes (14 people, 44%), followed by the Deliberation Recommendations (10 people, 31%), and the IOM Recommendations (8 people, 25%).

These findings are worth discussing in more detail. The largest number of professionals chose the Education Recommendation set as the best overall, and also rated it as being the most user friendly. This result may be a function of how the recommendation set was developed. Specifically, the research team compiled the open-ended answers from the surveys completed by the education group. These answers tended to be very short, which resulted in the development of concise, direct recommendations. Moreover, the Education Recommendations are oriented around individual actions that a person can take without reference to others (e.g., communicating clearly and efficiently, advocating for oneself, and being informed about one's health, symptoms, diagnosis, and treatment). Thus, the Education Recommendations are not only straightforward, but also more simplistic and less nuanced. Thus, it is not surprising that they were rated as being the most user-friendly and appropriate for guiding behaviors.

In contrast, the Deliberation Recommendations are more complicated and require a higher level of individual agency and facility. For example, Recommendation 1 provides nuanced language about discussing symptoms, Recommendation 2 asks patients to be assertive and ask detailed questions, and Recommendations 3 through 5 require coordination activities by patients. In short, these recommendations ask more of the patient: they require a higher level of involvement, more cognitive skill, greater levels of communication proficiency, better preparedness, and higher levels of other characteristics, such as self-efficacy. Thus, it is unsurprising that they were considered to be less user-friendly than the Education Recommendations, but more like to reduce diagnostic error and improve diagnostic quality.

Finally, the IOM Recommendation set was not only rated the worst overall, but also the worst in terms of user-friendliness, appropriateness, and likely impact. This is surprising given that these recommendations were developed by medical professionals over a long period of time. As a side note, it is interesting that healthcare professionals gave higher ratings to two recommendation sets developed by consumers than to a recommendation set developed by professional peers. We believe this indicates that patients have the ability to participate in healthcare issues and the diagnostic process, despite the negative views of professionals reported earlier in this document.

Conclusion

This report summarizes the statistical analyses from the pre-, post-, and recommendation assessment surveys collected from two events that engaged healthcare professionals. In addition to showing participant diversity, the results reveal several interesting, but statistically insignificant, individual-level changes. Specifically, the professionals' views on various issues regarding patient engagement and citizen participation in health policy tended to improve – if only slightly – after participation. Furthermore, the results show that professionals thought more highly of recommendations developed by consumers than recommendations developed by the IOM, and believed that the Deliberative Recommendations created as a part of this project were the most likely to have positive impacts on reducing diagnostic error and improving diagnostic quality. Of course, these results are limited due to the small sample sizes and statistical insignificance of most results. Nevertheless, they suggest that deliberative sessions could help to change professionals' attitudes about patient engagement. Moreover, the assessment results show that patients are able to develop recommendations that are as good as (or even better) than those developed by professionals. This result speaks directly to the ultimate goal of this project.

Appendix 1: Clinician Support for Patient Activation Measure (CS-PAM)

Clinicians have different views and expectations about their patients. Please respond to the statements below as they apply to you and your practice. If the statement does not apply, select N/A.

As a Clinician, how important is it to you that your patients with chronic conditions:

a.	Are able to take actions that will help prevent or minimize symptoms associated with their health condition(s)?	Not Important	Somewhat Important	Important	Extremely Important	N/A
b.	Are able to make and maintain lifestyle changes needed to manage their chronic condition?	Not Important	Somewhat Important	Important	Extremely Important	N/A
c.	Can follow through on medical treatments you have told them they need to do at home?	Not Important	Somewhat Important	Important	Extremely Important	N/A
d.	Understand which of their behaviors make their chronic condition better and which ones make it worse?	Not Important	Somewhat Important	Important	Extremely Important	N/A
e.	Know what each of their prescribed medications is for?	Not Important	Somewhat Important	Important	Extremely Important	N/A
f.	Are able to figure out solutions when new situations or problems arise with their health condition(s)?	Not Important	Somewhat Important	Important	Extremely Important	N/A
g.	Are able to determine when they need to go to a medical professional for care and when they can handle the problem on their own?	Not Important	Somewhat Important	Important	Extremely Important	N/A
h.	Want to be involved as a full partner with you in making decisions about their care?	Not Important	Somewhat Important	Important	Extremely Important	N/A
i.	Tell you the concerns they have about their health even when you do not ask?	Not Important	Somewhat Important	Important	Extremely Important	N/A
j.	Want to know what procedures or treatments they will receive and why before the treatments or procedure are performed?	Not Important	Somewhat Important	Important	Extremely Important	N/A
k.	Understand the different medical treatment options available for their chronic condition(s)?	Not Important	Somewhat Important	Important	Extremely Important	N/A
l.	Look for trustworthy sources of information about their health and health choices, such as on the web, news stories, or books?	Not Important	Somewhat Important	Important	Extremely Important	N/A
m.	Bring a list of questions to their office visit?	Not Important	Somewhat Important	Important	Extremely Important	N/A

Appendix 2: Three Sets of Recommendations in Assessment Survey

SET A: Recommendations by Participants in Deliberation

Recommendation 1 – *Present symptoms clearly and completely*

- Be truthful about your symptoms and other behaviors when telling your doctor about your history to ensure information is accurate.
- Be prepared to discuss your symptoms. For example, 8 characteristics of symptoms are quantity, quality, aggravating factors, alleviating factors, setting, associated symptoms, location, and timing.

Recommendation 2 – *Assert yourself in the relationship*

- Be clear, concise, and persistent in communicating your symptoms and concerns.
- Ask detailed questions of your doctor, including a plan to arrive at a diagnosis so the doctor remains engaged and focused on your concerns. For example, “could these symptoms indicate something else or an additional issue?”
- Notify your health care provider if your condition worsens, does or doesn’t improve, or if new symptoms develop.
 - The treatment plan could change based on new information and potentially a new diagnosis.
 - Potential new urgency could affect the health care provider’s level of attention.
- If you’re concerned about the accuracy of the diagnosis, seek a second opinion.

Recommendation 3 – *Coordinate your care*

- Find a primary care provider/family doctor so that they can better coordinate and manage your health care.
- Enlist a patient advocate, as needed, to assist you in coordinating care.
- Have your primary care provider manage all your records to ensure they are accessible to other providers.
- Seek out a health system where different doctors work together frequently, share consistent information, and coordinate services effectively.

Recommendation 4 – *Ensure accurate records and tests*

- Maintain and update your own medical record, which includes test results, doctor notes, images, communication with providers, and other information pertinent to your medical history.
- If you have access to your electronic medical records or a patient portal, use that. If you don’t have access, ask for a physical copy of your records and/or any recent updates.
- If you notice a factual inaccuracy with your medical record, advocate and insist to have the error corrected.

Recommendation 5 – *Manage your care*

- Ensure communications and expectations are clear between you and your health care provider.
- Throughout the relationship, follow through on your health care provider’s recommendations regarding the course of action to reach an accurate diagnosis. For example, completing lab tests, going to appointments with specialists, taking medications as prescribed.
- Follow up with your health care provider after appointments to obtain test results to ensure proper testing was conducted. Thus, both patient and health care provider are accountable.

SET B: Recommendations by Professionals (Institute of Medicine)

Recommendation 1 – *Facilitate more effective teamwork in the diagnostic process among health care professionals, patients, and their families*

- Health care organizations should recognize that the diagnostic process is a dynamic team-based activity.
- Health care organizations should ensure that health care professionals have the appropriate knowledge, skills, resources, and support to engage in teamwork in the diagnostic process.

Recommendation 2 – *To improve the diagnostic process, health care organizations should facilitate and support:*

- Inter-professional and intra-professional teamwork in the diagnostic process.
- Collaboration among pathologists, radiologists, other diagnosticians, and treating health care professionals to improve diagnostic testing processes.

Recommendation 3 – *Health care professionals and organizations should partner with patients and their families as diagnostic team members and facilitate patient and family engagement in the diagnostic process, aligned with their needs, values, and preferences. To accomplish this, they should:*

- Provide patients with opportunities to learn about the diagnostic process.
- Create environments in which patients and their families are comfortable engaging in the diagnostic process and sharing feedback and concerns about diagnostic errors and near misses.
- Ensure patient access to electronic health records (EHRs), including clinical notes and diagnostic testing results, to facilitate patient engagement in the diagnostic process and patient review of health records for accuracy.
- Identify opportunities to include patients and their families in efforts to improve the diagnostic process by learning from diagnostic errors and near misses.

SET C (Recommendations by Education-only Participants)

Recommendation 1 – *Communicate clearly and efficiently*

- Listen carefully to your health care providers and present your symptoms clearly.
- Be honest and give full information to your health care providers.
- Come prepared to the visit. Bring a list of questions, concerns, or issues to share with your health care provider.

Recommendation 2 – *Advocate for yourself actively*

- Be confident about your rights in the relationship with health care providers.
- If you disagree with your diagnosis, seek a second opinion.
- Get support from your advocates (family members or friends) during the visits.

Recommendation 3 – *Be informed about your health, symptoms, diagnosis, and treatment.*

- Know your family history about health-related problems.
- Do your own research on your symptoms and the diagnoses you have received.
- Have information about each medicine you take and its possible side effects.
- Keep records of your own health and behaviors.

Appendix 3: Comparison of Assessment Scores of All the Recommendations

Recommendation	Under-stand	Likely Use	Diff to use	Improve	Approp. You	Approp. other
<p>Category #1: Present symptoms clearly and completely. (Deliberation)</p> <ul style="list-style-type: none"> • Be truthful about your symptoms and other behaviors when telling your doctor about your history to ensure information is accurate. • Be prepared to discuss your symptoms. For example, 8 characteristics of symptoms are quantity, quality, aggravating factors, alleviating factors, setting, associated symptoms, location and timing. 	24/9	3.21	2.76.	4.11	4.63	4.54
<p>Category #4: Assert yourself in the relationship. (Deliberation)</p> <ul style="list-style-type: none"> • Be clear, concise, and persistent in communicating your symptoms and concerns. • Ask detailed questions of your doctor, including a plan to arrive at a diagnosis so the doctor remains engaged and focused on your concerns. For example, “could these symptoms indicate something else or an additional issue?” • Notify your health care provider if your conditions worsens, does or doesn’t improve, or if new symptoms develop. <ul style="list-style-type: none"> • The treatment plan could change based on new information and potentially a new diagnosis. • Potential new urgency could affect the health care provider’s level of attention. • If you’re concerned about the accuracy of the diagnosis, seek a second opinion 	25/9	3.04	2.64	4.11	4.54	4.31
<p>Category #6: Coordinate your care. (Deliberation)</p> <ul style="list-style-type: none"> • Find a primary care provider/family doctor so that they can better coordinate and manage your health care. • Enlist a patient advocate, as needed, to assist you in coordinating care. • Have your primary care provider manage all your records to ensure they are accessible to other providers. • Seek out a health system where different doctors work together frequently, share consistent information, and coordinate services effectively. 	31/3	2.97	2.29	4.23	4.46	4.47
<p>Category #8: Ensure accurate records and tests. (Deliberation)</p> <ul style="list-style-type: none"> • Maintain and update your own medical record, which includes test results, doctor notes, images, communication with providers, and other information pertinent to your medical history. • If you have access to your electronic medical records or a patient portal, use that. If you don’t have access, ask for a physical copy of your records and/or any recent updates. • If you notice a factual inaccuracy with your medical record, advocate and insist to have the error corrected. 	32/3	2.53	2.24	3.76	4.09	3.88
<p>Category #10: Manage your care (Deliberation)</p> <ul style="list-style-type: none"> • Ensure communications and expectations are clear between you and your health care provider. • Throughout the relationship, follow through on your health care provider’s recommendations regarding the course of action to reach an accurate diagnosis. For example, completing lab tests, going to appointments with specialists, taking medications as prescribed. • Follow up with your health care provider after appointments to obtain test results to ensure proper testing was conducted. Thus, both patient and health care provider are accountable. 	32/2	2.89	2.79	4.16	4.63	4.43

<p>Category #3: Communicate clearly and efficiently. (Education)</p> <ul style="list-style-type: none"> • Listen carefully to your health care providers and present your symptoms clearly. • Be honest and give full information to your health care providers. • Come prepared to the visit. Bring a list of questions, concerns, or issues to share with your health care provider. 	33/2	3.76	3.31	4.26	4.69	4.50
<p>Category #7: Advocate for yourself actively. (Education)</p> <ul style="list-style-type: none"> • Be confident about your rights in the relationship with healthcare providers. • If you disagree with your diagnosis, seek a second opinion. • Get support from your advocates (family members or friends) during the visits 	31/4	3.23	2.89	3.57	4.09	3.86
<p>Category #11: Be informed about your health, symptoms, diagnosis, and treatment. (Education)</p> <ul style="list-style-type: none"> • Know your family history about health-related problems. • Do your own research on your symptoms and the diagnoses you have received. • Have information about each medicine you take and its possible side effects. • Keep records of your own health and behaviors. 	34/1	2.79	2.69	3.49	4.26	4.11
<p>Category #2: Facilitate more effective teamwork in the diagnostic process among healthcare professionals, patients, and their families. (IOM)</p> <ul style="list-style-type: none"> • Health care organizations should recognize that the diagnostic process is a dynamic team-based activity. • Health care organizations should ensure that health care professionals have the appropriate knowledge, skills, resources, and support to engage in teamwork in the diagnostic process. 	34/0	3.43	2.40	4.35	4.77	4.54
<p>Category #5: To improve the diagnostic process, health care organizations facilitate and support: (IOM)</p> <ul style="list-style-type: none"> • Inter-professional and intra-professional teamwork in the diagnostic process. • Collaboration among pathologists, radiologists, other diagnosticians, and treating health care professionals to improve diagnostic testing processes. 	33/0	3.57	2.60	4.40	4.74	4.61
<p>Category #9: Health care professionals and organizations should partner with patients and their families as diagnostic team members and facilitate patient and family engagement in the diagnostic process, aligned with their needs, values, and preferences. To accomplish this, they should: (IOM)</p> <ul style="list-style-type: none"> • Provide patients with opportunities to learn about the diagnostic process. • Create environments in which patients and their families are comfortable engaging in the diagnostic process and sharing feedback and concerns about diagnostic errors and near misses. • Ensure patient access to electronic health records (EHRs), including clinical notes and diagnostic testing results, to facilitate patient engagement in the diagnostic process and patient review of health records for accuracy. • Identify opportunities to include patients and their families in efforts to improve diagnostic process by learning from diagnostic errors and near misses. 	33/2	2.63	2.36	3.79	4.23	4.06