

**Initial Phases of a Randomized Study of
Public Deliberation about Diagnostic Error:
An Analysis of the 2016 Healthcare Consumer Event***

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Executive Summary

This report presents the results from the third healthcare consumer event held as part of the research study, *Using Public Deliberation to Define Patient Roles in Reducing Diagnostic Error*. Specifically, this report summarizes the analyses from the pre- and post-surveys collected at the healthcare consumer event held on February 6, 2016 at the OnCenter in Syracuse, New York. During this event, the participants in this group learned about and discussed diagnostic error, and reviewed the recommendations developed in 2015 by a deliberation group.

We present the results in four broad categories: (1) demographics; (2) individual-level impacts, including patient activation, trust in doctors, perceptions and knowledge about diagnostic error, perceptions about patient engagement, and health literacy; (3) assessment of the recommendations for improving the diagnostic process and reducing diagnostic error; and (4) participant satisfaction. Overall, the results show that:

- Participants were diverse across a number of *socio-demographic indicators*.
- Participants experienced statistically significant increases in *patient activation, trust in doctors, and perceptions about diagnostic error*.
- The percentage of participants who correctly answered a question measuring their *knowledge about diagnostic error* increased.
- Participants' *perceptions about patient engagement* changed after deliberation, with statistically significant changes in their beliefs about the *role of patients in the diagnostic process*.
- Participants experienced a statistically significant increase in *health literacy*.
- Participants judged *the recommendations* for improving the diagnostic process and reducing diagnostic error as being understandable, feasible, easy to follow, and impactful.
- Participants reported high levels of *satisfaction* with all elements of the event.

Initial Phases of a Randomized Study of Public Deliberation about Diagnostic Error: An Analysis of the 2016 Healthcare Consumer Event

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 errors, 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 groups), and assess the perceived quality of recommendations developed through a deliberative process.

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 a deliberation group, an education group, a participatory feedback group, and a control group. In 2015, participants in the education and deliberation group received the same, 3-hour information session. Participants in the deliberation group discussed this information and focused on: (1) the roles patients are willing and able to play in preventing, identifying, and reporting diagnostic error; (2) the strategies that should be used to enable patients to play those roles; and (3) the changes needed in systems and structures for patients to assume those roles. Based on their discussions, the deliberation group then developed a set of practical, patient-focused recommendations for reducing diagnostic error.¹

The participatory feedback group, which consisted of 95 randomly selected individuals, met on February 6, 2016 at the OnCenter in Syracuse, New York. Upon arrival, each person joined their randomly assigned table, which included approximately 6-8 diverse participants and a table facilitator, and completed a pre-intervention survey. The event opened with an introductory lecture by an expert in diagnostic error, which was followed by a question and answer session with the presenters. The facilitation team then described the process in which the deliberation group engaged in 2015, and representatives from the deliberation group discussed their experience and responded to questions. Next, the participants were presented with the recommendations produced by the deliberation group and asked to complete a short survey to assess various facets of their quality. Participants in the consumer feedback group engaged in a series of deliberative discussions about diagnostic error through the remainder of the day and completed a post-intervention survey at the close of the event.

This report presents analyses of the data from the pre- and post-intervention surveys and the survey about the recommendations. We present the results in four broad categories: (1) demographics; (2) individual-level impacts, including patient activation, trust in doctors, perceptions and knowledge about diagnostic error, perceptions about patient engagement, and health literacy; (3) assessment of the recommendations for improving the diagnostic process and reducing diagnostic error; and (4) participant satisfaction.

Demographics

Table 1 provides demographic information for 92 of the 95 participants.¹ The table shows that the participants were fairly diverse on a number of indicators, including gender, race, age, education, employment status, and income.

Of the 92 respondents, 31 were male, 61 were female. The participants were also racially diverse: 58 were White, 18 were African American, 5 were Hispanic, 1 was Asian, and 8 were Multi-Ethnic. Two participants reported “other” for race.

In terms of employment status, 20 participants were unemployed, 22 were employed part-time, 26 were employed full-time, and 9 were retired. Of the remaining participants, 5 were in school and 10 indicated “other.”

There was also a broad range of annual income distributions among the participants: 49 earned less than \$29,999; 26 earned between \$30,000 and \$59,999; 6 earned between \$60,000 and \$89,999; and 10 earned more than \$100,000.

Finally, almost all the participants (84 out of 90) indicated that they had access to the Internet.

¹ A total of 95 people participated in the event. Of those 95 people, 93 people completed the pre- survey, 91 people completed post- survey, and 89 people completed both. Questions for demographic information were asked only in pre- survey; however, one participant did not answer this set of questions. Of the 92 participants who did respond to these questions, one person did not report age, one person did not report income, and two people did not provide information about internet access.

Table 1: Demographic Information of Participants

		Participatory Feedback Group (N=92)
Gender	Male	31
	Female	61
Race	Black/African American	18
	White/Caucasian	58
	Hispanic/Latino(a)	5
	Asian/Asian-Indian	1
	Multi-Ethnic	8
	Other	2
	Unknown	0
Age	18-21	4
	22-35	32
	36-45	17
	46-55	20
	56-65	12
	66-75	5
	Over 76	1
Education	Some high school	5
	High school graduate	15
	Some college, no degree	29
	Associate's degree	10
	Bachelor's degree	11
	Graduate or professional degree	22
Employment	Unemployed	20
	Part-time	22
	Full-time	26
	Retired	9
	In school	5
	Other	10
Income	Under \$10,000	18
	\$10,000-\$19,999	16
	\$20,000-\$29,999	15
	\$30,000-\$39,999	14
	\$40,000-\$49,999	6
	\$50,000-\$59,999	6
	\$60,000-\$69,999	2
	\$70,000-\$79,999	3
	\$80,000-\$89,999	1
	\$90,000-\$99,999	0
\$100,000 or more	10	
Internet	Yes	84
	No	6

Individual-Level Impacts

This section reports on the impacts of the participatory feedback session on various individual-level outcomes, including: patient activation, trust in doctors, perceptions and knowledge about diagnostic error, perceptions about patient engagement, and health literacy. To measure patient activation, we use the Patient Activation Measure, 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 the statistical analyses and the results are reported in a series of tables and figures that provide pre-post comparisons. Below we present and discuss the results for each of the individual-level impacts.

Patient Activation

The Patient Activation Measure (PAM), licensed by Insignia Health, uses a Guttman scale to assess individuals' "knowledge, skills and confidence for managing their own health."² Specifically, the 13-item measure (see Appendix 1) places individuals on a 0-100 scale, where higher scores indicate greater levels of patient activation and empowerment. The scores can be further segmented into four activation levels: (1) the individual is disengaged and overwhelmed; (2) the individual is becoming aware, but is still struggling; (3) the individual is taking action; and (4) the individual is maintaining behaviors and pushing further to adopt a healthy lifestyle. Thus, this measure conceptualizes patient activation as a hierarchically structured development process, where individuals can progress through the levels to become more fully activated in their health management. The levels of patient activation are described further in Figure 1.



Figure 1: Four Levels of the Patient Activation Measure

Table 2 shows that on average, participants experienced a statistically significant increase in their PAM scores. Specifically, the group's mean PAM score increased by 2.45, which is statistically significant at the 5% level. This result suggests that receiving information about diagnostic error and engaging in deliberative discussion can have a powerful impact on patient activation.

² J.H. Hibbard, et al. (2004). Development of the Patient Activation Measure (PAM): Conceptualizing and Measuring Activation in Patients and Consumers, *Health Service Research*, 39(4): 1005–1026.

Table 2: Patient Activation

N	88
Before	63.01
After	65.46
Difference	2.45**

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

To further assess patient activation, we more closely examined variations in PAM levels before and after the intervention. As noted above, the PAM measure segments people into one of four levels based on their scores.³ Level 1, where patients “may not yet believe that the patient role is important,” includes individuals with a PAM score of 47.0 or lower. Level 2, where patients “lack confidence and knowledge to take action,” includes individuals with a PAM score between 47.1 and 55.1. Level 3, where patients are “beginning to take action,” includes individuals with a PAM score between 55.2 and 67.0. Level 4, where patients “have made most of the necessary behavior changes, but may have difficulties maintaining behaviors over time,” includes individuals with a PAM score of 67.1 or higher.

Figure 2 shows the cumulative changes in PAM levels among the participatory feedback group as a whole, and uses the data from all of the pre- and post-surveys. The results show that participation increased the number of people in PAM Level 4, which represents the highest level of patient activation, and decreased the number of people in PAM Levels 2 and 3. More specifically, prior to the event, 22 participants were at Levels 1 or 2 (3 and 19 respectively) and 70 were at Levels 3 and 4 (51 and 19 respectively). After the event, 19 participants were at Levels 1 or 2 (4 and 15 respectively), and 72 were at levels 3 and 4 (47 and 25 respectively).

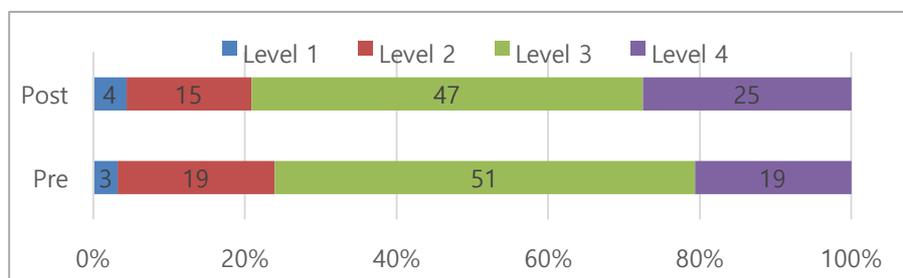


Figure 2: PAM Levels Before and After the Event

An assessment of the individual results among the Participatory Feedback Group provides a more nuanced analysis of the changes in PAM scores. Table 3 reports data from the 88 participants who completed all of the PAM questions on both the pre- and post-surveys. In this table, 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 PAM level on the pre-survey, and the columns indicate the number of individuals at each PAM level on the post-survey. The shaded cells show those participants whose PAM levels did not change after the event. The cells

³ Insignia Health, 2013. *Patient Activation Measure (PAM) 13 License Materials*. 1-9. (<http://drierivieren.be/resources/resellers/37/38/27/files/Patient%20Survey%20-%20PAM%2013%20license%20package%202013.pdf>)

below the shaded ones show the number of participants whose PAM levels decreased, while the cells above show the number of participants whose PAM levels increased.

Several points from this table are worth noting. First, the majority of participants (53) experienced no change in their PAM levels. Specifically, two participants began and ended the event at Level 1, six began and ended at Level 2, thirty-one began and ended at Level 3, and fourteen began and ended at Level 4. Second, fourteen participants experienced a decrease in their PAM levels, with two moving from Level 2 to Level 1, seven moving from Level 3 to Level 2, and five moving from Level 4 to Level 3. Finally, twenty-one participants experienced an increase in their PAM levels, with one participant moving from Level 1 to Level 2, nine participants moving from Level 2 to Level 3, two participants moving from Level 2 to Level 4, and nine participants moving from Level 3 to Level 4.

Table 3: Individual PAM Level Changes Before and After the Event

PAM Level Pre-Survey	PAM Level Post-Survey				Total
	1	2	3	4	
1	2	1	0	0	3
2	2	6	9	2	19
3	0	7	31	9	47
4	0	0	5	14	19
Total	4	14	45	25	88

Trust in Doctors

To measure trust in doctors, we use an additive index ($\alpha=0.73$) consisting of three 5-point Likert scale items, where 1 = strongly disagree to 5 = strongly agree:

1. “Doctors are extremely thorough and careful.”
2. “I trust my doctors’ decisions about which medical treatments are best for me.”
3. “All in all, I trust doctors completely.”

As seen in Table 4, the group experienced a statistically significant increase in their mean scores for trust in doctors. The before-after difference for the participants was 0.15, which is significant at the 5% level. It is interesting to note, however, the nature of this movement. Specifically, the participants entered and left the session feeling rather neutral on the issue of trust in doctors, with a mean score before and after of 3.06 and 3.21 respectively. Thus, while there was movement in a positive and statistically significant direction, the group did not leave the sessions with high level of trust in doctors.

Table 4: Trust in Doctors

N	84
Before	3.06
After	3.21
Difference	0.15**

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

Perceptions and Knowledge about Diagnostic Error

To measure for participants' perceptions about the seriousness of diagnostic errors, we constructed an additive index ($\alpha=0.48$)⁴ using two 5-point Likert scale questions, where 1 = strongly disagree and 5 = strongly agree:

1. "Diagnostic errors are a serious issue in the medical profession."
2. "Diagnostic error is an under-recognized and under-studied problem."

The results, shown in Table 5, show that the participants entered the event believing diagnostic error to be an important problem, and experienced a statistically significant increase in their perceptions about the seriousness of diagnostic error after the event. Specifically, the difference was 0.22, which is significant at the 1% level. This increase is not surprising, given that the group was presented with ample information about the frequency, causes, and consequences of diagnostic error.

Table 5: Perceptions about Diagnostic Error

N	83
Before	3.95
After	4.18
Difference	0.22**

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

In addition to perceptions about diagnostic error, we also attempted to measure 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 6 shows the percentage of people who selected the correct answer ("1 in 10") before and after the session. Although we cannot calculate statistical significance, the results are noteworthy. Prior to the event approximately 26% of participants answered the question correctly. After the event, approximately 37% of participants answered the question correctly.

Table 6: Knowledge about Diagnostic Error

Before Event	20 out of 76 (26%)
After Event	28 out of 74 (37%)

Perceptions about Patient Engagement

We have two measures for perceptions about patient engagement. The first assesses perceptions about who has responsibility for diagnostic errors; the second assesses perceptions about the role of patients in the diagnostic process.

To measure responsibility for diagnostic error, we created an additive index ($\alpha=0.71$) using two

⁴ The alphas for this index were higher in previous studies. Thus, despite the low alpha here, we have opted to keep the measure for the purposes of consistency across reports.

5-point Likert scale items, where 1 = strongly disagree and 5 = strongly agree:

1. “Diagnostic error is the sole responsibility of physicians.”
2. “Patients do not contribute to diagnostic error.”

Higher numbers attribute the responsibility for diagnostic errors to healthcare providers, while lower numbers indicate that patients can (and perhaps should) take responsibility in the diagnostic process. The results, presented in Table 7, show that the participants’ perceptions about responsibility for diagnostic error declined slightly (-0.13), but not significantly. Specifically, although they attributed less responsibility to providers and more to patients, this change is not strong.

Table 7: Responsibility for Diagnostic Error

N	84
Before	2.54
After	2.41
Difference	-0.13

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

To measure perceptions about the role of patients in the diagnostic process, we created another additive index ($\alpha=0.67$) using three 5-point Likert scale items, where 1 = strongly disagree and 5 = strongly agree:

1. “If doctors and patients interacted more during visits, then the frequency of diagnostic error could be reduced.”
2. “Patients can play a critical role in improving diagnostic quality.”
3. “I find patient engagement to be an interesting medical issue.”

Higher numbers indicate more positive perceptions about the role a patient can play in the diagnostic process. The results, presented in Table 8, show that the participants experienced a statistically significant change in the perceptions about the role of patients in the diagnostic processes. Specifically, the increase was 0.24, which is significant at the 1% level. This suggests that participants recognized the importance of their roles in healthcare and that participation can improve perceptions about patient engagement in the diagnostic process.

Table 8: The Role of Patients in the Diagnostic Process

N	86
Before	4.13
After	4.38
Difference	0.24***

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

Health Literacy

Health literacy, defined as “the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions,”⁵ is an important indicator in developing patient-focused strategies in healthcare service delivery. We measure health literacy using three individual survey items, all of which use a 5-point Likert scale, where 1 = strongly disagree to 5 = strongly agree.⁶ The results for each individual question are reported in Table 9.

The first item is: “I am confident that I can review and understand results from diagnostic tests.” As Table 9 shows, participants experienced a statistically significant increase in their belief that they could review and understand test results. Specifically, the increase was 0.23, which is significant at the 1% level.

The second item is: “I can communicate with my doctor electronically (via a computer or smart phone) about my healthcare questions, concerns, or comments.” The results show that the participants experienced an increase of 0.73, which is significant at the 1% level.

The final item is: “I am willing to ask my healthcare provider to wash his or her hands (if I did not see them do this) before examining me.” The results again show that participants experienced a statistically significant increase. Specifically, the increase was 0.23, which is significant at the 1% level.

In short, participants experienced a statistically significant increase on all indicators of health literacy. Together, these results suggest that deliberative discussions can improve health literacy.

Table 9: Health Literacy

	Question 1 - Review and Understand Test Results	Question 2 – Electronic Communication with Doctors	Question 3 – Ask Provider to Wash Hands
N	88	88	86
Before	3.56	2.7	3.82
After	3.80	3.43	4.0
Difference	0.23**	0.73***	0.23***

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

Assessment of the Recommendations for Improving Diagnosis

As noted in the introduction, a different group met in August and October 2015 to develop a set of recommendations for improving the diagnostic process and reducing diagnostic error. At

⁵ U.S. Department of Health and Human Services. (2000). *Healthy People 2010: General Data Issues*. Washington, DC: U.S. Government Printing Office.

(http://www.cdc.gov/nchs/data/hpdata2010/hpdata2010_general_data_issues.pdf)

⁶ A factor analysis revealed that the three items measure different aspects of health literacy. Because the items did not cluster into a single factor, we could not construct a health literacy index.

the third event in February, the participatory feedback group was presented with the recommendations and asked to complete a survey that assessed various facets of their quality. Specifically, the participants were asked to answer the following four questions for each recommendation:

1. Do you understand this recommendation? (Yes or No)
2. How likely is it that you would use this recommendation in your own healthcare? (5-point scale: Extremely Unlikely, Unlikely, Neutral, Likely, Extremely Likely)
3. How difficult would it be for you to use this recommendation in your own healthcare? (5-point scale: Very Difficult, Difficult, Neutral, Easy, Very Easy)
4. If patients followed through on this recommendation, how much would it improve diagnostic quality? (5-point scale: No Improvement, Minor Improvement, Neutral, Moderate Improvement, Major Improvement)

The results for all recommendations are presented in Table 10, which shows the responses to each question about the recommendations, including frequencies and percentages. In the following discussion, we show each recommendation in a box and report the results.

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 generally positive. Specifically, the results show that almost all of the respondents (97.8%) understand this recommendation. Moreover, 91.3% of participants reported that they are extremely likely or likely to use this recommendation in their own healthcare; however, only 79.2% of participants responded that it would be very easy or easy to use it. Finally, 93.5% of participants reported that this recommendation would have a major or moderate impact on improving diagnostic quality.

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 also generally positive. Specifically, all of the participants understand this recommendation, and 94.6% are extremely likely or likely to use

it in their own healthcare. However, only 75.9% of participants responded that it would be very easy or easy to use this recommendation. Nevertheless, 92.3% of participants believed that it would have a major or moderate impact on improving diagnostic quality.

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.

The results for Recommendation 3 are good, but generally weaker than the others. Specifically, while almost all respondents (98.9%) understand this recommendation, only 74.5% reported that they are extremely likely or likely to use it in their own healthcare and only 64.9% of respondents stated that it would be very easy or easy to use. However, despite the potential challenges of using the recommendation, 86.9% of participants responded that it would have a major or moderate impact on improving diagnostic quality.

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.

The assessments of Recommendation 4 are also good, but not as strong as the others. Although all of the participants understood this recommendation, only 81.1% of reported that they are extremely likely or likely to use it in their own healthcare, and only 63.3% responded that it would be very easy or easy to use. Again, however, despite the potential challenges of using the recommendation, 86.7% of participants believed that it would have a major or moderate impact on improving diagnostic quality.

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.

The assessments of Recommendation 5 are generally very positive. Specifically, all of the participants understand this recommendation. Moreover, 91.1% reported that they are extremely likely or likely to use it in their own healthcare, 78.9% of participants responded that it would be very easy or easy to use, and 91.2% responded that this recommendation would have a major or moderate impact on improving diagnostic quality.

Table 10: Assessments of Recommendations

		Rec 1	Rec 2	Rec 3	Rec 4	Rec 5
<i>Do you understand this recommendation?</i>	Yes	89 (97.8%)	91 (100%)	90 (98.9%)	90 (100%)	90 (100%)
	No	2 (2.2%)	0 (0.0%)	1 (1.1%)	0 (0.0%)	0 (0.0%)
<i>How likely is it that you would use this recommendation in your own healthcare?</i>	Extremely Unlikely	0 (0.0%)	0 (0.0%)	1 (1.1%)	3 (3.3%)	0 (0.0%)
	Unlikely	2 (2.2%)	1 (1.1%)	6 (6.7%)	5 (5.6%)	2 (2.2%)
	Neutral	6 (6.6%)	4 (4.4%)	16 (17.8%)	9 (10.0%)	6 (6.7%)
	Likely	36 (39.6%)	43 (47.3%)	35 (38.9%)	37 (41.1%)	39 (43.3%)
	Extremely Likely	47 (51.7%)	43 (47.3%)	32 (35.6%)	36 (40.0%)	43 (47.8%)
<i>How difficult would it be for you to use this recommendation in your own healthcare?</i>	Very Difficult	0 (0.0%)	1 (1.1%)	4 (4.4%)	4 (4.4%)	0 (0.0%)
	Difficult	8 (8.8%)	10 (11.0%)	6 (6.6%)	12 (13.3%)	5 (5.6%)
	Neutral	11 (12.1%)	11 (12.1%)	22 (24.2%)	17 (18.9%)	14 (15.6%)
	Easy	43 (47.3%)	34 (37.4%)	33 (36.3%)	28 (31.1%)	38 (42.2%)
	Very Easy	29 (31.9%)	35 (38.5%)	26 (28.6%)	29 (32.2%)	33 (36.7%)
<i>If patients followed through on this recommendation, how much would it improve diagnostic quality?</i>	No Improvement	0 (0.0%)	0 (0.0%)	0 (0.0%)	3 (3.3%)	0 (0.0%)
	Minor Improvement	1 (1.1%)	1 (1.1%)	2 (2.2%)	1 (1.1%)	1 (1.1%)
	Neutral	5 (5.5%)	6 (6.6%)	10 (11.0%)	8 (8.9%)	7 (7.8%)
	Moderate Improvement	36 (39.6%)	33 (36.3%)	30 (33.0%)	26 (28.9%)	32 (35.6%)
	Major Improvement	49 (53.9%)	51 (56.0%)	49 (53.9%)	52 (57.8%)	50 (55.6%)

In sum, the results suggest that the recommendations developed by the deliberative group in 2015 were well received by the participatory feedback group. Nearly all of the recommendations were understood by all of the participants: 100% reported understanding

Recommendations 2, 4, and 5, and 98% and 99% reported understanding Recommendations 1 and 3 respectively.

In general, however, although participants understood the recommendations, Figure 3 shows that they responded more strongly to Recommendations 1, 2, and 5 than to Recommendations 3 and 4, in terms of likelihood of use, ease of use, and potential impact. First, in terms of likelihood of use, more participants reported being likely to use Recommendations 1 (91.2%), 2 (94.6%), and 5 (91.1%), than Recommendations 3 (74.5%) and 4 (81.1%). Moreover, 7.7% and 8.9% of participants reported being unlikely to use Recommendations 3 and 4 respectively, as compared to approximately 2% or fewer of participants for the other recommendations.

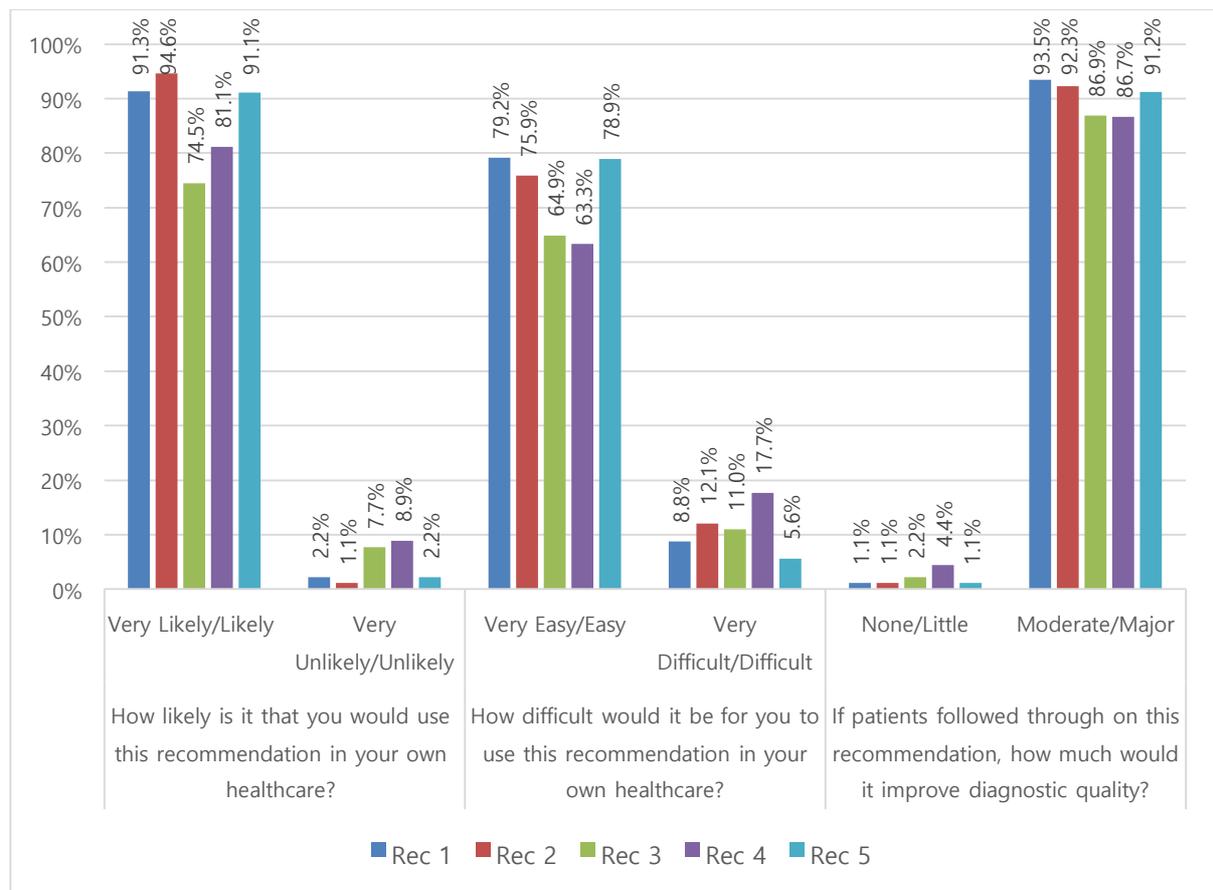


Figure 3: Summary of Recommendation Assessments

Second, the likelihood of using a recommendation seems to correspond with how easy participants believed it would be to use, and at least to some extent, to how much impact they believed it would have. Thus, the percentage of participants who believed that Recommendations 1 (79.1%), 2 (75.8%), and 5 (78.9%) would be very easy or easy to use was higher than the percentage of participants who believed that Recommendations 3 (64.8%) and 4 (63.3%) would be very easy or easy to use. Recommendation 4 was perceived as being the most challenging to use, with nearly 18% of participants suggesting that it would be very difficult or difficult to use in their own healthcare.

Similarly, the percentage of participants who believed that Recommendations 1 (93.4%), 2 (92.3%), and 5 (91.1%) would have a major or moderate impact was higher than the percentage

of participants who believed that Recommendations 3 (86.8%) and 4 (86.7%) would have a major or moderate impact. That said, it is interesting to note that only 4.4% thought Recommendation 4 would have little or no impact, and approximately only 2% or less thought that the other recommendations would have little or no impact.

Together, these results suggest that as the Society to Improve Diagnosis in Medicine works to transform these recommendations into materials that patients and providers can use to improve diagnostic quality in various healthcare settings, it should pay close attention to improving the ease with which the recommendations can be used and to improving the perceived potential for positive impact on diagnostic error.

Participant Satisfaction

This section reports on participants’ satisfaction with the event. We looked at the mean value of the survey questions related to participant satisfaction, all of which were over 4 (on 5-point Likert scale), without exception. This indicates that, on average, the participants “agreed” or “strongly agreed” that all aspects of the event were satisfactory.

Satisfaction with the Informational Session

As noted above, the participants engaged in a brief informational session at the event. Specifically, they received information about the frequency, causes, and consequences of diagnostic error, and received information on the recommendations developed by the deliberation group in 2015. To measure satisfaction with this informational session, we used seven 5-point Likert scale items, where 1 = strongly disagree to 5 = strongly agree. Table 11 reports the mean responses to these items. The mean responses range from 4.34 to 4.57, showing that the participants were highly satisfied with the informational session, including how it improved their knowledge and prepared them to participate, as well as the quality of materials offered by the presenters.

Table 11: Satisfaction with Informational Session

Survey Item	Mean
I am satisfied with the overall quality of this education session.	4.40
I enjoyed participating in this education session.	4.57
This education session improved my knowledge about diagnostic error.	4.53
This education session improved my knowledge about patient engagement.	4.47
The educational session prepared me to participate in the deliberations.	4.34
The presenters delivered clear and useful information.	4.48
The presenters offered objective and accurate information.	4.47

Satisfaction with Deliberation

To measure satisfaction with the deliberative aspects of the event, we used several 5-point Likert scale items, where 1 = strongly disagree to 5 = strongly agree. Overall, the mean

satisfaction score for all items indicate that participants were generally very satisfied with the deliberations. The following tables report participants' satisfaction with different components of deliberations, including their satisfaction with the quality, fairness and diversity, knowledge generation, and event moderators.

Table 12 reports on the satisfaction with the overall quality of deliberation, including the quality of outcomes, issues addressed, and discussions. Participants were very satisfied across all indicators, with mean scores ranging from 4.39 to 4.61.

Table 12: Satisfaction with Overall Quality of Deliberation

Survey Item	Mean
I am satisfied with the overall quality of the deliberations.	4.44
I am satisfied with the recommendations and other outcomes of the deliberations.	4.43
I am satisfied with the issues addressed in the deliberations.	4.39
I am satisfied with the quality of the discussions during the deliberations.	4.47
I enjoyed participating in the deliberations.	4.61

Table 13 shows participants' satisfaction with the fairness and diversity of the deliberations. The results show that participants were very satisfied with fairness of the process, their opportunity to participate, as well as the diversity of participants and views, with mean scores ranging from 4.40 to 4.53.

Table 13: Satisfaction with the Fairness and Diversity of the Deliberations

Survey Item	Mean
The deliberations were fair.	4.40
I had an equal opportunity to participate in the deliberations.	4.53
I am satisfied with the diversity of the people present in the deliberations.	4.48
I am satisfied with the diversity of views and opinions expressed in the deliberations.	4.49

Table 14 shows participants' satisfaction with the knowledge generated during event. The results show mean scores ranging from 4.35 to 4.52, which suggests that participants were highly satisfied with how the discussions improved their knowledge, helped them understand issues, and prepared them for participation in the event.

Table 14: Satisfaction with the Knowledge Generated

Survey Item	Mean
The deliberations improved my knowledge about diagnostic error.	4.52
The deliberations improved my knowledge about patient engagement.	4.52
The deliberations helped me understand issues related to diagnostic error and quality.	4.35
The deliberations helped me understand issues related to patient engagement.	4.40

Table 15 shows participants' satisfaction with the moderators, who played a critical role in facilitating the event. With mean scores between 4.39 and 4.56, the participants were generally very satisfied with the moderators, including their neutrality and objectiveness, performance, and fairness, as well as their treatment of participants.

Table 15: Satisfaction with Session Moderators

Survey Item	Mean
The moderator(s) of the deliberations were neutral and objective.	4.39
I am satisfied with the performance of the moderator(s) during the deliberations.	4.54
I am satisfied with the fairness of the moderator(s) during the deliberations.	4.55
I am satisfied with the way I was treated by the moderator(s) during the deliberations.	4.56
I am satisfied with the way others were treated by the moderator(s) during the deliberations.	4.56

Conclusion

This report summarizes the statistical analyses from data collected from the consumer participatory feedback event held on February 6, 2016. In addition to showing the diversity of the participants, the results show several interesting individual-level effects of the impacts of deliberative participation on issues related to diagnostic error. Specifically, participation in this event had statistically significant and positive impacts on patient activation, trust in doctors, perceptions about diagnostic error, perceptions about patient engagement, and health literacy. Moreover, the percentage of participants who answered a question measuring their knowledge about diagnostic error also increased. These results suggest that this participatory event had meaningful individual-level impacts.

The report also explored how the participatory feedback group responded to and assessed the recommendations developed by the deliberation group. The results show that 98 to 100 percent of the participants thought the recommendations were understandable. Moreover, although there was some variation, a majority of the participants (74.5 to 94.6 percent) reported being likely to use the recommendations, a majority (63.3 to 79.2 percent) believed that the recommendations would be easy to use, and, a majority (86.7 to 93.5 percent) believed that the recommendations would have a positive impact on the diagnostic process.

Finally, the report presented information about participant satisfaction with the event. With mean responses on all satisfaction questions over 4 (on a 5-point scale), the participants were generally very satisfied with the event, including the informational session and various aspects of the discussions.

Appendix 1: Patient Activation Measure (PAM)

a.	When all is said and done, I am the person who is responsible for taking care of my health.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
b.	Taking an active role in my own health care is the most important thing that affects my health.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
c.	I am confident I can help prevent or reduce problems associated with my health.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
d.	I know what each of my prescribed medications do.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
e.	I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
f.	I am confident that I can tell a doctor concerns I have even when he or she does not ask.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
g.	I am confident that I can follow through on medical treatments I may need to do at home.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
h.	I understand my health problems and what causes them.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
i.	I know what treatments are available for my health problems.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
j.	I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
k.	I know how to prevent problems with my health.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
l.	I am confident I can figure out solutions when new problems arise with my health.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A
m.	I am confident that I can maintain lifestyle changes, like eating right and exercising, even during times of stress.	Disagree Strongly	Disagree	Agree	Agree Strongly	N/A