# AHRQ Grant Final Project Report

## Title of Project

Using Public Deliberation to Define Patient Roles in Reducing Diagnostic Error

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# Structured Abstract

**Purpose**: To engage healthcare consumers in deliberation to develop patient-centered recommendations for reducing diagnostic error and to investigate the efficacy of deliberative methods for engaging consumers in healthcare issues.

**Scope**: This project assessed the individual level impacts of participation on healthcare consumers and professionals, examined consumer and professional perceptions about the quality of the recommendations, and gauged the degree to which the Society to Improve Diagnosis in Medicine (SIDM) intends to use the recommendations in strategic planning efforts.

**Methods**: A randomized and controlled experimental design was used to engage consumers in a control group or one of three treatment groups: (1) an education group that learned about diagnostic error, (2) a deliberation group that developed recommendations, or (3) a participatory feedback group that assessed the quality of the recommendations. A nonexperimental pre-posttest design was used to engage professionals in participatory focus groups during which they learned about diagnostic error and evaluated the quality of the recommendations.All consumers and professionals were administered pre and post surveys, along with other survey instruments when necessary. A debriefing session was held with SIDM personnel to discuss how the project results would inform its strategic planning.

**Results**: The deliberation group developed a set of recommendations that was well received by other healthcare consumers and professionals. Deliberation was found to have stronger individual-level effects on participants than education or participatory feedback. SIDM was pleased with the outcomes of the project and plans to use the recommendations in future efforts.

**Key Words**: Diagnostic Error, Patient Safety, Public Deliberation

# Purpose

This innovative project, *Using Public Deliberation to Define Patient Roles in Reducing Diagnostic Error,* responded to AHRQ's interest in exploring the use of deliberative methods for convening patients (or the public) to address complex issues related to the implementation of healthcare policies, programs, or other decisions relevant to healthcare research or policymaking. Per the grant requirements, awardees were expected to (1) use deliberation to generate public input on a significant healthcare issue that would be used by a partner organization in its activities and (2) assess the efficacy of deliberation as compared to an education-only treatment.

To address the first requirement, this project used deliberative methods to engage healthcare consumers in the development of patient-centered recommendations for reducing diagnostic error. Specifically, a group of healthcare consumers explored: (1) the role(s) that 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 in systems and structures needed for patients to assume those roles. Based on their deliberations, this consumer group developed a set of patient-centered recommendations for reducing diagnostic error and improving diagnostic quality (see Results section). The Society to Improve Diagnosis in Medicine (SIDM), a partner organization, agreed to use the recommendations to inform its strategic planning for patient engagement, education, and advocacy efforts.

To investigate the efficacy of deliberative methods, this project engaged healthcare consumers in either a control group or one of three treatment groups: (1) an education group that learned about diagnostic error, (2) a deliberation group that learned about diagnostic error and developed recommendations, or (3) a participatory feedback group that learned about diagnostic error and assessed the quality of the recommendations. The project also engaged healthcare professionals in two participatory focus groups during which they learned about diagnostic error and assessed the quality of the recommendations. Our investigation included four sets of assessments:

1. *Comparative Individual-Level Impacts on Healthcare Consumers* of three participatory interventions (education, deliberation, participatory feedback).
2. *Individual-Level Impacts on Healthcare Professionals* of the participatory focus groups.
3. *Quality of the Recommendations* as perceived by healthcare consumers in the feedback group and by healthcare professionals in the focus groups.
4. *Degree to which the SIDM Intends to Use the Recommendations* in strategic planning.

## Scope

### Background and Context

*Diagnostic errors*, or diagnoses that are wrong, missed, or delayed, occur in 5-15% of cases.[1] Although exact error rates are unknown, available data suggest that it is a serious issue in both inpatient and outpatient settings. Diagnostic error is the leading cause of medical malpractice claims in the United States; when claims involve a death, diagnostic error is far and away the top allegation, at 26%.[2] It is also the number one cause of claims in ambulatory care and the number two cause of claims in hospitals, after improper performance of a procedure.[3] Based on the available data, the National Academies of Science, Engineering, and Medicine's Committee on Diagnostic Error in Health Care concluded that "most people will experience at least one diagnostic error in their lifetime, sometimes with devastating consequences."[4]

In general, diagnostic error is under-recognized, under-studied, and not integrated into quality assurance measures or activities.[5,6] Moreover, even though the system related and cognitive root causes of diagnostic error have been clarified, interventions to reduce the risk of diagnostic error are relatively new and largely untested.[7,8,9] Moreover, most proposals to reduce diagnostic error focus on physicians and health systems but may have limited impact, because both parties deny ownership of the problem: Healthcare organizations view diagnostic error as the responsibility of its physicians, who in turn believe that they are practicing at high levels.[10]

Few efforts are made to engage patients – the consumers of healthcare services – in preventing, identifying, reporting, and otherwise reducing the risk of harm from diagnostic error.[11,12] Thus, patients represent a large, untapped, and important resource for influencing and improving diagnostic quality and may be the key to making rapid and significant gains in safety. Simply put: the health field requires patient-focused strategies to reduce diagnostic error, improve patient safety and healthcare delivery, and ultimately ensure better quality health outcomes.

However, although patients report being concerned about diagnostic error and patient safety,[13] they lack understanding of diagnostic error, including what it is and how and why it occurs, and they do not know what their roles could (or should) be in preventing and reporting incidents. Moreover, traditional education or information-sharing mechanisms do not allow for the robust discussions needed to develop patient-centered recommendations, and conventional methods of inquiry, such as surveys and focus groups, do not allow for the educational element needed for patients to participate meaningfully in discussions about this complex issue. In contrast, public deliberation has the potential not only to increase patients' knowledge of issues and concepts related to the topic of diagnostic error and its reduction but also to help generate creative and practical solutions that are informed by a variety of perspectives and interests.

*Public deliberation* is an approach to participation that allows people to carefully examine an issue and arrive at a well-reasoned judgment after a period of inclusive, respectful consideration of diverse points of view.[14] More specifically, public deliberation enables people to take part in an open and accessible process of reasoned discussion during which they reflect carefully on a matter, weigh the strengths and weakness of alternative views, and aim to arrive at a decision or judgment based not only on facts and data but also on values, emotions, and other less technical considerations. It also requires that all participants have an adequate opportunity to speak and that they listen attentively, carefully consider the contributions of others, and treat each other with respect. The goal of public deliberation is to elicit how people think and feel about an issue once they learn more about it and hear from others. The process results in opinions that are not only more informed but also more stable and representative of how the public feels about an issue than opinions gathered through more traditional forms of consultation, such as polling. Accordingly, the results of public deliberation are particularly useful to policy and decision makers who want to understand how an informed public views an issue.

Public deliberation has been used to elicit input on a variety of health-related issues[15]; however, this is the first project to apply deliberative methods to the issue of diagnostic error. The project is innovative in at least three other ways. First, it used a randomized and controlled experimental design, which is seldom seen in deliberative efforts.[15,16] Second, the project and evaluation designs allowed for the exploration of the comparative impacts of three participatory models – a traditional educational approach (undertaken by the education group), a Citizen Jury approach to public deliberation (undertaken by the deliberation group), and a large-scale, but less intensive, form of deliberation (undertaken by the participatory feedback group). Finally, SIDM agreed to use the deliberatively produced recommendations to inform its strategic planning efforts.

## Participants

As noted above, this project engaged two populations: healthcare consumers and healthcare professionals. Each is discussed briefly below. (Appendix 1 provides additional demographic data for all of the healthcare consumer and healthcare professional groups.)

### *Healthcare Consumers*

All healthcare consumers were randomly selected to form a demographically representative, microcosm of the greater Syracuse, NY, area, which has higher proportions of AHRQ priority populations than the nation as a whole. Our goal was to oversample participants from several AHRQ priority populations by about 10%. Through an intensive recruitment process (discussed in the Methods section), 242 healthcare consumers were engaged in one of four groups:

1. **Education Group**. On August 27, 2015, 21 people participated in a 3-hour information session about diagnostic error that was provided by health professionals and content-matter experts.

2. **Deliberation Group**. On August 27 through August 29, 2015, 20 people participated in the deliberation group. They attended the same information session noted above but, following that session, remained and engaged in approximately 18 hours of deliberation over the remainder of the weekend, including the opportunity to interact with subject matter experts. The deliberations centered on the roles patients are willing and able to play in preventing, identifying, and reporting diagnostic error. Based on their discussions, the group produced draft recommendations for improving diagnostic quality and reducing diagnostic errors. The deliberation group reconvened October 8 through 10, 2015. They received feedback gathered by project team members at the September 2015 Diagnostic Error in Medicine Conference and then spent approximately 20 hours over the weekend deliberating and engaging in participatory activities to refine and finalize their recommendations (see Results section). They also identified obstacles to patients using the recommendations and suggested strategies to overcome those obstacles.
3. **Participatory Feedback Group**. On February 6, 2016, a participatory feedback group that included 95 individuals was convened at the OnCenter in Syracuse, NY. Upon arrival, each participant was randomly assigned to sit at a table with approximately 6-8 other participants and a table facilitator. The event opened with an introductory lecture by an expert on diagnostic error, which was followed by a question and answer session. Project team members then described the process in which the deliberation group engaged, 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, given the opportunity to discuss them in a deliberative format, and asked to assess their quality on a number of dimensions. The participants engaged in a series of deliberative discussions about diagnostic error and potential use of the recommendations through the remainder of the day.
4. **Control Group**. The control group, consisting of 108 individuals, did not participate in any project events.

Analyses of demographic information show that the four groups of healthcare consumers were fairly diverse on a number of indicators, including gender, race, age, education, employment status, and income, and that most had internet access. Analyses also show that the project was generally successful at over-enrolling women and minority participants. (See Appendix 1 for additional demographic information on the healthcare consumer groups.)

### *Healthcare Professionals*

Two groups of healthcare professionals (including physicians, nurses, and others, such as directors of surgical quality control and risk/patient safety) were engaged in two separate participatory focus group sessions:

1. **DEM Group**. The first group of healthcare professionals was convened on November 6, 2016, at the Diagnostic Error in Medicine (DEM) Conference in Los Angeles, California. A total of 18 professionals participated in the DEM group.
2. **Crouse Group**. The second group of healthcare professionals was convened on February 16, 2017, at Crouse Hospital in Syracuse, New York. A total of 17 professionals participated in the Crouse group.

Both sessions opened with an informational presentation about diagnostic error, followed by questions and answers with an expert. Next, the professionals engaged in a participatory focus group format, during which they were presented with the recommendations produced by the consumer deliberation group, given the opportunity to discuss them in a deliberative format, and asked to assess their quality on a number of dimensions. Analyses of demographic information show that the professionals in both groups were fairly diverse on a number of indicators, including gender, age, profession, and years of practice. (See Appendix 1 for additional demographic information on the healthcare professional groups.)

## Methods

### Study Design

As noted above, the overarching goals for the project were to (1) engage healthcare consumers in deliberation to develop patient-centered recommendations for reducing diagnostic error and (2) investigate the efficacy of deliberative methods for engaging consumers in important healthcare issues. We further specified the second goal as having four parts, including (a) assessing the individual level impacts on consumers of three interventions (education, deliberation, participatory feedback), (b) assessing the individual level impacts of the participatory focus groups on professionals, (c) examining the perceived quality of recommendations from the perspectives of healthcare consumers and professionals, and (d) gauging the degree to which SIDM intends to use the recommendations in strategic planning efforts. To achieve these goals, the project used a randomized and controlled experimental design to engage consumers and a non-experimental pre-post test design to engage professionals. The project team also held a debriefing session with SIDM personnel to discuss the project, its results, and how the recommendations and research would inform future activities.

### *Healthcare Consumers: Randomized and Controlled Experimental Design*

Healthcare consumers were selected and randomly assigned to participate in (1) an education group, (2) a deliberation group, (3) a participatory feedback group, or (4) a control group. Below, we discuss participant recruitment, the interventions, and data sources and collection.

**Participant Recruitment**: Several steps were taken to recruit healthcare consumers. First, a marketing firm sent a letter to 15,000 residents of Onondaga County, NY, and ads were posted on Facebook and Craigslist. The letter and the ads included information about the project and invited those interested in participating to complete an application either online or by phone. The application collected basic demographic data (gender, age, race, ethnicity, education, socioeconomic status) and information about people's recent experiences in healthcare settings (number of visits to a doctor or other healthcare professional in the past 12 months; confidence in ability to tell concerns to a doctor or other healthcare professional, even when he or she does not ask). A total of 276 consumers applied to participate. Second, the demographic and healthcare data were used to stratify the applicants into matched pairs. The research team then contacted all applicants to confirm their availability for events. Those who were no longer able to participate were replaced in the matched pairs. Finally, individuals from the matched pairs were randomly assigned to participate in either the education group or deliberation group. The remaining applicants were placed into the control group. To recruit participants for the participatory feedback group, we contacted individuals who had applied but were unavailable during the dates of the education and deliberation sessions, and we did another round of advertising on Facebook and Craigslist. After demographically stratifying the applicants, we randomly selected 100 people for the participatory feedback group. All participants in all groups received a monetary stipend that varied based on the time commitment, and participants in the education, deliberation, and participatory feedback groups received meals and were compensated for travel expenses.

**Interventions**: In addition to using a control group, three interventions were tested in this project (see the Scope section for details): (1) *Education-Only*: a 3-hour information session about diagnostic error that was provided by health professionals and experts; (2) *Deliberation*: a 6-day session modeled on the Citizen Jury,[17] which is akin to the Citizens' Panel[16] ; and (3) *Participatory Feedback*: a 6-hour event modeled on large-scale, less intensive deliberative formats.[14]

**Data Sources & Collection**: All members of all healthcare consumer groups were asked to complete pre and post surveys that captured demographic information and contained individual-level measures for patient activation,[18] trust in doctors, perceptions and knowledge about diagnostic error, perceptions about patient engagement, and health literacy. The surveys also contained, when relevant, a series of questions about satisfaction with the activities in which they engaged. In addition, members of the participatory feedback group were asked to complete a survey assessing the quality of the recommendations developed by the deliberation group. Finally, all qualitative information captured during the interventions was transcribed. Table 1 shows the overall project structure for the consumer groups, the dates of survey administration, and the number of responses.

**Table 1: Consumer Group Project Structure, Participant Numbers, and Survey Dates**

| | Intervention Groups | | | | Control Group |
|---|---|---|---|---|---|
| | Education Group | Deliberation Group | | Participatory Feedback Group | |
| | | Session 1 | Session 2 | | |
| Pre-Survey | 21<br>*(8/27/15)* | 20<br>*(8/27/15)* | --<br>*(10/8/15)* | 93<br>*(2/6/16)* | 108<br>*(10/16)* |
| Post-Survey | 21<br>*(8/27/15)* | 18<br>*(8/29/15)* | 17<br>*(10/10/15)* | 91<br>*(2/6/16)* | 73<br>*(5/16)* |
| Completed Both Pre- and Post-Survey | 21 | 16 | | 89 | 71 |
| Recommendation Assessment Survey | -- | -- | | 91<br>*(2/6/16)* | -- |

***Healthcare Professionals: Non-Experimental Pre-Post Test Design***

A non-experimental, pre-post test design was used to engage two groups of healthcare professionals in two separate participatory focus groups sessions. Below we discuss participant recruitment, the intervention, and data sources and collection.

**Participant Recruitment**: The first group of healthcare professionals (DEM Group) was convened in November at the 2016 Diagnostic Error in Medicine (DEM) Conference in Los Angeles, California. Participants 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. The second group of healthcare professionals (Crouse Group) was convened in February 2017 at Crouse Hospital in Syracuse, New York. Participants for the Crouse group were recruited through an invitation distributed by Crouse Hospital to medical staff. Attendees received three continuing medical education credits (CMEs) and a complimentary dinner.

**Interventions**: Both the DEM and Crouse groups engaged in a participatory focus group format. The intervention design for both was the same (see Scope section for details), but each was delivered by different project team members. During the 2.5-hour sessions, participants received information about diagnostic error from an expert followed by a question and answer session and then engaged in small-group discussions about diagnostic error and the recommendations.

**Data Sources & Collection**: All participants in both professional groups were asked to complete pre- and post-surveys that captured demographic information and individual-level measures for clinician support for patient activation,[19] 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. In addition, all participants were asked to complete a survey that assessed the quality of the recommendations developed by the deliberation group and to compare the quality of those recommendations with two other sets of recommendations. Finally, all qualitative information captured during the sessions was transcribed. Table 2 shows the overall structure for the professional groups, including the dates of the interventions and the number of responses to the three surveys.

**Table 2: Professional Group Project Structure, Survey Dates, and Participant Numbers**

| | DEM Group<br>*(11/6/16)* | Crouse Group<br>*(2/16/17)* |
|---|---|---|
| Pre Survey / Post Survey / Completed Both | 17 / 17 / 17 | 17 / 17 / 17 |
| Recommendation Assessment Survey | 18 | 17 |

### *Debriefing Session with SIDM*

On March 20, 2017, the project team held a meeting in Chicago (near SIDM headquarters) for project partners to review outcomes and consider strategic implications for SIDM. In addition to several project team members (Tina Nabatchi, Kyle Bozentko, Larry Pennings, Paul Epner), Diana Rusz (a research associate at SIDM), Peggy Zuckerman (co-chair of the SIDM patient engagement committee), and Pat Merryweather (Partnership for Patient Safety) participated in the meeting. The group discussed a strategic report[20] written by project team members for SIDM, which reviewed the overall project, summarized the outcomes and findings, and made suggestions for future SIDM action. In addition, the group discussed the implications of the report, generated new ideas, and reflected on practical and immediate next steps.

## Limitations

Perhaps the greatest limitation of this study is the possibility of self-selection bias in the consumer and professional groups: Those who applied or registered were likely to already be interested in healthcare or diagnosis. Although we used various incentives (e.g., monetary compensation for consumers, and CMEs or free registration for professionals) to help mitigate this issue, we might have found different results from a less-interested cohort. Another set of limitations includes the small sample sizes, especially for the consumer education and deliberation groups and the healthcare professional groups, as well as the limited geographic scope. Finally, although some measures on the surveys have been validated in scholarly research, others were developed by the project team, and most are perceptual rather than objective.

## Results

The *Patient-Centered Recommendations for Reducing Diagnostic Error and Improving Diagnostic Quality* are the major output or product of this project. In total, the consumer deliberation group developed 16 recommendations in five overarching categories.

### 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, eight 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 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.

### 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 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 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.

In addition to the recommendations, the participants also identified several obstacles that could reduce the effectiveness of the recommendations, as well as solutions that may mitigate the negative impacts of the obstacles. For the recommendations, obstacles, and solutions, see https://jefferson-center.org/patient-prescriptions/. The recommendations, obstacles, and solutions shed light on the implications of this project and are germane to follow-up studies and actions.[20]

## Principle Findings

Per the aims guiding our investigation of deliberative methods, we discuss four sets of principle findings from this project.[21,22,23,24] All analyses were conducted using STATA.

### *Comparative Individual Level Impacts on Healthcare Consumers*

With data from the pre and post surveys of the consumer groups, we used t-tests, OLS regressions, and descriptive statistics to assess the individual level impacts of three participatory formats (education, deliberation, and participatory feedback) on healthcare consumers.[21,22,23]

- T-tests suggest that all treatment groups, including the deliberation group ($p<.01$), education group ($p<.05$), and participatory feedback group ($p<.05$), experienced statistically significant increases in *patient* activation.[18] The control group did not experience significant changes on this measure. Moreover, OLS regression results indicate that, in comparison to the control group, the magnitude of the changes in patient activation was greatest for the deliberation group ($p<.01$).

- T-tests suggest that the deliberation group ($p<.05$), education group ($p<.10$), and participatory feedback group ($p<.10$) experienced statistically significant increases in *trust in doctors*, whereas the control group did not. OLS regression results indicate that, in comparison to the control group, the magnitude of changes for trust in doctors was greatest for the deliberation group ($p<.01$).

- T-tests indicate that the education group and deliberation group experienced an increase in their *perceptions about the seriousness of diagnostic error*; however, given that they strongly agreed diagnostic error was a problem at the start of their interventions, the increases were not statistically significant. In contrast, t-tests indicate that the participatory feedback group experienced a statistically significant ($p<.05$) increase in perceptions about the seriousness of diagnostic error, but OLS regression results suggest that this change was insignificant compared to the change in the control group.

- T-tests suggest that the education ($p<.10$), deliberation ($p<.01$), and participatory feedback ($p<.05$) groups experienced statistically significant increases in their *perceptions about patient participation* and specifically about the *role of patients in the diagnostic process*. However, the OLS regression results suggest that, compared to the control group, only the change for the feedback group was significant (p<.05).

- T-tests indicate that the deliberation and participatory feedback groups had statistically significant increases on three measures of *health literacy*, including the ability to (1) review and understand test results (p<.10); (2) engage in electronic communication with doctors (p<.05); and (3) ask providers to wash their hands (p<.10). OLS regression results suggest that the changes across all three measures were greatest for the deliberation group (p<.05). The education and control groups did not experience significant changes on these measures.
- The education, deliberation, and feedback groups seem to have experienced gains in *knowledge about diagnostic* error, as evidenced by the increased percentage of correct answers to a question. There was no change in the control group.
- All treatment groups reported high levels of *satisfaction* with all elements of the events in which they participated. Specifically, on a 5-point satisfaction scale, in which 5 indicates "very satisfied," the mean response for all groups on all questions was greater than 4.

### Individual-Level Impacts on Healthcare Professionals

Using data from the pre and post surveys of both professional groups, we assessed the individual-level impacts of the participatory focus groups with t-tests and descriptive statistics.[24]

- Descriptive statistics indicate that the two professional groups differed on a number of issues related to *diagnostic error* and *patient* engagement. In general, the responses to 5-point Likert scale questions indicate that the DEM group was more interested in diagnostic error and more positive about patient engagement than the Crouse group was.
- T-tests suggest that the participants in both groups experienced positive, but insignificant, changes on most individual-level indicators, including *Clinician Support for Patient Activation* (CS-PAM),[19] *perceptions about patient roles in the diagnostic process,* and *perceptions about citizen participation in health policy and diagnosis*.
- T-tests indicate that the DEM group experienced significant and positive changes in their *willingness to use the recommendations* developed by healthcare consumers (p<.01) and their *willingness to encourage other healthcare professionals to use the recommendations* (p<.10). The Crouse group did not experience significant changes on these measures.
- Both groups seem to have experienced gains in *knowledge about diagnostic error,* as evidenced by the increased percentage of correct answers to a question.

### Quality of the Recommendations

With data from the recommendation assessment surveys administered to the consumer participatory feedback group and to both of the professional groups, we used descriptive statistics and t-tests to assess the perceived quality of the recommendations.[22,24]

- Descriptive statistics show that healthcare consumers in the participatory feedback group gave positive reviews to the five overarching recommendations in terms of *understandability*, *usability*, and *potential impact*. Specifically, nearly all participants reported understanding the recommendations (98% to 100%), and a strong majority indicated that they were likely to use the recommendations in their own healthcare (75% to 95%). Moreover, a strong majority believed the recommendations would be easy to use (63% to 79%) and would have a positive impact on diagnostic quality (87% to 94%).

- Descriptive statistics show that the professionals gave mixed reviews to the five overarching recommendations in terms of *appropriateness*, *understandability*, *usability*, and *potential impact*. Specifically, they generally believed that it was appropriate for patients to use the recommendations (80% to 97%) and that the recommendations would have positive impacts on diagnostic quality (74% to 91%). However, they were skeptical about patients' ability to understand the recommendations (73% to 94%), believed that patients would find the recommendations difficult to use (37% to 71%), and doubted that patients would use the recommendations in their own healthcare (17% to 40%).
- T-tests indicate that the differences in consumer and professional views on the recommendations in terms of *understandability*, *likelihood of use*, *ease of use*, and *potential impact* on diagnostic quality were statistically significant (p<.01), with consumers being much more positive on all of these indicators.
- Compared to two other sets of recommendations developed by the project team (one from work by the National Academies of Sciences, Engineering, and Medicine,[4] and one from work by the consumer education group), healthcare professionals evaluated the recommendations created by the deliberation group as being the *most likely to reduce diagnostic error*. Specifically, on a 10-point scale, the deliberation recommendations received an average score of 7.58; the National Academies recommendations received a 7.00, and the consumer education group recommendations received a 6.69.

### *Degree to which SIDM Plans to Use the Recommendations*

At the conclusion of the grant, we held a debriefing session to assess the degree to which SIDM plans to use the recommendations in strategic planning, particularly for its patient engagement, education, and advocacy efforts. SIDM was highly satisfied with the overall project and its results and was particularly pleased with the efficacy of deliberation and the recommendations created by consumers. During our discussion of the strategic report,[20] SIDM representatives asserted that they need to factor the consumer recommendations and other input into existing organizational priorities but must also recognize that they cannot directly influence patient actions and behaviors. Discussion about the potential implications of the report generated several new ideas, including asking SIDM's public relations firm to use project results in developing new messaging and working to raise professional expectations about the capacities of patients to participate in the diagnostic process. In terms of practical, immediate actions, SIDM representatives discussed (a) creating education modules to advance the recommendations; (b) engaging with patient advocacy organizations to distribute materials for education; (c) clarifying in activities that diagnosis is a *process* and that patients play an important role; and (d) offering training to clinicians on effective interactions with patients. Finally, SIDM representatives acknowledged that they plan to share the strategic report at the board retreat and with the recently formed Coalition to Improve Diagnosis and that they plan to use the project results to revisit the charge of its Patient Engagement Committee with the members.

## Discussion, Implications, and Conclusion

The results from this project not only demonstrate the efficacy of deliberation as a tool that can successfully engage patients and the public on complex healthcare issues but also suggest that deliberation is more meaningful than traditional methods of participation, such as education.

First, the results suggest that various kinds of participatory arrangements, from simple education, to intensive deliberation, to shorter and less intensive participatory feedback sessions, can be satisfying to participants and have meaningful individual level impacts on a variety of measures. However, only the deliberation group and the participatory feedback group experienced statistically significant increases on most measures, including patient activation, trust in doctors, perceptions about the seriousness of diagnostic error, perceptions about patient participation, and health literacy. Moreover, the magnitude of these changes were greater for the deliberation group than for the participatory feedback group (which engaged in less intensive deliberation). Together, these results suggest that deliberative methods are more effective than other participatory interventions in producing individual-level changes and that the degree of impact increases with the intensity of the deliberative methods used.

Second, most professionals in both groups agreed that patient activation and patient engagement in the diagnostic process were important issues; however, their responses may be a function of social desirability bias or the tendency of respondents to answer questions in a manner that will be viewed favorably by others. Moreover, with the exception of the DEM group's willingness to use and encourage others to use the recommendations developed by consumers, the participatory focus group sessions did not lead to significant changes in the attitudes and perceptions of healthcare professionals. This suggests that the traditional formats for engaging medical professionals, like CMEs and professional development seminars, may not produce the kind of attitudinal (and concomitant behavioral) changes desired by the consumer participants.

Third, and perhaps most important, the results indicate that healthcare consumers can generate recommendations that other consumers understand and find both practical and usable. The consumers in the participatory feedback group gave high scores to the recommendations, with a majority indicating they were willing and able to use the recommendations in their own healthcare. In contrast, the healthcare professionals generally believed that patients would understand the recommendations but not use them or find them to be easy to use, even though they would improve diagnostic quality. In short, the professionals doubted the value and usability of the recommendations for consumers even though the consumers themselves indicated that the recommendations were valuable and usable. When considered in light of other results, this may suggest that healthcare professionals are skeptical about the ability of patients to engage in health management activities and specifically to engage in the activities suggested in the recommendations (even when consumers say they can do it).

Fourth, SIDM was impressed with the quality of the recommendations and plans to use them in its strategic planning efforts. SIDM staff also plan to use other data from the project to inform their education and advocacy work and believe that recognizing healthcare consumers as the source of recommendations may increase audience receptivity to educational efforts. Moreover, SIDM and members of the Coalition to Improve Diagnosis plan to delve deeper into the consumer-identified obstacles and potential solutions to find and develop additional interventions and strategies to encourage effective patient action and to improve diagnostic quality. That SIDM is prepared to take action on the recommendations developed by healthcare consumers is more evidence that deliberative methods can be used successfully to convene patients or members of the public to address complex healthcare issues.

Finally, this project suggests directions for future work aimed at addressing diagnostic error and improving diagnostic quality. Many practitioners experience medicine as a technical discipline, but the diagnostic process is also a relational discipline. Although there is a general recognition that diagnosis works best as a partnership, many factors inhibit effective collaboration, including mistrust of medical professionals, underestimation of patient capacities, power differentials, and mutual misperceptions. Therefore, high-impact interventions will likely need to focus on the doctor-patient relationship. Helping consumers and professionals navigate this relational territory so that important information is offered and understood effectively may reap benefits. Future efforts could focus on improving communication, for example by providing education about what and how to communicate or by developing tools that facilitate the communication process. Similarly, a turning point occurred in the deliberation group when the participants realized that diagnosis is a process rather than a one-time event led by an expert. This realization opened the door for them to imagine and active role for patients as partners in the process. Thus, addressing misconceptions and reframing diagnosis as a partnership may lead to more mutually supportive interactions. Effectively communicating the concept of diagnosis as an ongoing process should be a high priority for strengthening patient involvement efforts. A final direction for future research, one that the project team is currently exploring, is to test all (or some) of the patient-centered recommendations in simulated or real clinical settings.

## List of Publications and Products

### Products

Patient Recommendations to Reduce Diagnostic Error and Improve Diagnostic Quality. Available at https://jefferson-center.org/patient-prescriptions/.

Jefferson Center. Clearning the Error: Using Public Deliberation to Define Patient Roles as Partners in the Diagnostic Process – Strategic Report. Minneapolis: Jefferson Center; 2017. https://jefferson-center.org/wp-content/uploads/2017/06/Clearing-the-Error-Final-Report.pdf.

### Reports (all reports are available at https://jefferson-center.org/patient-dx/)

Nabatchi T, Jo S, Salas A. Initial Phases of a Randomized Study of Public Deliberation about Diagnostic Error: A Preliminary Analysis of Three Healthcare Consumer Events in 2015. Syracuse, NY: PARCC, Syracuse University; March 2016.

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## Appendix 1: Demographic Information for Consumer and Professional Groups

### Healthcare Consumers

Analyses of demographic data collected from all four healthcare groups suggests that the participants were diverse across a number of sociodemographic indicators and that the research team was generally successful in over-enrolling women and minority participants.

Table A provides demographic information for the participants in the four groups. The table shows that the participants in all groups were fairly diverse across gender, race, age, education, employment status, and income. Moreover, most participants in all groups had internet access.

Table B examines the percentage of participants in each group as compared the percentage of the overall population of Onondaga County for several demographic characteristics. As part of our overall recruitment strategy, we planned to over-enroll women and minority participants. The data show that we were moderately successful at this effort:

1. Female Enrollment: 52% of the population in Onondaga County is female. We achieved this percentage or greater in the education group (52%), the feedback group (64%), and the control group (69%); however, our deliberation group was only 44% female.

2. Black/African American Enrollment: 11% of the population in Onondaga County is Black or African American. We exceeded this percentage in all of the groups, including the education group (14%), the deliberation group (13%), the feedback group (19%), and the control group (15%).

3. Hispanic/Latino(a) Enrollment: 4% of the population in Onondaga County is Hispanic/Latino(a). We exceeded this percentage in the education group (5%), the deliberation group (6%), and the feedback group (5%) but not in the control group (2%).

4. Asian/Asian-Indian Enrollment: 3% of the population in Onondaga County is Asian/Asian-Indian. We exceeded this percentage in the education group (5%) and met it in the control group (3%) but fell short in both the deliberation group (0%) and the feedback group (1%).

### Healthcare Professionals

Analyses of demographic data collected from both healthcare professional groups show that the participants were diverse across a number of indicators. Specifically, Table C shows that the participants were diverse in terms of gender, age, medical profession, and years of medical practice. Moreover, all the physicians indicated that they use electronic medical records.

## Table A: Demographic Information for All Healthcare Consumer Groups

| | | **Education Group** (N=21) | **Deliberation Group**[1] (N=16) | **Feedback Group**[2] (N=95) | **Control Group** (N=108) |
|---|---|---|---|---|---|
| Gender | Male | 10 | 9 | 31 | 34 |
| | Female | 11 | 7 | 61 | 74 |
| Race | Black/African American | 3 | 2 | 18 | 16 |
| | White/Caucasian | 14 | 12 | 58 | 85 |
| | Hispanic/Latino(a) | 1 | 1 | 5 | 2 |
| | Asian/Asian-Indian | 1 | 0 | 1 | 3 |
| | Multi-Ethnic | 0 | 1 | 8 | 1 |
| | Other | 1 | 0 | 2 | 1 |
| | Unknown | 1 | 0 | 0 | 0 |
| Age | 18-21 | 2 | 0 | 4 | 3 |
| | 22-35 | 2 | 3 | 32 | 30 |
| | 36-45 | 3 | 2 | 17 | 19 |
| | 46-55 | 6 | 5 | 20 | 26 |
| | 56-65 | 4 | 2 | 12 | 21 |
| | 66-75 | 4 | 3 | 5 | 5 |
| | Over 76 | 0 | 1 | 1 | 2 |
| Education | Some high school | 0 | 1 | 5 | 1 |
| | High school graduate | 1 | 4 | 15 | 14 |
| | Some college, no degree | 7 | 5 | 29 | 24 |
| | Associate’s degree | 4 | 1 | 10 | 15 |
| | Bachelor’s degree | 4 | 3 | 11 | 25 |
| | Graduate or Prof. degree | 5 | 2 | 22 | 28 |
| Employment | Unemployed | 3 | 2 | 20 | 7 |
| | Part-time | 5 | 0 | 22 | 25 |
| | Full-time | 4 | 4 | 26 | 48 |
| | Retired | 4 | 5 | 9 | 12 |
| | In school | 0 | 0 | 5 | 2 |
| | Other | 5 | 5 | 10 | 14 |
| Income | Under $10,000 | 3 | 3 | 18 | 18 |
| | $10,000-$19,999 | 6 | 0 | 16 | 17 |
| | $20,000-$29,999 | 0 | 3 | 15 | 11 |
| | $30,000-$39,999 | 4 | 3 | 14 | 15 |
| | $40,000-$49,999 | 1 | 1 | 6 | 10 |
| | $50,000-$59,999 | 0 | 1 | 6 | 4 |
| | $60,000-$69,999 | 1 | 1 | 2 | 8 |
| | $70,000-$79,999 | 1 | 2 | 3 | 5 |
| | $80,000-$89,999 | 1 | 0 | 1 | 4 |
| | $90,000-$99,999 | 0 | 0 | 0 | 3 |
| | $100,000 or more | 4 | 2 | 10 | 12 |
| Internet | Yes | 19 | 16 | 84 | 99 |
| | No | 2 | 0 | 6 | 7 |

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[1] Data are from the 16 participants who attended and completed surveys in both August and October.

[2] Of the 95 total participants, 93 completed the pre-survey, 91 completed the post-survey, and 89 completed both. Demographic questions were asked only in the pre-survey. Of the 92 that answered these questions, one did not report age, one did not report income, and two did not answer the internet access question.

## Table B: Characteristics of Healthcare Consumer Group vs. Onondaga County, NY

| | | **Education Group** (N=21) | **Deliberation Group** (N=16) | **Feedback Group** (N=95) | **Control Group** (N=108) | **Onondaga County** |
|---|---|---|---|---|---|---|
| Gender | Male | 48% | 56% | 33% | 31% | 48% |
| | Female | 52% | 44% | 64% | 69% | 52% |
| Race | Black/African American | 14% | 13% | 19% | 15% | 11% |
| | White/Caucasian | 67% | 75% | 61% | 79% | 81% |
| | Hispanic/Latino(a) | 5% | 6% | 5% | 2% | 4% |
| | Asian/Asian-Indian | 5% | 0% | 1% | 3% | 3% |
| Age | 18-35 | 19% | 19% | 38% | 31% | 31% |
| | 36-65 | 62% | 56% | 52% | 61% | 50% |
| | 66 & over | 19% | 25% | 6% | 6% | 19% |
| Education | Some high school | 0% | 6% | 5% | 1% | 10% |
| | High school graduate | 5% | 25% | 16% | 13% | 45% |
| | Associate's or Bachelor's | 38% | 25% | 22% | 37% | 30% |
| | Grad. or Prof. degree | 24% | 13% | 23% | 26% | 15% |

## Table C: Demographic Information for Healthcare Professional Groups

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

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[3] 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 include only 34 participants.