# CLEARING THE ERROR

Using Public Deliberation to Define Patient Roles as Partners in the Diagnostic Process

STRATEGIC REPORT

ACKNOWLEDGMENTS

Clearing the Error is a collaborative effort between the Society to Improve Diagnosis in Medicine, the Maxwell School of Citizenship and Public Affairs at Syracuse University, and the Jefferson Center, with funding from the Agency for Healthcare Research and Quality.
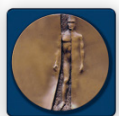
SOCIETY to IMPROVE DIAGNOSIS in MEDICINE

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The Society to Improve Diagnosis in Medicine works to improve diagnostic quality through research, education, and advocacy. SIDM is committed to a world where diagnosis is accurate, timely, and efficient.

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The Maxwell School of Citizenship and Public Affairs is Syracuse University's home for innovative, interdisciplinary teaching and research in the social sciences, public policy, public administration, and international relations.

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The Jefferson Center is a nonpartisan nonprofit that engages Americans directly to solve shared challenges and craft better policy. Our mission is to strengthen democracy by advancing informed, citizen–developed solutions to challenging public issues.

AHRQ Agency for Healthcare Research and Quality
Advancing Excellence in Health Care

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EXECUTIVE SUMMARY

The Agency for Healthcare Research and Quality (AHRQ) funded a collaborative research project involving the Society to Improve Diagnosis in Medicine (SIDM), the Program for the Advancement of Research on Conflict and Collaboration (PARCC) at the Maxwell School of Citizenship and Public Affairs at Syracuse University, and the Jefferson Center (JC). The project utilized deliberative approaches to engage healthcare consumers in developing informed, practical, patient-focused recommendations for improving diagnostic quality.

SIDM's stated desirable outcome of the deliberation was an understanding of what actions patients might be willing and able to take to improve the quality of diagnosis in order to inform their strategic planning for educational and advocacy efforts. This outcome was achieved through a multi-stepped process.

First, a Citizens Jury (CJ), composed of twenty individuals, met for two three-day weekends and produced a set of sixteen specific recommendations regarding actions patients might take to improve diagnostic quality. The CJ also identified systemic obstacles that might hinder patients in taking these actions and brainstormed potential solutions to overcome those obstacles.

Second, a group of ninety healthcare consumers was convened to review the CJ recommendations and provide feedback indicating whether they felt willing and able to perform the recommended actions. With some variation between recommendations, a large majority of this group found the recommendations understandable, perceived they would make a positive impact on diagnostic quality, and indicated they would be likely and able to apply the recommendations in their own healthcare encounters.

In the final step, the recommendations were presented to focus groups of medical professionals in two settings to gain a sense of how medical professionals would respond to these patient-focused recommendations. Generally, these groups perceived that following the recommendations would improve diagnostic quality and they expressed a significant degree of openness to patients taking such actions.

Data from the project can inform patient education strategies, and recognizing healthcare consumers as the source of recommendations may increase audience receptivity to educational efforts. The identified systemic obstacles and potential solutions may also suggest specific systemic interventions which SIDM and other members of the Coalition to Improve Diagnosis may wish to test in clinical settings to encourage effective patient action to improve diagnostic quality.

This report describes the project's process and results in detail, providing observations regarding strategic implications that might be drawn from the research where appropriate.

STRATEGIC CONTEXT

The strategic vision of the Society to Improve Diagnosis in Medicine is:

Creating a world where no patients are harmed by diagnostic error.

The organization describes its mission in this way:

SIDM catalyzes and leads change to improve diagnosis and eliminate harm, in partnership with patients, their families, the healthcare community and every interested stakeholder.

SIDM is committed to exploring multiple ways of improving diagnostic quality and reducing diagnostic error. In its recent strategic plan, SIDM identified patient engagement as a priority in that effort:

Patient Engagement: Engage and integrate patients and their families in all diagnostic improvement efforts in order to achieve outcomes that matter to patients.

Three goals have been identified for this priority.

1. Ensure SIDM maintains the highest level of patient-centeredness by meaningfully engaging patients and their families in the planning and conduct of SIDM's work.

2. Increase knowledge about the magnitude and impact of diagnostic error within the patient community.

3. Develop and engage patients and patient advocates as thought leaders in diagnostic safety.

As the sponsor of this research effort, and in line with a broader trend in the healthcare field toward greater patient involvement, the Society to Improve Diagnosis in Medicine's patient engagement priorities and related goals serve as the guiding principles in this project.

BACKGROUND

From September 2014 through March 2017, SIDM, PARCC, and JC partnered in a research project funded by AHRQ to determine how patient and healthcare consumer input could inform education and advocacy to reduce diagnostic error and shift the growing conversation on diagnostic error in ways that empower patients and their advocates. This project contributed significantly to strategic goal 5(a) by soliciting informed input from healthcare consumers to inform SIDM's strategic planning processes.

JC staff designed and conducted deliberative processes, which were evaluated by PARCC to assess the impact and effectiveness of consumer deliberation to inform healthcare policies. Participants discussed (1) the roles patients were 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 effectively assume those roles. Participants then identified practical, impactful, and feasible patient–focused recommendations for reducing diagnostic errors.

A Citizens Jury (CJ) was convened in Syracuse, NY, for two 3-day sessions in August and October 2015, involving twenty Onondaga County residents randomly selected and stratified to reflect the diversity of the region. The group received informational presentations from diagnostic quality researchers and advocates, and deliberated for 8½ days, asking questions of doctors, healthcare researchers, and patient advocates before creating their draft recommendations. The draft recommendations were presented for feedback to participants at the Patient Summit, held at SIDM's 2015 Diagnostic Error in Medicine Conference (DEM).

The initial CJ reconvened for an additional 3 days to finalize their recommendations, incorporating feedback from the DEM that they found useful. The group finished their deliberation by highlighting systemic obstacles that might prevent patients from pursuing the recommended strategies effectively and identifying potential solutions health systems could implement to minimize those obstacles.

A panel of 93 citizens met for 6 hours in February 2016 to assess these recommendations for their relevance, impact, and feasibility from the perspective of healthcare consumers who did not experience the level of education and deliberation provided to the CJ. This panel evaluated the recommendations through deliberation and scenario testing.

Two focus groups of medical professionals also discussed and assessed the recommendations. The first focus group was held at SIDM's 2016 DEM, and the second was held at Crouse Hospital in Syracuse, NY.

Results and consultant observations from each of these three activities are provided in the following sections.

The CJ produced sixteen final recommendations regarding what patients and/ or their advocates might do to improve the quality of diagnosis. These sixteen recommendations were grouped into five overarching categories. Category numbers are for reference only and do not represent any order of prioritization.

Category #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, the 8 characteristics of symptoms are quantity, quality, aggravating factors, alleviating factors, setting, associated symptoms, location, and timing. Here's an example description:

    Physician: "What brings you in to see us?"

    Patient: "Well, I've been having these headaches for the past couple of months. I never used to get headaches, but for the past couple of months, I get one every two or three days, usually in the late afternoon or early evening, and they last a couple of hours. The first time, I was driving home from work. They're mostly in the front and in both temples and they've been getting worse. It feels like a tight band around my head and I'd say it's about a 5 or 6 on a scale of 10 in terms of severity. Lying down seems to help and Tylenol helps a little but doesn't make them go away completely. They're usually worse after a stressful day, but they can come on a normal day too. Bending over also makes them worse. I haven't noticed anything else like a fever or vomiting or anything."

Category #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.

Category #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.

Category # 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.

Category # 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.

After finalizing their recommendations, CJ participants considered three different scenarios and discussed which recommendations patients might perform would be most important and impactful in that scenario. The scenarios were as follows:

Scenario # 1

You have been experiencing coughing, aches, and respiratory problems for 2 weeks. You go to your primary care provider who tells you that it may be a cold, flu, or it that there is a chance it could be something more serious. She advises you to take an over the counter pain decongestant and pain reliever and to let her know if your symptoms don't improve in 10 days.

Scenario # 2

You have been feeling low-energy and noticing some unintentional weight loss for about 9 months. You saw your primary care provider after about 3 months. Routine blood work did not reveal anything out of the ordinary. You returned after another 2 months with no improvement. Reviewing a second round of blood tests, the doctor suggested you may be anemic and prescribed a course of supplements. He also asked if you had been feeling depressed lately. The supplements haven't done any good. You're losing weight more rapidly and you are noticing some discomfort in your abdominal area. You had an ultrasound 3 weeks ago but haven't heard any results from that.

Scenario # 3

You take your 10-year-old daughter to Urgent Care because she has been running a fever for a couple days and complaining of aching and stiffness in her neck and joints. The doctor examines her and suggests she has the flu. You're instructed to watch her and return if she doesn't get better in 5 days. That night, her fever spikes to 103 degrees. You take her to the emergency room, where you wait several hours before you are seen and they decide to admit her overnight to observe and administer IV fluids. You spend the night by her bed in the hospital where the staff comes in to check vitals every couple hours. Toward morning, she has a seizure. A doctor examines her and tells you not to worry because that just happens sometime with a high fever. You are highly concerned and want answers.
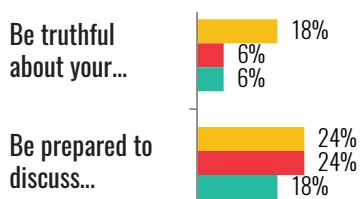
Each participant selected four recommendations they believed would be most important and impactful in each scenario. Table 1 shows the percentage of participants who selected each recommendation as one of their four options for each scenario.
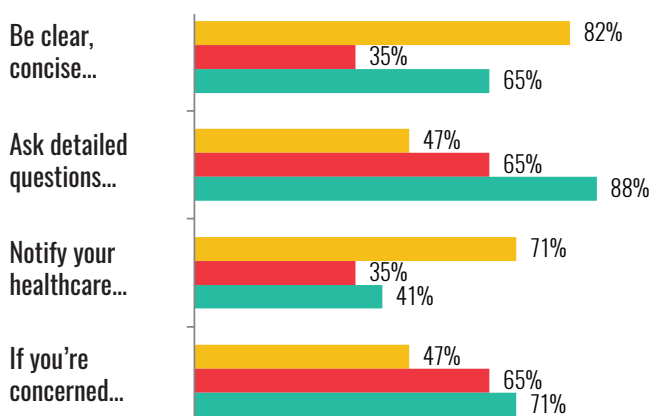
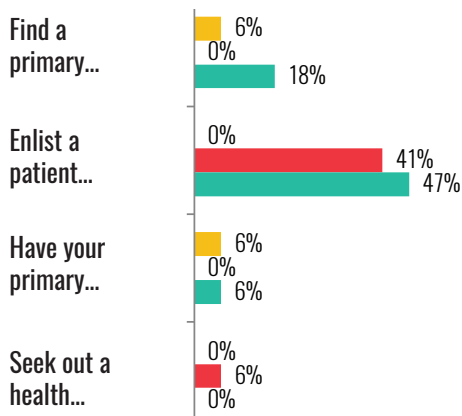## MOST IMPORTANT AND IMPACTFUL RECOMMENDATIONS
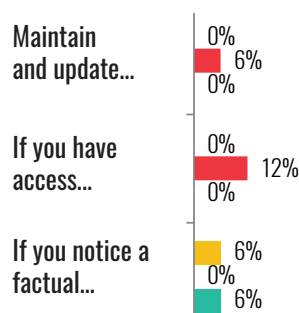
Table 1

Present symptoms clearly/completely

Be truthful about your...
- 18%
- 6%
- 6%

Be prepared to discuss...
- 24%
- 24%
- 18%

Assert yourself in the relationship

Be clear, concise...
- 82%
- 35%
- 65%

Ask detailed questions...
- 47%
- 65%
- 88%

Notify your healthcare...
- 71%
- 35%
- 41%

If you're concerned...
- 47%
- 65%
- 71%

Coordinate your care

Find a primary...
- 6%
- 0%
- 18%

Enlist a patient...
- 0%
- 41%
- 47%

Have your primary...
- 6%
- 0%
- 6%

Seek out a health...
- 0%
- 6%
- 0%

Ensure accurate records and tests

Maintain and update...
- 0%
- 6%
- 0%

If you have access...
- 0%
- 12%
- 0%

If you notice a factual...
- 6%
- 0%
- 6%

Manage your care

Ensure communications...
- 53%
- 18%
- 29%

Throughout the...
- 12%
- 6%
- 6%

Follow up with your...
- 6%
- 76%
- 0%

■ Scenario # 1

■ Scenario # 2

■ Scenario # 3
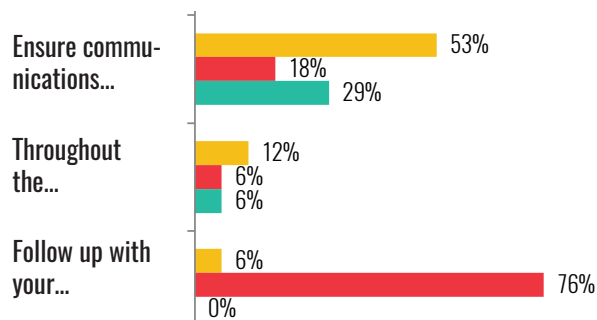
STRATEGIC OBSERVATIONS

- Responses were concentrated in the categories of presenting symptoms clearly and completely, patients asserting themselves in the relationship (patient communication), and managing care (follow-up). Anecdotal observation of the deliberation suggests that this was a consequence of learning throughout the process, since many expressed hesitancy regarding such actions at the beginning of the process. This may indicate that educational efforts for consumers might focus on giving them permission and skills to engage more assertively with healthcare professionals, and efforts for professionals might focus on helping them invite and respond positively to patient initiatives in the relationship.

- Responses to this exercise highlight a difference in the type of recommendations. Some recommendations are about patient/healthcare professional encounters and others have to do with systems (provider and record keeping systems). The latter type of recommendations has to do with patients having a structure in place to support encounters. This suggests that educational efforts might make a distinction between being prepared for a successful encounter and the encounter itself. Encouraging action prior to an actual encounter may require educational strategies that clearly explain how such action contributes to a quality diagnosis (i.e., it may not be immediately apparent to a healthcare consumer why accurate record keeping is critical, since that is an "unseen" aspect of the process). This may also suggest an area where SIDM and others might continue developing questionnaires, apps, or other tools to assist patients in preparing to share their histories and/or symptoms effectively and to manage their records more readily.

- The modest concentration in the category of presenting symptoms clearly and completely, combined with anecdotal observation of the process, suggests potential benefit in educating patients about what should be shared with medical professionals, along with clear and usable tools to facilitate information sharing. Anecdotal observation would suggest that educating medical professionals to communicate without judgment about patient lifestyles may increase a patient willingness to communicate openly.
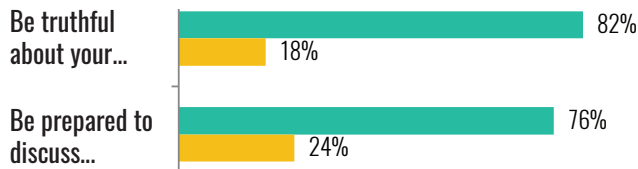
CITIZENS JURY RESULTS

CJ participants reviewed their recommendations and discussed what might make it challenging for patients to perform them and what someone might do to be more able to act. Following their discussions, they rated each of their recommendations according to whether they personally would be willing and able to take the action.

Their response options were: (1) I would; (2) I might; (3) I don't know; (4) I doubt it; and (5) I would not. Table 2 indicates the percentage of participants who responded with "I would" or "I might" for each recommendation.
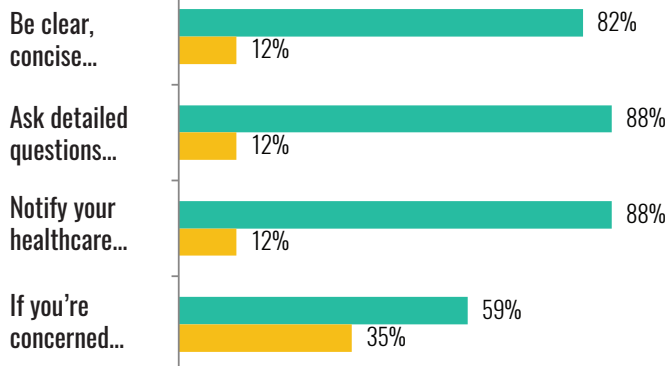
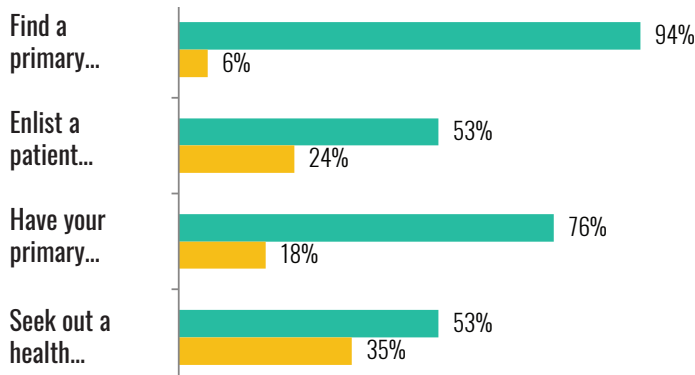## WILLINGNESS AND ABILITY TO TAKE ACTION
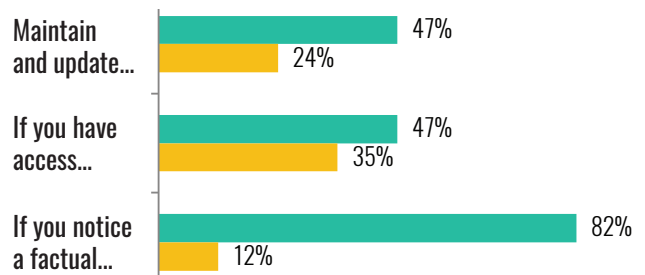
Table 2

Present symptoms clearly/completely

Be truthful about your…	82% (I Would) / 18% (I Might)
Be prepared to discuss…	76% (I Would) / 24% (I Might)

Assert yourself in the relationship

Be clear, concise…	82% (I Would) / 12% (I Might)
Ask detailed questions…	88% (I Would) / 12% (I Might)
Notify your healthcare…	88% (I Would) / 12% (I Might)
If you're concerned…	59% (I Would) / 35% (I Might)

Coordinate your care

Find a primary…	94% (I Would) / 6% (I Might)
Enlist a patient…	53% (I Would) / 24% (I Might)
Have your primary…	76% (I Would) / 18% (I Might)
Seek out a health…	53% (I Would) / 35% (I Might)

Ensure accurate records and tests

Maintain and update…	47% (I Would) / 24% (I Might)
If you have access…	47% (I Would) / 35% (I Might)
If you notice a factual…	82% (I Would) / 12% (I Might)

Manage your care

Ensure…	88% (I Would) / 12% (I Might)
Through-out…	76% (I Would) / 24% (I Might)
Follow up…	88% (I Would) / 0% (I Might)

■ I Would
■ I Might

STRATEGIC OBSERVATIONS

- Keeping in mind that these results reflect CJ participants' perceptions following extensive education and discussion, it is striking to note that degrees of willingness and ability are relatively high for most recommendations. Anecdotal observation would suggest that responses may have been different at the outset. Early in the process, some participants were disinclined to share information due to mistrust of medical professionals and did not have any model for sharing symptoms or understand the value of clear medical history to the diagnostic process. High willing and able scores here indicate that educational strategies for patients might include providing the rationale for giving full histories and ensuring confidentiality. For medical professionals, education might focus on helping patients give clear histories and building trust (so that patients are willing to divulge elements of their history that they may fear are liable to judgment or discrimination).

- The relatively lower scores related to managing one's own records may be indicative of an action area. Anecdotally, comments were heard to the effect that "that is too much work" and "I couldn't manage that." If this is an important component of reducing diagnostic error, education strategies might focus on why it is important, with practical (and simple) suggestions about how to do it. Systemic interventions might include making the process as easy for patients as possible, building some sort of review into the actual patient encounter, or developing user-friendly apps to assist in the process.

The CJ participants discussed systemic obstacles that might make it difficult for patients to follow their recommendations and brainstormed potential solutions. They prioritized obstacles according to which would be most important to address. For suggested solutions under each obstacle, they prioritized according to which would be most likely to address the obstacle. The following lists reflect, verbatim, the identified obstacles (in bold) and the brainstormed solutions in order of priority. Participant vote totals are in brackets.

Different payment systems/insurance/ability to pay can limit choice and access or influence the course of diagnosis and treatment. [17]

- Provide patients with clear, practical information about signing up for insurance coverage [11]
- Standardized pricing for medical services [11]
- Ombudsman/liaison/advocate to help patient navigate choice managing cost vs. care [10]
- Doctors and nurses don't know what kind of insurance a patient has; only the billing department knows the insurance [8]
- Provide incentives so doctors accept all forms of insurance [8]
- Mandate generic drugs (where available) [2]
- Doctor can waive certain charges [1]
- Sliding scale charge for certain procedures [0]

Fragmented, decentralized healthcare systems inhibit effective communication and information-sharing across systems and between providers. This fragmentation can also reduce provider collegiality/collaborative problem solving. [9]

- Transition from many proprietary EHR systems to one system so there is greater interoperability across providers [11]
- Primary care provider should be responsible for coordinating communication between all different providers [8]
- Patients go to portal to review or verify records; if they don't have a computer, review notes before they leave the office [7]
- Develop protocols for sharing information between providers [7]
- Patients have permission to opt-in to include information in database; opt-in to share information with other providers [5]
- Insurers should provide incentives for primary care provision (so everyone has a primary care provider) [4]
- Develop standards for doctor communication in different situations [3]
- More frequent telephone calls (direct interaction) between doctors to discuss diagnoses [3]
- Provide patients with SD cards to bring to appointments (includes medical records); updates after each appointment [2]
- Convene meetings within HC settings or require continuing education opportunities related to improving communications between providers, across networks [0]

Patients don't know how to communicate symptoms effectively. [7]

- Video loop/poster/flyer in office/clinic/healthcare setting – potential questions for your doctor, potential information to cover --> "Help your doctor help you"; include examples [12]
- Kiosk/iPad at clinic/office at check–in that presents interactive/animated questions to address 8 characteristics [10]
- Questionnaire before appointment (when you make appointment) asking about 8 characteristics of symptoms [7]
- After appointment questionnaire/feedback evaluating communication during appointment – did you forget to say something to your doctor, etc.? [7]
- Incorporate how to choose doctor/how to communicate symptoms/how to have productive appointment into ongoing health education (middle school, high school, college, senior/ community education, etc.) [7]
- Mass media PSAs; informational flyers in SS, IRS, Medicare communications to reach more people; clear, accessible language [5]
- Appointment scheduler could triage to help patient prioritize comments to doctor [2]
- Website that guides patients in what questions they should ask their doctor [1]
- Coaching/guidance to help patients present information clearly and coherently [0]

The complexity of the healthcare system makes it difficult for patients to help coordinate the diagnostic process (e.g. following up with multiple doctors, tracking personal medical record and history, making sure test results are analyzed, etc.) [7]

- Access to patient portal in office, with opportunity to print records, notes, treatment plan, test results, and other information [15]
- Patient Review Board for missed diagnosis to review implementation of practices aimed at improving diagnostic quality [7]
- A flag on EHR if information is added and indicates that primary care provider has read it [7]
- All patients have access to a trained, educated advocate (independent from immediate health system/provider); provided by insurer, state, health system [7]
- Checking test results leads to automatic conversation between patient and doctor/primary care provider [7]
- Designated personnel to walk through patient portal/patient records, if needed [5]
- Educate doctors and patients that records can be shared with patients [1
- Nationwide source (call center/website) where advocates can answer questions or offer other resources [1]
- Health system identifies family member or other advocate/proxy on behalf of patient, if patient is unable [1]

Culture encourages doctors to be efficient and productive; patients have limited time to interact with doctors face-to-face. [4]

- Doctor has another staff person write electronic medical record and perform other tasks to allow more time for interaction with patient [14]
- Shift culture of 15 minute appointments to 20 minutes; 5 minutes makes a difference [9]
- Doctor has patient information (8 characteristics, etc.) before appointment begins [7]
- Change payment structure to encourage longer visits or at least focus on better health outcomes; Payment structure reflects "success rate" – such as better health, fewer follow-up visits [7]
- Have provider address most important issue first [7]
- Nurse line or similar where patients can consult with a medical professional to plan appointment, think about what needs to be said during appointment [3]
- Offer other resources [1]
- Remove clocks/watches from doctor's view during appointments [1]
- Don't talk to doctor when they're taking notes/on the computer [1]
- Video loop in waiting room/before appointment about what to expect during appointment [1]
- Provide incentives to increase number of doctors [0]

Patients don't necessarily know what their options might be for asserting themselves. [3]

System Focus

- Mandatory debriefing between provider and patient to ensure clarity of next steps during visit [10]
- Change provider reimbursement system to incentivize/allow more time with patients [9]
- Compensate/reimburse doctors for collaborating and communicating results/treatments/etc.
- Health systems need to educate patients so they can advocate for themselves – education about what patients should expect/begin education early (like in elementary school—critical life skill) [8]
- The system initiates the questioning process (what else could it be/what did we miss?); require review of symptoms, history [7]
- Have someone in the system to represent the patient voice as an advocate (case manager/ navigator) [6]
- Infomercials and ads that help patients know/understand what their rights are and what they can do to communicate
- National or global department where errors are reported, analyzed, and disseminated – NTSB for diagnostic error. [4]
- Analysis of errors without sanctions so systems and Drs. can learn from their mistakes [4]
- The insurers require and pay for multiple opinions about diagnosis [2]

Patients don't necessarily know what their options might be for asserting themselves. [3]

Patient Focus

- Giving a letter/brochure/verbal instructions to patients that describe patient rights – to ask questions; 2nd opinion; to receive satisfactory answers to questions; to receive a summary of what's going on with your care [16]
- Be persistent, be a pain in the ass [13]
- Patient has clear expectations for the interaction with provider [9]
- Patient writes down their concerns and shares with Dr. or nurse before appointment [5]
- Build and provide a website and advertise to help people know their rights and to address questions about care [3]
- Patients need confidence to challenge the system [2]
- To advocate for yourself write governor, congressperson, others in power [1]

Patients don't necessarily trust providers. Provider attitudes or behavior can inhibit patient openness, receptivity, confidence, and/or satisfaction. [1]

- Doctor communicates uncertainty in the diagnosis appropriately. For example, "I don't have a clue what's wrong with you" vs. "I'm not sure what's wrong with you, I have a few ideas, but Tests X and Y will help me make a more accurate diagnosis." [17]
- Have an assistant type into EHR during encounter so that doctor can focus on patient conversation [7]
- Ongoing education for providers about interacting and communicating with patients [6]
- The doctor, office setting should ease patient stress; staff should set a tone of caring for the patient during office visits. [6]
- Make statistics about doctors publicly available ex. success rates of cardiologist, malpractice suit data, official reprimands, and so on [4]
- Provider periodically allows patient to evaluate the provider (via email or mail or..) [3]
- Have information about provider available in the waiting room so patient has a sense of/ introduction to provider [3]
- Doctor should always introduce themselves [2]
- Doctor hosts informal "get to know me" to build relationship with patients [2]

STRATEGIC OBSERVATIONS

- Considering the list of identified obstacles alone (without reference to brainstormed solutions) may indicate that informed healthcare consumers have the capacity to think clearly about systemic challenges in healthcare delivery. This may suggest the advisability of including consumers early in the process of policy development, rather than the more common approach of asking them to respond to proposals developed primarily by professionals.

- The identified obstacles could be interpreted as revealing key consumer frustrations with the healthcare system and diagnostic processes. Inference could be made that taking action to address these obstacles would increase both patient satisfaction and diagnostic quality.

- Review of brainstormed suggestions may reveal specific strategies/ protocols that could be piloted to test their effectiveness in clinical settings. Funding may be available to test the effectiveness of specific interventions recommended through deliberative processes.

- Review of these obstacles may uncover specific systemic interventions that SIDM and/or members of the Coalition to Improve Diagnosis might choose to advocate for and may suggest areas where additional research and investigation is needed.

In February 2016, 93 healthcare consumers were convened to learn about the CJ recommendations and provide feedback regarding their willingness and ability to follow the recommendations.

After a brief introduction to the problem of diagnostic error and explanation of the Citizens Jury process, participants reviewed and discussed scenarios #2 and #3 (time limits prohibited discussing all three).

After discussion, participants individually prioritized the recommendations by choosing the 3 actions that would be most important and impactful for patients to perform in the scenario and choosing 3 actions that they personally would feel willing and able to perform in the scenario.

Table 3 shows the percentage of participants who selected each recommendation as one of three options they felt would be most important and impactful for a patient to perform in the corresponding scenario.

Table 4 shows the percentage of participants who selected each recommendation as one of the three they would be most willing and able to perform in the corresponding scenario.
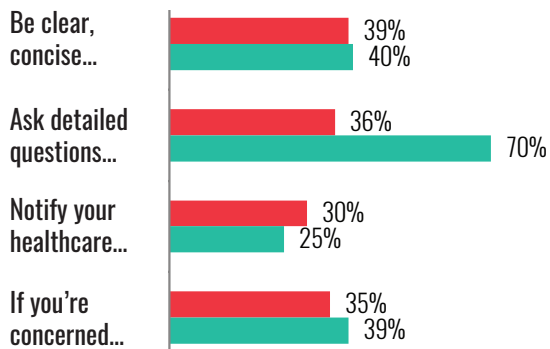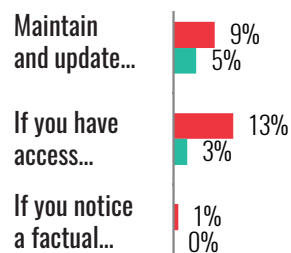
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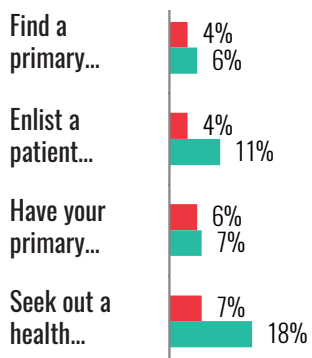
Table 3

Present symptoms clearly/completely

Be truthful about your…
- 39%
- 23%

Be prepared to discuss…
- 26%
- 19%

■ Scenario # 2
■ Scenario # 3

Assert yourself in the relationship

Be clear, concise…
- 39%
- 40%

Ask detailed questions…
- 36%
- 70%

Notify your healthcare…
- 30%
- 25%

If you're concerned…
- 35%
- 39%

Ensure accurate records and tests

Maintain and update…
- 9%
- 5%

If you have access…
- 13%
- 3%

If you notice a factual…
- 1%
- 0%

Coordinate your care

Find a primary…
- 4%
- 6%

Enlist a patient…
- 4%
- 11%

Have your primary…
- 6%
- 7%

Seek out a health…
- 7%
- 18%

Manage your care

Ensure…
- 10%
- 19%

Through-out…
- 11%
- 8%

Follow up…
- 30%
- 19%
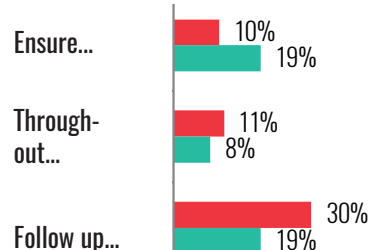
WILLINGNESS & ABILITY

Table 4

Present symptoms clearly/completely

Be truthful about your…
- Scenario # 2: 47%
- Scenario # 3: 24%

Be prepared to discuss…
- Scenario # 2: 37%
- Scenario # 3: 30%

■ Scenario # 2
■ Scenario # 3

Assert yourself in the relationship

Be clear, concise…
- Scenario # 2: 38%
- Scenario # 3: 40%

Ask detailed questions…
- Scenario # 2: 30%
- Scenario # 3: 53%

Notify your healthcare…
- Scenario # 2: 37%
- Scenario # 3: 34%

If you're concerned…
- Scenario # 2: 17%
- Scenario # 3: 30%

Ensure accurate records and tests

Maintain and update…
- Scenario # 2: 9%
- Scenario # 3: 7%

If you have access…
- Scenario # 2: 9%
- Scenario # 3: 1%

If you notice a factual…
- Scenario # 2: 3%
- Scenario # 3: 7%

Coordinate your care

Find a primary…
- Scenario # 2: 6%
- Scenario # 3: 6%

Enlist a patient…
- Scenario # 2: 4%
- Scenario # 3: 10%

Have your primary…
- Scenario # 2: 1%
- Scenario # 3: 6%

Seek out a health…
- Scenario # 2: 9%
- Scenario # 3: 12%

Manage your care

Ensure…
- Scenario # 2: 13%
- Scenario # 3: 19%

Through-out…
- Scenario # 2: 13%
- Scenario # 3: 9%

Follow up…
- Scenario # 2: 28%
- Scenario # 3: 16%

STRATEGIC OBSERVATIONS

- While this data cannot be directly compared to the Citizens Jury (since the CJ chose 4 recommendations and this group chose 3 recommendations), the general pattern indicates a similar insight regarding a potential distinction between patient/professional encounters and the less immediate (and therefore less visible) recommendations regarding records and primary care. This suggests the possibility that if the latter are important, education efforts may need to include explanation of their contribution to diagnostic quality in order to motivate patients to take action.

- Comparison between importance scores and willingness and ability scores may be instructive. While willingness and ability scores correspond roughly to most important scores, there was a significant drop in willingness and ability to ask detailed questions in the scenario where a child might be in imminent danger, even though that recommendation was rated most important and impactful. This might prompt exploration regarding how patients need to be supported in taking assertive action in high-stakes situations.

- There is a marked contrast between the willingness and ability scores of this group and those of the CJ on almost all recommendations. The CJ participants indicated significantly higher scores on willingness and ability to implement the recommendations. That may suggest the value of in depth education and engagement with consumers, particularly educational efforts designed to move from initial fear and mistrust to a sense of personal competence through engaging with content and with medical professionals in a way that develops personal connection.

Participants in the Consumer Feedback event engaged in table discussions regarding what might make it difficult for patients to adopt the recommendations and what might be done to increase the likelihood of patients adopting them. The obstacles identified during the CJ had not been shared with this group prior to their discussion. For purposes of comparison and analysis, JC staff reviewed the list of obstacles identified by the Consumer Feedback group and aligned them with the obstacles identified by the CJ (in bold font). Ideas generated from the Consumer Feedback tables are numbered and in plain font. They are presented, unedited, as recorded at tables, in order to provide the reader a direct sense of consumer experience.

Different payment systems/insurance/ability to pay can limit choice and access or influence the course of diagnosis and treatment.

1. Insurance coverage
2. Cost to implement and to have access
3. Socio-economic issues: age, social class, education, income, culture, disabilities/ special needs, language barrier
4. Insurance issues: lack of insurance, costs, rules/referrals
5. Limited access to healthcare: Rural areas, people with disabilities and lack technology
6. People are worried about if their insurance is able to cover the cost, or even if they could afford the hospital visit

Fragmented, decentralized healthcare systems inhibit effective communication and information-sharing across systems and between providers. This fragmentation can also reduce provider collegiality/ collaborative problem solving.

1. System: not set up efficiency for second opinions
2. Access to information, doctors and enrollment, records, insurance
3. Not options to coordinate care: insurance, disability, language

Patients don't know how to communicate symptoms effectively.

1. The language to discuss symptoms

The complexity of the healthcare system makes it difficult for patients to help coordinate the diagnostic process (e.g. following up with multiple doctors, tracking personal medical record and history, making sure test results are analyzed, etc.)

1. Competition (bars coordination)

Culture encourages doctors to be efficient and productive; patients have limited time to interact with doctors face-to-face.

1. Time

Patients don't necessarily know what their options might be for asserting themselves.

1. Confidence of the patient
2. Communication problems are a continued theme: being able to tell truth, assert want of different care, getting follow-up
3. Fear: stressful to assert
4. Conditioned: taught to trust
5. People don't really feel comfortable questioning the doctors professional diagnosis
6. Feeling like you cannot challenge the "all knowing" doctor, which leads to problems asserting and asking for follow up

Patients don't necessarily trust providers. Provider attitudes or behavior can inhibit patient openness, receptivity, confidence, and/or satisfaction.

1. Language barriers: a) English may not be a first language; b) doctors speak in medical terms
2. Trust issues: Negative responses or lack of response from doctors and nurses
3. Relationship/trust
4. Communication: respect between doctor/patient (lacking); patient personality (not feel worthy, lack of education); follow status quo; lack of privacy; can't understand doctor talk; people with disabilities or special needs
5. Pigeonholed/stereotype
6. How well the doctor listens to the patient
7. Discrimination
8. Patients not telling the truth, sometimes a factor of not having a good relationship with the doctor
9. Insecurity, discomfort: fear of judgments by medical professionals, causes patients to be less honest, hesitant; many recommendations require assertiveness that this undermines
10. Doctor/patient power differential, being intimidated or not comfortable enough talking about issues/symptoms, or asking questions
11. Sex, culture, age, language, disability
12. Being judged (habits, smoking for example)
13. Denial admitting to a problem

Other (These did not fit obviously into CJ–identified categories)

1. Lack of information
2. Literacy: docs written above reading level, in non–native languages, people unfamiliar with terminology even if given info
3. Lacking of diligence in managing/coordinating care on patient's side of responsibility
4. Patient disability limiting communication, especially if the office is not set up to promote communication for disabled individuals
5. People have a hard time not only receiving the information, but also understanding it.

STRATEGIC OBSERVATIONS

- Reviewing this list, JC staff observed the similarity in energy and theme to the first days of the CJ. The highest volume of ideas clustered around access, power differentials, and lack of trust in medical professionals.

- The frustration with unequal access may indicate an area where SIDM might concentrate advocacy in policy development. If quality diagnosis is ultimately cost-effective and diagnostic quality is improved by access, this might provide a leverage point in arguing for increased equality of access to healthcare.

- The striking number of responses related to power differential and trust in medical professionals suggests that including education for professionals about relating to patients may be a strategy to improve diagnostic quality. If patients' involvement in the diagnostic process is desirable, then medical professionals may need to manage the relationship in new ways to increase patients' willingness to engage. Education topics might include:

    - Raising sensitivity to the power differential and strategies to communicate respect to patients and empower them in the relationship.

    - Cultural sensitivity so that patients experience an attitude of acceptance and non-judgment.

    - Interpersonal skills to communicate lifestyle recommendations sensitively, without condemnation.

- JC staff observed an interaction at the 2016 DEM Patient Summit which may also be suggestive in this regard. Both patients and physicians were in the group, discussing obstacles to patients presenting symptoms clearly. Physicians heard patients express their perception that office protocols (such as telling the nurse symptoms before seeing the doctor) were blocks to sharing symptoms effectively and so they may intentionally not cooperate, since patients didn't want to repeat the same information over multiple interactions. And patients heard physicians explain that the protocols were designed to enhance symptom sharing. That experience suggests that one way to address the power differential and trust problems might be to engage patients and providers in direct interaction where they can learn how the system is experienced from both sides. This might facilitate development of strategies and processes that could work optimally for both professional and patient.

Training for medical professionals to increase likelihood of patient trust

1. Patient has lack of confidence and trust with medical providers
2. Doctors and staff should have more sensitivity training
3. Sensitivity training for healthcare providers
4. Treating a person as a whole human being: empathy, customer service approach
5. Doctors need to be taught more about how to be personable, better communicator, good relationship builders: how to breakdown difficult topics to less educated, a class in med school and continued professional development on bedside manner
6. "Walk in my shoes" kind of training – bedside manner
7. Regular sensitivity training
8. Doctor education: communication (effective), diverse (socio education, age, race, etc.
9. Culturally and socio/economically sensitive
10. One to one conversation, empathy, training

Build more open relationship between medical professionals and patients

1. Respect, time, trust and communication between patient and doctor
2. Doctors should encourage patients to ask questions if they don't understand the information
3. More personal visit to office along with the professional
4. Also, something a patient can do, needs to make sure to have a good relationship with their doctor
5. Video intros before you pick doctors

Increase time spent with patients

1. Limit the amount of patients a doctor can see per day, and require the insurance companies to compensate appropriately per time spent
2. Incentives for doctors to spend more time listen to patients
3. Annual discussion: discuss all or any factors of health

Improve patients' access to their medical records

1. Universal Patient Portal (with prompt update): Full providers access and input, med records, full patient access and input
2. My idea for this problem is better organization concerning patient records, meds list not 3 different ones.
3. Mechanisms to ensure that patients know how and where to access all their records: feel empowered to do so
4. Records sent to other contacts of patient automatically

Build in capacity for patients to evaluate medical professionals

1. An evaluation of doctors and facilities to come up with a protocol to treat people as equally as possible. Being conscientious of medically relevant differences in individuals
2. Make care more accountable through widespread use of Yelp style doctor review sites
3. Making the doctor a little more accountable, i.e.: A signed explanation of the visit
4. Incentives to doctors for patients positive feedback (survey) based on communication
5. Patient – doctor survey
6. Patient–doctor surveys which get sent to a 3rd party agencies for quality of care audits

Education for healthcare consumers

1. Knowing your medical rights
2. A way to educate patients on their rights and how to be more assertive and acess those rights
3. Patient education could improve clarification, as well as expedite diagnosis/treatment process
4. Patients responsibilities/rights to made more clear
5. Provide a checklist of symptoms to patients to facilitate doctor/patient discussion. Include 8 characteristics of symptoms
6. Educate. Patients clearly knowing their rights and responsibilities. Therefore they can also hold the provider to the level of care that they expect
7. Doctors should also hand out recommendations (i.e. like handout given at this event) to patients. Doctors educating patients on patient engagement
8. A displayed document listing patients' rights
9. Patient education: Referrals, interview doctors, persistence/patience, be fearless, get an advocate
10. Create advocacy groups for patients: patient feedback, patient education to positive attitude/knowledge
11. Infographics, multimedia (video, audio)

Introduce more coordination into the healthcare system

1. Office to office relationships better
2. Pick two primary care people who have to cross check each other's work

Improve clarity and methods of communication between patient and medical professional

1. Want the doctor to be more clear and informative of diagnosis and side effects
2. More forms of communication (skype, text, email, etc.), doctors on demand, internet "patients' portals" everybody should have access to.
3. Need doctor and patient to work together. Patient need to present symptom clearly and completely and doctors need to take what's said and help coordinate

Create structures for advocacy to assist patients in navigating the system

1. Bring a friend or family member to advocate for you
2. Having more advocates, social workers available in all healthcare settings
3. Dedicated patient advocate in office, less bureaucracy between patient and doctor
4. Mediator between patient and doctor (doctor advocacy)
5. Patient advocate language services: cultural and language guide, voluntary network of health professionals, improving accessibility of information
6. Having a social worker or advocate
7. Patient advocacy for disabled patients, unconscious patients, uneducated/undereducated patients (doesn't know to speak up)

Make sure that materials and services are fully accessible to those with varying languages and abilities

1. Make required info/paper work accessible to all patients. i.e.: blind: audio format, illiterate/ nonreaders: various languages.
2. Helping for disabled patients
3. Translators via web available during meetings

Increase access to health services

1. Single payer insurance, or accept a variety of insurance plans
2. Improve the problem by not discriminating between Medicare and Medicaid

Other ideas

1. Making the recommendations list shorter
2. Alma Sana project
3. Mandatory sick days for employers regardless of employment types
4. Dental issues should be considered a medical necessity, and not a luxury

STRATEGIC OBSERVATIONS

- Corresponding to the high number of times that power differential and trust were identified as obstacles, a number of people suggested strategies to educate medical professionals in relationship, communication and cultural sensitivity. In addition to training ideas suggested above, this also suggests the possibility of inquiring into whether being a skilled diagnostician requires both sound technical/scientific skills and sound relational and interpersonal skills. If relational abilities improve diagnostic success, it might be worth considering whether SIDM might advocate for or offer additional interpersonal training for those specialties most often engaged in diagnosis.

- This group's suggestions also confirm the perceived value of equipping healthcare consumers with knowledge and skills to navigate the healthcare system more effectively.

In the post-event survey, participants were asked to review the five categories of recommendations, and indicate how well they understood the set of recommendations, whether they would use the recommendations in their own healthcare, how much impact the recommendations would have on diagnostic quality if followed, and how easy it would be for them to use the recommendations.

The results for each of the categories of recommendations are provided in the following section.

Category 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.
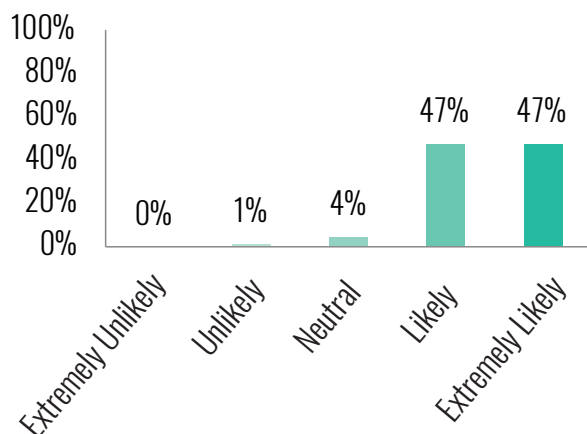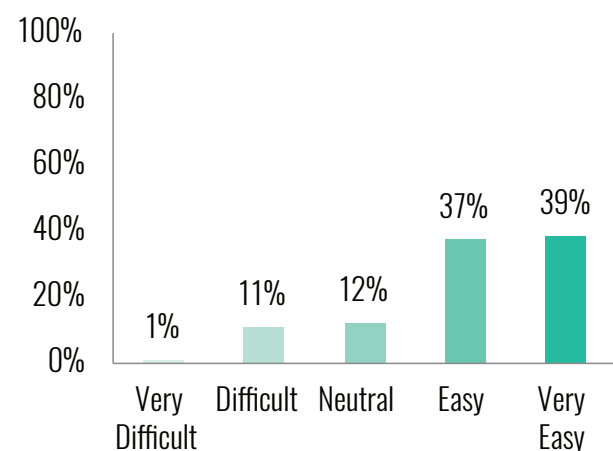
Do you understand this recommendation?

If patients followed through on this recommendation, how much would it improve diagnostic quality?

How likely is it that you would use this recommendation in your own healthcare?

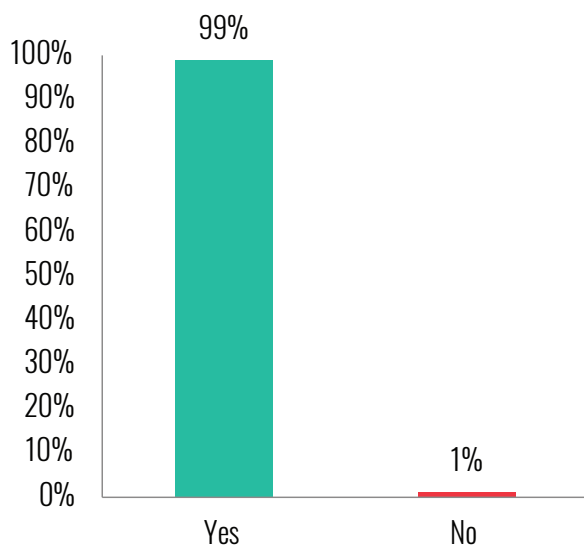How difficult would it be for you to use this recommendation in your own healthcare?

Category 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.

- If you're concerned about the accuracy of the diagnosis, seek a second opinion.

Do you understand this recommendation?

If patients followed through on this recommendation, how much would it improve diagnostic quality?

How likely is it that you would use this recommendation in your own healthcare?

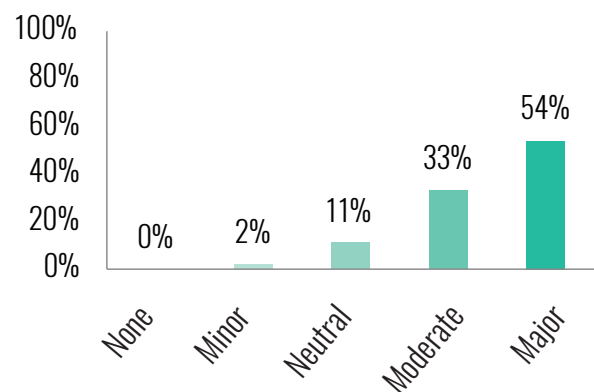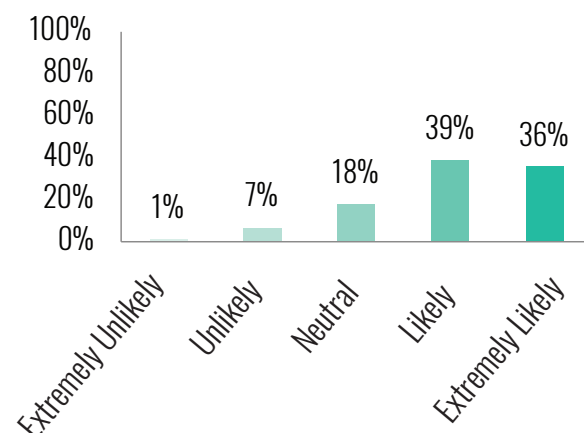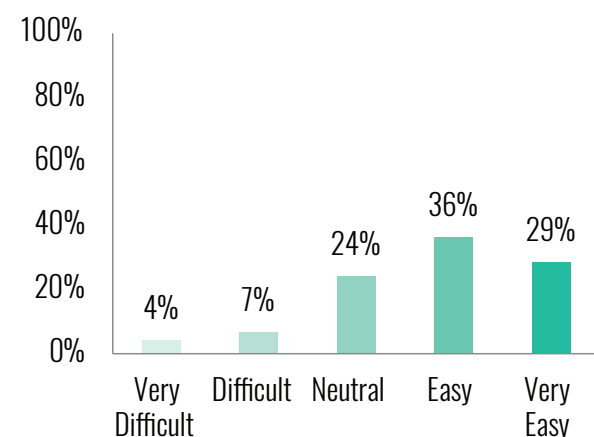How difficult would it be for you to use this recommendation in your own healthcare?

Category 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.

Do you understand this recommendation?

If patients followed through on this recommendation, how much would it improve diagnostic quality?

How likely is it that you would use this recommendation in your own healthcare?

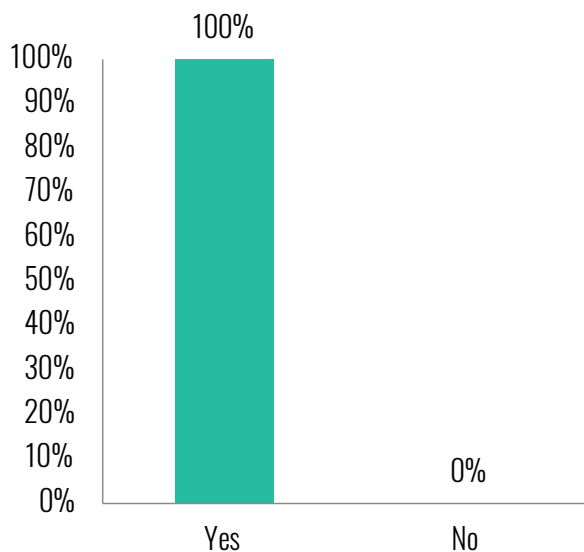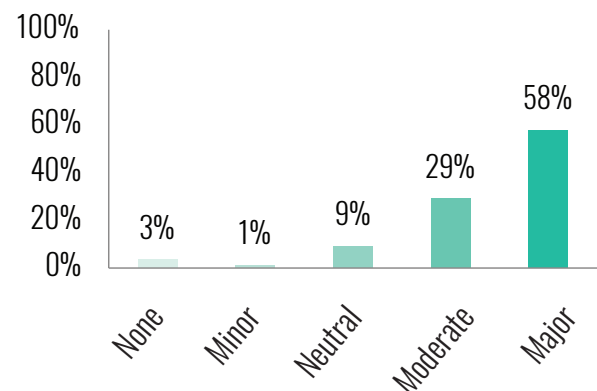How difficult would it be for you to use this recommendation in your own healthcare?

Category 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.
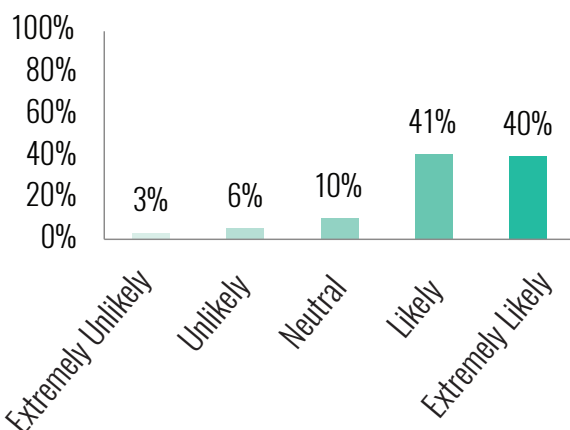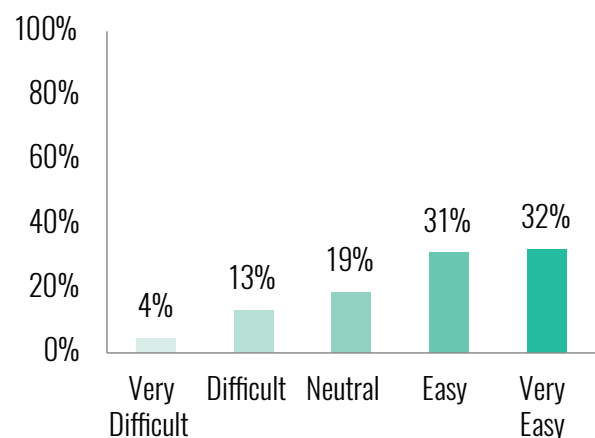
Do you understand this recommendation?

If patients followed through on this recommendation, how much would it improve diagnostic quality?

How likely is it that you would use this recommendation in your own healthcare?

How difficult would it be for you to use this recommendation in your own healthcare?

Category 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.

Do you understand this recommendation?

If patients followed through on this recommendation, how much would it improve diagnostic quality?

How likely is it that you would use this recommendation in your own healthcare?

How difficult would it be for you to use this recommendation in your own healthcare?
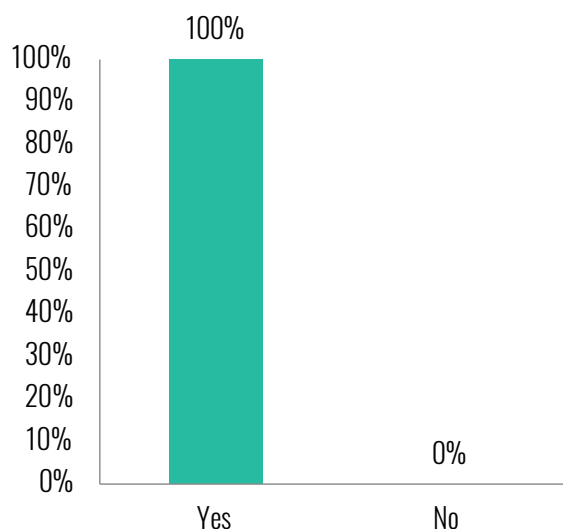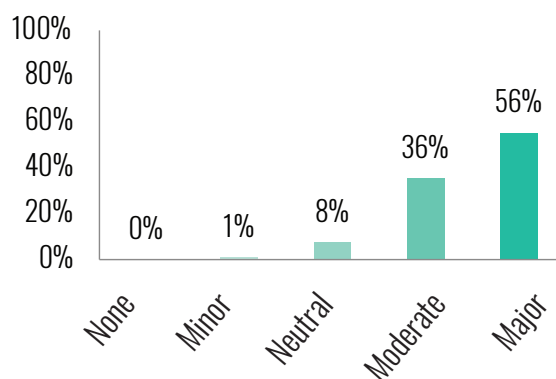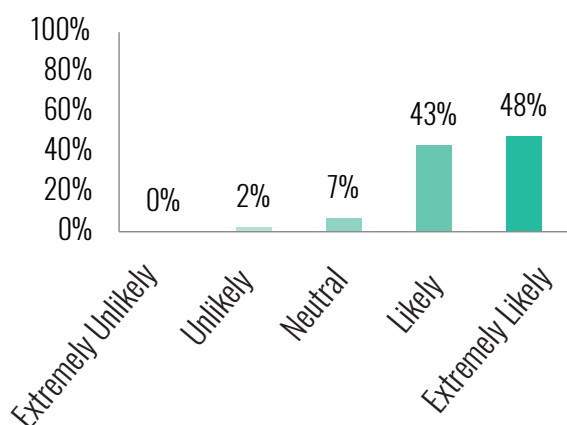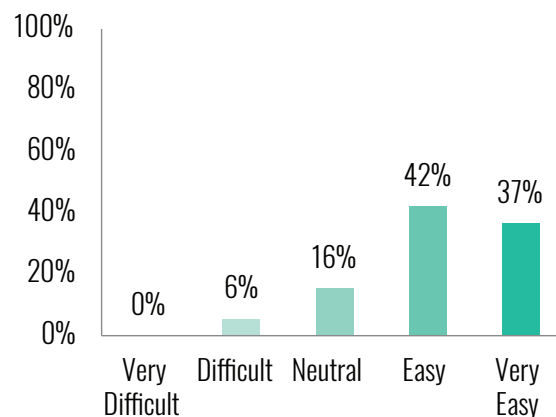
STRATEGIC OBSERVATIONS

- This data addresses SIDM's primary goal from the deliberation: to understand what actions patients might be willing and able to take to improve the quality of diagnosis in order to inform SIDM strategic planning for educational and advocacy efforts.

- The consumer feedback group indicated that all of the actions recommended by the CJ were understood by nearly the entire feedback group.

- A strong majority of the feedback group perceived that all of the categories of recommended actions would have moderate or major impact on diagnostic quality.

- A strong majority of the feedback group indicated they would be likely or very likely to use the recommendations in their own healthcare. Note that the recommendation category, "to coordinate your care" was the only one that fell below 80% indicating likelihood.

- A slightly smaller majority of the feedback group indicated that the recommendations would be easy or very easy to use in their own healthcare. Again, "coordinate your care" fell markedly below others.

- This suggests that patient education about these recommendations may be a valuable strategy and increase the frequency of their practice.

- Considering the context in which this receptivity was demonstrated may suggest important elements of education strategy. They first learned some basic information about the problem of diagnostic error. Then they considered applying the recommendations in actual scenarios. Perhaps successful educational strategies might include explaining the problem, describing how suggested strategies would address the problem, and helping learners see how they apply in real–life situations.

MEDICAL PROFESSIONAL FEEDBACK

In November, 2016, a focus group involving 17 medical practitioners was held prior to SIDM's Diagnostic Error in Medicine Conference in Los Angeles, CA. A similar focus group was held on February 16, 2017, with a group of 17 medical professionals from Crouse Hospital in Syracuse, NY. Results from the two focus groups are combined for the purposes of this report. Specific comments are labeled to identify the source event.

Before the event began, participants were invited to review recommendations and respond to six questions. The five groups of recommendations from the CJ were included, along with sets created by researcher, Dr. Tina Nabatchi, based on the Institute of Medicine report on diagnostic error and compiling ideas offered by an "education-only" group who heard an initial presentation about diagnostic error and completed a survey.

Results of the survey are presented as composite scores by each question, showing comparative responses for each recommendation.

Will patients understand this recommendations?

Chart showing "Will patients understand this recommendations?"

Category	Yes	No
Category 1	24	11
Category 2	25	10
Category 3	31	4
Category 4	32	3
Category 5	32	3

Legend: Yes, No, n=34
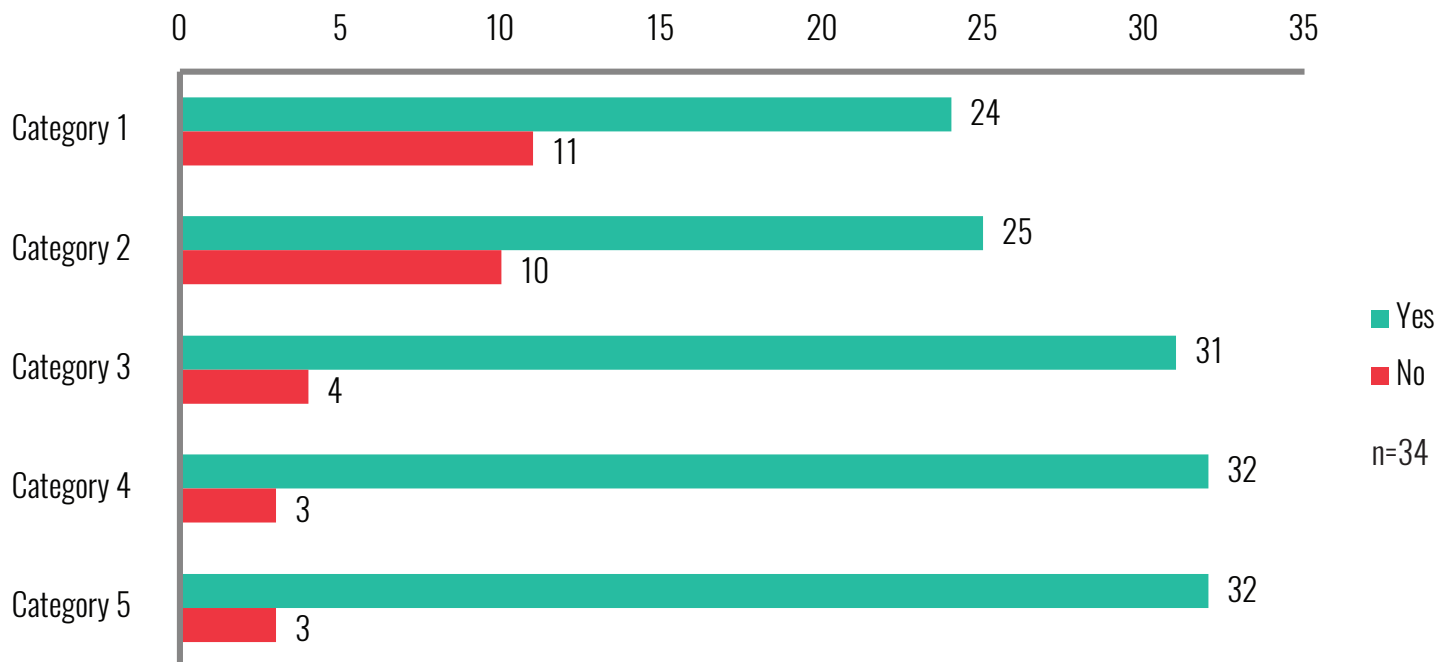
How likely is it that patients will use this recommendation?
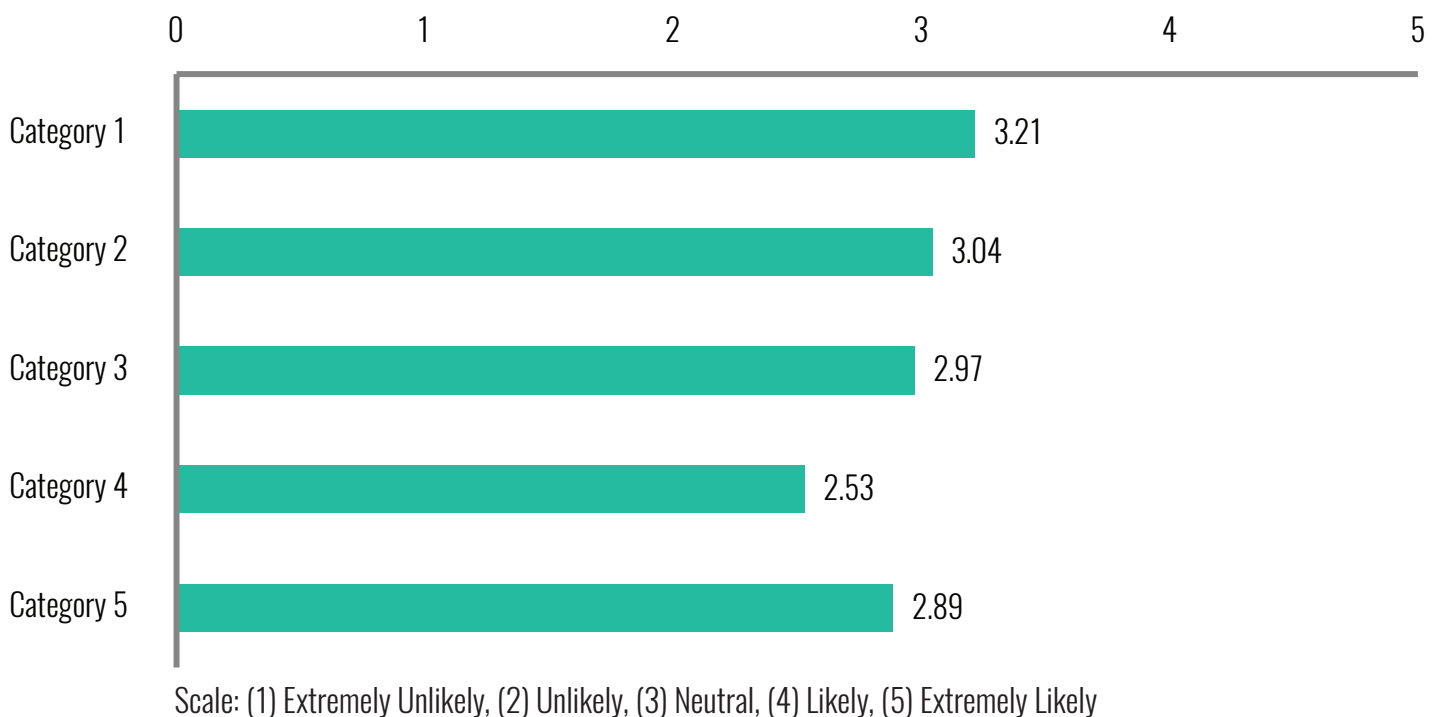
Category	Value
Category 1	3.21
Category 2	3.04
Category 3	2.97
Category 4	2.53
Category 5	2.89

Scale: (1) Extremely Unlikely, (2) Unlikely, (3) Neutral, (4) Likely, (5) Extremely Likely

How difficult would it be for patients to use this recommendation?

	0	1	2	3	4	5
Category 1				2.76		
Category 2				2.64		
Category 3			2.29			
Category 4			2.24			
Category 5				2.79		

Scale: (1) Extremely Difficult, (2) Difficult, (3) Neutral, (4) Easy, (5) Very Easy
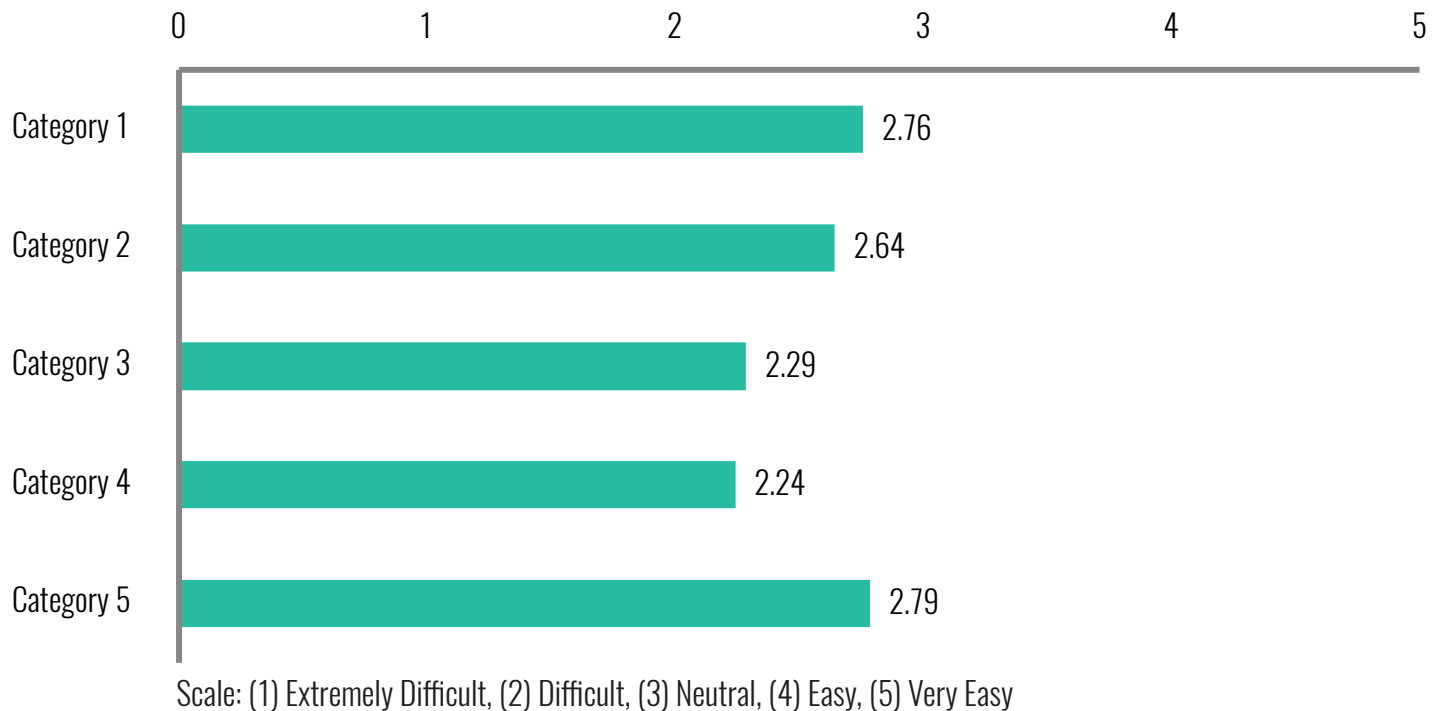
If used, how much would this recommendation improve diagnostic quality?

	0	1	2	3	4	5
Category 1					4.11	
Category 2					4.11	
Category 3					4.23	
Category 4				3.76		
Category 5					4.16	

Scale: (1) No Improvement, (2) Minor Improvement, (3) Neutral, (4) Moderate Improvement, (5) Major Improvement
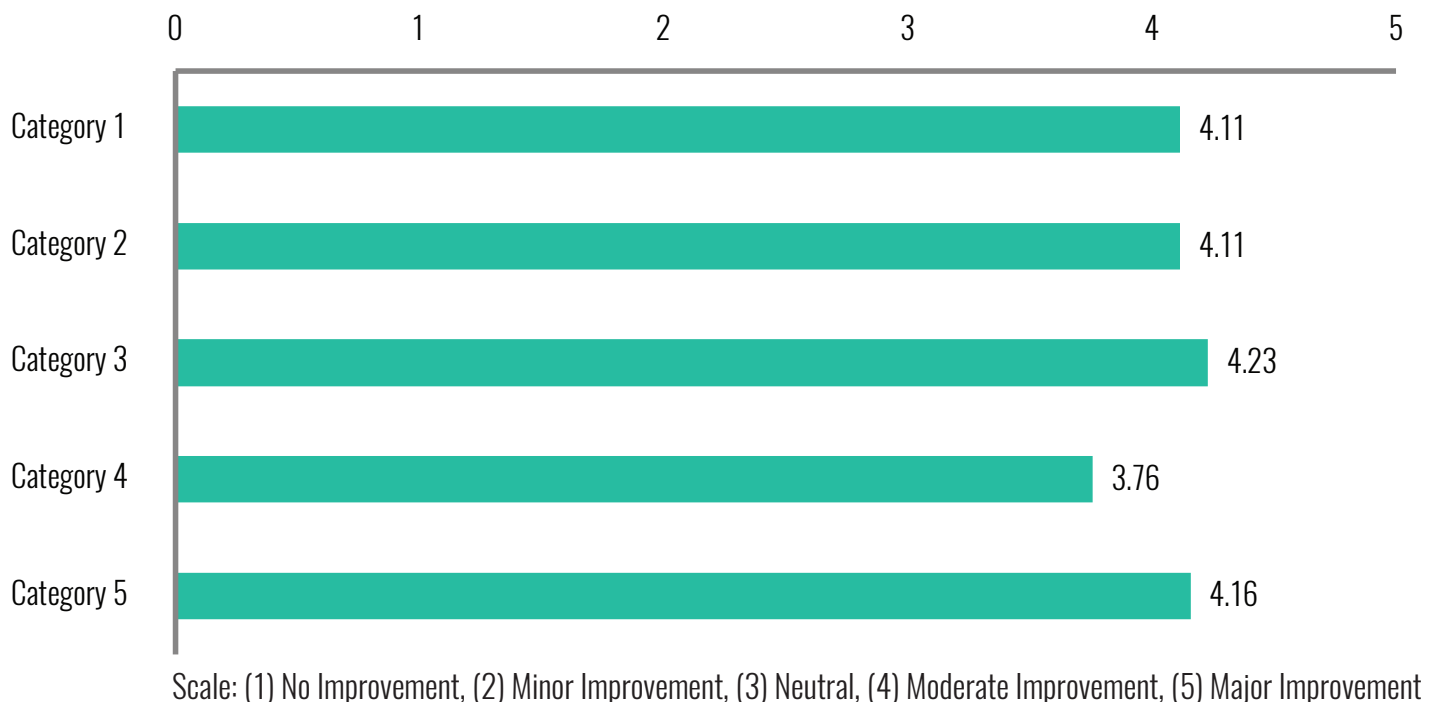
MEDICAL PROFESSIONAL FEEDBACK

How appropriate do you believe it is for patients to follow through on this recommendation?
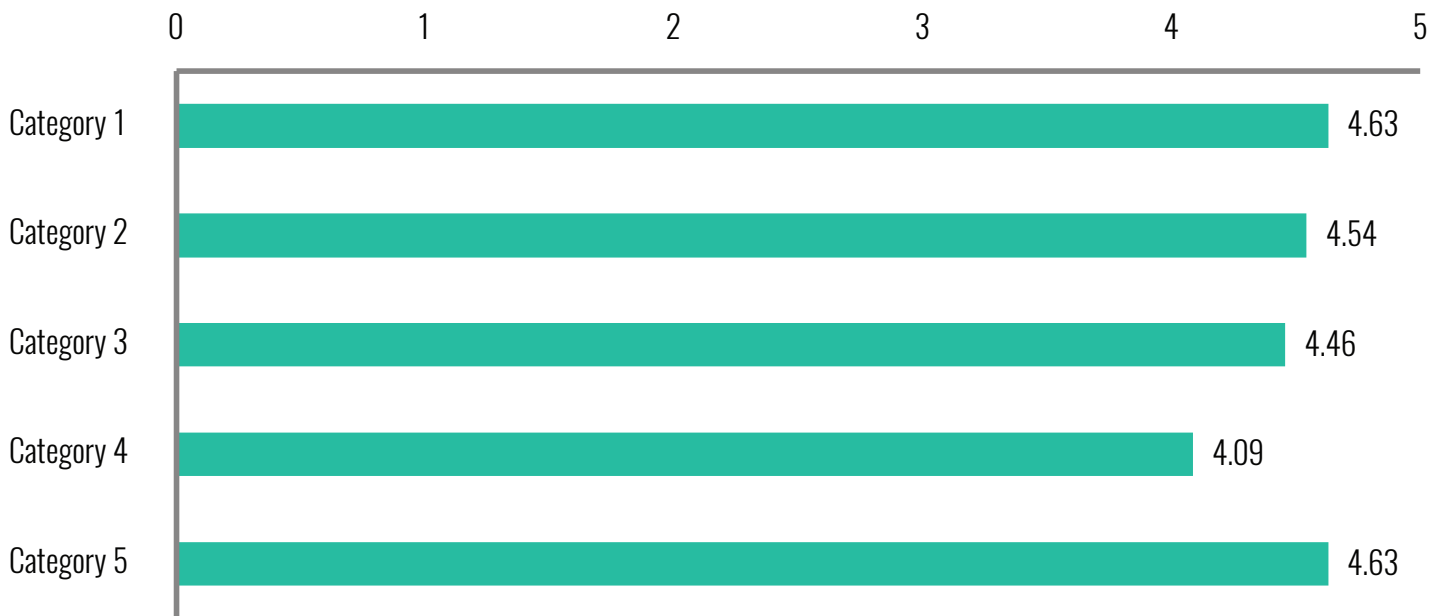
Category	Value
Category 1	4.63
Category 2	4.54
Category 3	4.46
Category 4	4.09
Category 5	4.63

Scale: (1) Absolutely Inappropriate, (2) Slightly Inappropriate, (3) Neutral, (4) Slightly Appropriate, (5) Absolutely Appropriate

How appropriate would other medical professionals find it if patients were to follow through on this recommendation?
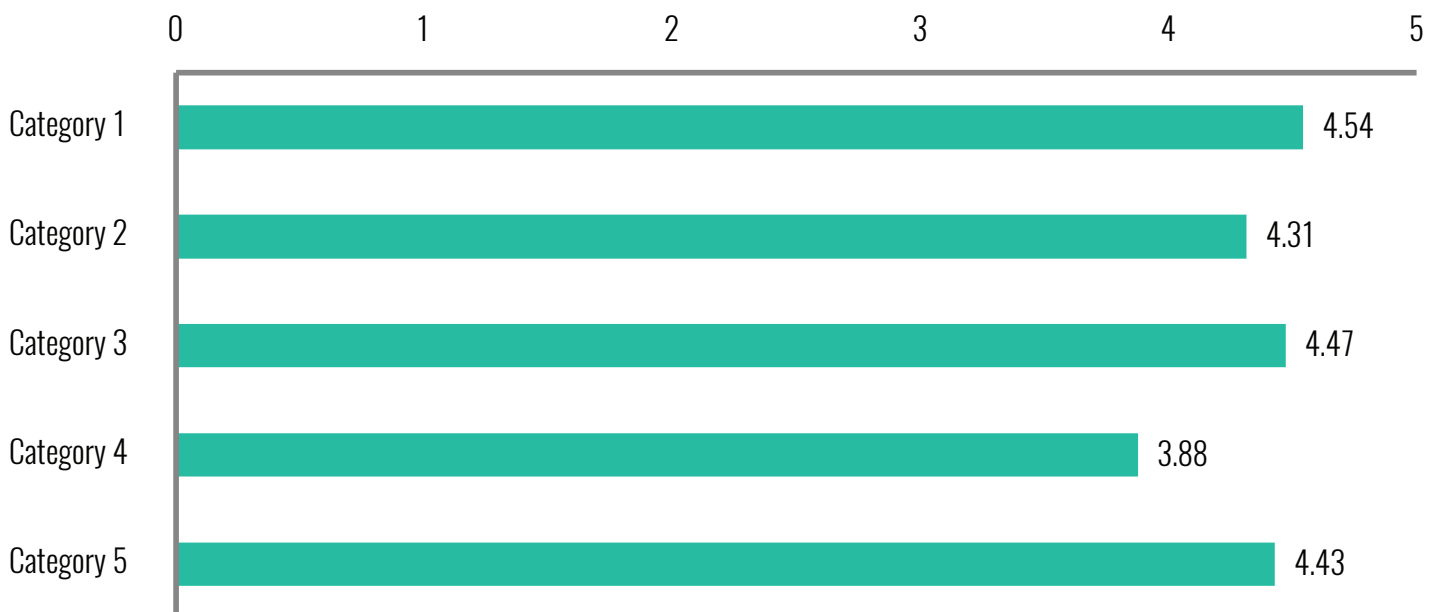
Category	Value
Category 1	4.54
Category 2	4.31
Category 3	4.47
Category 4	3.88
Category 5	4.43

Scale: (1) Absolutely Inappropriate, (2) Slightly Inappropriate, (3) Neutral, (4) Slightly Appropriate, (5) Absolutely Appropriate

STRATEGIC OBSERVATIONS

- A majority of the medical professionals agreed that following the recommendations would make moderate or major improvement in diagnostic quality. A majority also indicated that they and colleagues perceive patients taking such action as appropriate (with a noticeable dip in the category relating to health records). This data may indicate receptiveness in the medical community to SIDM's efforts to further patient involvement in the diagnostic process. The dip in perceived levels of appropriateness related to health may reflect an area for further discussion and/or education within the medical community.

- The relative agreement between the medical professionals and the consumer feedback group regarding the potential positive impact of these patient actions on diagnostic quality may provide motivation for SIDM and others to continue to advocate for increased patient engagement in the diagnostic process.

- There are, however, interesting contrasts between consumer and medical professional perceptions. Medical professionals seemed to have lower expectations of patient understanding than consumers reported. They also tended to perceive patients as being less likely and less able to take the actions than consumers perceived themselves. This suggests that there may be a perception gap between the two populations. It may prove valuable to explore this gap further.
    - If patients are, indeed, more capable of understanding and practicing the recommendations than professionals perceive, the perception of professionals may subtly limit the opportunity for patients to act. Thus, efforts could be made to increase professionals' trust in patient capabilities.
    - If, however, the professionals' perspective is more accurate, educational efforts could be focused on increasing patients' understanding and capacity to act.
    - Moreover, if the professionals' perspective is more accurate, then one fruitful intervention strategy might be to select actions judged as having high impact and higher difficulty and take actions that would diminish the difficulty for patients to follow the recommendations.

MEDICAL PROFESSIONAL FEEDBACK

Medical professionals at Crouse and DEM participated in table discussions in which they identified the challenges that medical professionals experience when patients take initiative in the diagnostic process and the positive aspects of their experience when patients take initiative in the diagnostic process.

CHALLENGES

- Patients uncooperative, misinformed, or asking for unhelpful interventions
- Mental health issues
- Lack of trust
- Managing patient expectations
- Communications
- Inaccurate history
- Provider issues

POSITIVE IMPACTS

- Family involvement
- Patient assertiveness/ persistence
- Good information from patients
- Build relationship
- Second opinion

The overwhelming number of identified challenges had to do with patients asserting themselves in less than helpful ways, while the largest group of positive aspects focused on the value of patients being assertive and persistent. This suggests a possible line of inquiry and education for both professionals and consumers:

- Assertion/persistence is definitely perceived as valuable by providers, yet it becomes a block when applied in unhelpful way.

- For consumers, educational efforts to help them understand the nuances of beneficial and non-beneficial types of assertion and tools or checklists that reinforce helpful assertion might be provided to assist them in knowing when and how to assert.

- For professionals, education might serve to sensitize them to look for helpful patient assertion because too much experience with unhelpful may increase the possibility of dismissing the helpful variety. Training might be offered in working with patients to uncover the useful feedback that may be delivered in a non-useful manner by consumers who may not be skilled in communicating what they need.

- Increase face to face time by reducing documentation time or shifting resources

- Rooming staff member asking, "Reason for visit?"

- Give patients "8 questions" while waiting

- Post visit reflection/debrief with opportunity to ask additional questions

- Pre-work before visits: get information online or at in-office kiosks

- Proactive patient advisory councils: patient involvement in improvement work

- Candid, safe discussion of errors – requires [D] (sic) in legal, risk

- What's critical to success? Why? "What's in it for me" for all involved.

- Appointment reminder cards

- Reverse said: "Ask [doctor] 3 questions: What's wrong with me? What should I do about it? Why is it important?"

- How do we evaluate impact of intervention?
  - Need randomized control trial
  - Need to get better at measuring diagnostic error so we can better evaluate interventions to address it
    - DX is very field-specific
    - Need good baseline data

- Follow up letters or calls
  - Many throw letters away
  - What's the difference between verbal and written communications?

- Open access to test results/records
  - Do fewer things fall through the cracks?
  - Do people access their records?

> In considering systemic interventions to improve diagnostic quality that may be tested in clinical settings, the suggestions from the CJ and medical professionals provide a "menu" of options for pilot testing.

CONCLUSION

The aim of this research project was to strengthen SIDM's education and advocacy efforts by providing better information about the actions patients are willing and able to take to improve the quality of diagnosis. The multi-phased deliberation produced a set of 16 recommended actions. The CJ participants themselves and the consumer feedback group both expressed a high degree of willingness and capacity to take these actions. Medical professionals judged these actions as having strong potential to improve diagnostic quality and most deemed it appropriate for patients to follow the recommendations.

A theme running throughout this report suggests that a high impact intervention will likely focus on the doctor-patient relationship. There is a general recognition that diagnosis works best as a collaboration, but many factors inhibit effective collaboration, including mistrust of medical professionals, underestimation of patient capacities, power differentials, and mutual misperceptions.

Many of the recommendations address sharing information in a form and manner that can be readily received and acted upon. Relational factors hinder this process from both directions. Interventions to improve communication might provide education about what is important to communicate, how to communicate, and develop and share tools that would facilitate the process of communication.

Given that consumers are less informed about the benefits and methods of participation, it may fall to health care systems and professionals to develop (with consumer help) protocols, structures, and practices that will facilitate more effective patient and family participation in the diagnostic process.

Many practitioners experience medicine as a technical discipline. But the diagnostic process is also a relational discipline. Helping consumers navigate this relational territory so that important information is offered and understood effectively may reap benefits.

An anecdote may illustrate. During the CJ process, a physician shared that he liked patients to discuss 8 characteristics of their symptoms. There was immediate energy in the room around that idea, and group awareness of "sharing your symptoms" crystallized around that model.

CONCLUSION

In that moment of relationship between professional and consumer, consumers were empowered in a significant way because they gained clarity about needed information, how to communicate it (one paragraph) and had a tool to utilize (the 8 characteristics). It may be worth considering how similar patterns could be replicated at multiple levels in the healthcare system.

It is also significant to note that the realization, by CJ participants, that diagnosis is a process rather than a one-time event was a turning point in their understanding the potential for patients to take an active role as partners in the process. A misconception that diagnosis is a point-in-time activity conducted by an expert may lead to patients' underestimating the important role they play in reaching a diagnosis.

Re-framing diagnosis as a partnership between clinician and patient in a process 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 in efforts to improve diagnostic quality.

Additional process details, research data, and other resources are available online at:

jefferson-center.org/patient-dx