Implementing Shared Decision Making with Physicians and IBD Patients

Interview Guide for Physicians

December 2011

BENFIELD
The Benfield Group

Thank you for your time today. You'll receive a $350 honorarium for sharing your expertise during this interview. Where would you like the honorarium sent?

Name:

Address:

The SDM Physician/Patient Experience

1. Thinking about your patients, their ailments and the different treatment options available, what do you consider a successful treatment outcome?

2. As you know, the focus of this interview is shared decision making (SDM). There are many variations in how people define that term, so we'd like to ask, how do you define "shared decision making?"

    a. In what ways, if any, does SDM differ from informed decision making?

3. On a scale of 1 -10, where 1=you completely disagree and 10=you completely agree, rate the following statement: SDM leads to increased patient satisfaction.

    a. Why did you choose that rating? (Probe for experiences, impressions, etc. that impacted rating.)

4. On the same scale of 1 to 10, where 1=you completely disagree and 10=you completely agree, rate the following statement: SDM leads to better clinical outcomes.

    a. Why did you choose that rating? (Probe for experiences, impressions, etc. that impacted rating.)

The SDM Physician/Patient Experience

5. Thinking about the many patients you see and your experiences making treatment decisions with them or for them, how would you categorize different types of patients according to their decision making preferences?

   (Examples of buckets might be patients that: want decisions made for them, want to be involved in every decision, are apathetic to practice, are risk averse, etc.)

   a. Can you describe how these patients differ? That is, what are some of the attributes that tell you a patient is one or another type of decision-maker?

   Probe for attributes like: education level, disease knowledge, age, duration patient has had the disease, etc.

6. Would you say that you have a deliberate process and approach to engage patients in shared decision making?

   a. If no, why not?

   b. If yes
      i. With what percentage of patients?

      ii. Why not all patients?

   c. If sometimes or yes, walk us through your SDM process. Probe for:

      i. Is there a standard practice with every patient?

         1. If no, what determines whether you use it?

      ii. What tools are used (forms, information, web sites, etc.)

      iii. What issues are addressed in your process/tools?
         1. Patient preferences

         2. Benefits of alternative treatments

         3. Risks of alternative treatments

4. Costs (to patients) of alternative treatments

5. Other

iv. How are tools administered (verbal, paper, web, etc.)

v. What is the work flow/who does patient interact with through the process?

vi. When is the process implemented? (i.e., just initial treatment, to periodically evaluate current treatments vs. other options, when changing treatments?)

Creating the Ideal SDM Experience

7. In your opinion, what does an ideal SDM approach look like? <ask open ended, then probe for details for:>

    a. Role of other health professionals

    b. Timing of the SDM process (when to begin, reassess treatment, etc)

    c. Use of tools (including use of visuals in tools)

    d. Delivery of tools (e.g., web, phone app, paper, video)

8. What do you think are the key barriers preventing the ideal implementation of SDM?

    a. What do you think could and should be done to overcome these barriers?

9. On a 1-10 scale, where 1=not at all important and 10=extremely important, rate how important the following factors would be in increasing physician use of sound SDM tools and processes?

    a. Reimbursement for SDM process

    b. Linking SDM to certification and qualification for a quality designation

    c. Confidence that SDM will not create legal liability for physicians

d. Evidence that SDM will produce increased patient satisfaction

e. Evidence that SDM will produce better clinical outcomes

f. Having a flexible tool that patients could access by web, phone or paper

10. Which three of these factors would you rate as the most important to implement in order to increase the practice of SDM?

11. Thanks again for sharing your time and expertise today. Do you have any additional thoughts or comments you'd like to share before we end the interview?

Physician Research on Shared Decision-Making
Virtual Focus Group Script and Patient Comments

March 19, 2012

Script Introduction

This document contains excerpts from transcripts of interviews conducted with physicians on the topic of Shared Decision Making (SDM). These excerpts have been selected as content for a script that will be used in a Virtual Focus Group (VFG) with the following points in mind:

- The entire script, once written, can be no longer than about 5 minutes.
- Researchers focused on key issues/objectives that framed the interviews.
- To the extent possible, researchers included comments that are provocative along a spectrum of opinions to provide content that respondents can react to with their agreement/disagreement during the survey.

The script involves a moderator and four physicians.

Character	Narrative
SDM Defined	
Moderator	Thinking about your patients, their ailments and the different treatment options available, what do you consider a successful treatment outcome?
Physician 1	Well…I'd say it's when the patient doesn't have to think about her disease; that she is embracing opportunities in life that she may have put off because she was sick. From a clinical standpoint, it's when symptomatic control is achieved and the prognostic markers say that the patient is likely to do well in the future.
SDM leads to increased patient satisfaction?	
Moderator	OK, now I want to move on to the main focus of this discussion—Shared Decision Making, or as we may all refer to it going forward SDM. With that, do you think that SDM leads to increased patient satisfaction?
Physician 2	Generally, no. It seems to me that patients appreciate the information, but that doesn't necessarily lead to higher satisfaction. At the end, they almost always ask, "What would you do if you were me?" Ultimately, patients want guidance from their physician. That's what gives them satisfaction.
Physician 4	I think SDM does help patient satisfaction, because the patient knows their physician is taking his individual situation into consideration. Most patients want to be heard, and want to have a say in their treatment.
SDM leads to improved patient satisfaction and treatment outcomes?	

Character	Narrative
Moderator	Great. Now the next question is, whether or not SDM improves patient satisfaction, do you think shared decision making leads to better treatment outcomes?
Physician 4	Absolutely. This follows what I was just saying. When patients feel heard and are part of the decision process, they are more likely to buy into the treatment protocol. And, when they have bought into it, they are more likely to do it. Better adherence leads to more effective treatment.
Physician 2	I would like to believe that's true, but I don't think SDM changes clinical outcomes.
Physician 1	I'm with you. Just because a patient feels good a1bout his decision, or is confident in his choice, doesn't mean he's making a good decision. I had a patient that wanted to stay on steroids. I advised against it, citing the risks. He was insistent, so I told him I could no longer treat him.
Physician 4	I respectfully disagree with that approach. The spirit of SDM is that patients have a say in their treatment. As long as patients understand their choices and the associated risks and benefits, we need to respect their decisions…even if we disagree.
Physician 3	In my experience, patients find choosing a treatment difficult. As much as they may want to be part of the process, patients become overwhelmed and anxious when they realize how difficult the decisions are.
Addressing Barriers to SDM/Increasing SDM Implementation	
Moderator	It's clear that you all have a lot of experience helping patients make treatment decisions. Now, what are some of the barriers preventing physicians from practicing shared decision making more often and more consistently?
Physician 1	Time. Time is the number one barrier. It's hard to find the extra time needed to implement SDM the way I'd like to with my patients…the way I believe I should implement it.
Physician 3	Well, as they say: "What gets paid for gets done. It comes down to reimbursement. If physicians don't get paid for the time it takes them or their staff to implement a SDM process, it's just not going to get done…
Physician 4	Here's another reason SDM doesn't occur more often. It's not taught in most medical schools. We're not trained to "share" decision-making. The dominant philosophy is still "I'm the doctor; you're not. You should do what I say." We need a cultural shift in our profession that enables SDM to become the norm.
Physician 2	Well, patients are part of this too. Patients need to let their doctor know they want to play a role in making decisions. Just doing what the doctor says is a pretty entrenched idea. I'm not sure it's our role to pull people into the process if they're not interested.

Character	Narrative
Physician 3	The real issue is that most physicians don't know the data well enough to walk to their patients through making a decision. Most physicians don't share decision-making with their patients, because they don't understand treatment benefits and risks well enough to really explain them.
Moderator	I'm a bit surprised that nobody has mentioned concerns about liability yet. Is anyone concerned that SDM opens them up to law suits?
Physician 4	Quite to the contrary. The SDM process…by its very nature…creates a record that you explained the options to the patient, she understood them and selected the one she wanted to pursue. It would provide more protection than the status quo of simply prescribing a treatment without that level of patient involvement.
Physician 3	I think that the caveat is the need for good documentation, and that requires a systematic approach that's built into the practice model, and documented in the patient file. SDM won't protect us from liability if it's done informally.
Physician 1	I would be much more interested in practicing and documenting SDM if I knew it would protect me from liability.
Moderator	OK, then, let's talk about what it takes to make SDM the norm in a practice setting. What are some things you would recommend be part of a systematic approach to implementing SDM?
Physician 4	What we need most is a set of tools that patients can use to understand their disease, the treatment options and the benefits and risks of those options. If physicians have tools to cover the basics, they can focus their time helping patients further understand and weigh their treatment options.
Physician 2	By "tools" you mean…
Physician 4	A tool could be a worksheet, brochure, video, web-based program, or tutorial. Different patients are going to have different needs. Some patients may not have a computer at home, so a web site won't help them, but they may do just fine with a worksheet they can take home.
Physician 2	Hang on…I'm not so sure I want my patients looking at this information out of the office setting. They get a little information, and that leads to questions, and if they're not in my office, they look to the internet for answers, and God knows where that will lead them. I would much rather have my patients look at these tools in my office, where I, or one of my nurses, can be there to help them.
Physician 3	The internet train has left the station. Whether we like it or not, patients are using the web to get at all sorts of information outside of our offices, and of course, they're going to use it.

Character	Narrative
	Because of that, I think it's important for patients to have some kind of tool that provides accurate information about options that are approved, safe and effective.
Physician 1	Let's go back to that comment about nurses and tools. I think our nurses, PAs and nurse practitioners could be used more effectively when it comes to SDM. I'd like to see tools developed in a way that helps my staff become more engaged in the process…maybe in addition to tools, some basic training in helping patients understand the information.
Physician 4	I'll take it a step further. It would be helpful to have patient support groups. It might help patients understand their disease and treatment options if they can talk with other patients.
Physician 1	Most of the time, other patients are a terrible source of information. I don't think we want to facilitate the exchange of personal opinions about treatments.
Physician 3	I think support groups could be a good idea, but they need to be moderated by a healthcare professional who can be a resource for credible information. Then, I think patients groups can be really helpful to some patients.
Physician 4	You know, health plans have case managers to help patients manage other diseases, like diabetes. Maybe they could train case managers to provide patients with SDM support.
Physician 2	All of these suggestions—nurses, other patients, case managers…they just dilute the patient-physician relationship. It's the physician's role to help their patients understand treatment options and decide on a treatment plan with patients. The process is just too complicated for anyone but the physician to do.
The End	

Physician Research on Shared Decision-Making Survey

Approved Version

Background

Purpose
The purpose of the physician survey is to explore the experiences, concerns and the practicality of SDM with physicians.

Target Audience:
GI Physicians

Survey Length:
15 minutes (including 8 minutes of audio)

All questions will be forced unless stated otherwise.

Questions

Screening Questions

1. Are you a physician?
   A. Yes
   B. No <<If no, screen out>>

2. Are you a board certified physician in (select all that apply)

   A. Internal Medicine
   B. Gastroenterology
   C. Cardiology
   D. Oncology
   E. Pediatrics
   F. Other
   G. I am not a board certified physician <<Mutually exclusive to other responses>>

   <<note: respondents will continue with survey if they select gastroenterology only or gastroenterology and another specialty. Respondents who do not select gastroenterology will be screened out>>

3. How long have you practiced gastroenterology?
   A. Fewer than 3 years
   B. 3-9 years
   C. 10-19 years
   D. 20 years or more

4. How many Inflammatory Bowel Disease (IBD) patients do you see in an average month?
   A. Fewer than 10
   B. 10-25
   C. 26-75

D. 76 or more

5. On a 1-5 scale, where 1=not at all familiar, 3= somewhat familiar and 5=extremely familiar, rate how familiar you are with shared decision making (SDM).

> The Informed Medical Decisions Foundation defines Shared Decision Making (SDM) as: "a collaborative process that allows patients and their providers to make health care treatment decisions together, taking into account the best scientific evidence available, as well as the patient's values and preferences."

6. Given the above definition, when do you use SDM in making treatment decisions?
   A. Never. <<Skip to 8, then skip to audio segment>>
   B. Only with patients who indicate that they have a strong interest in participating in their treatment decisions.
   C. I try to get all my patients to understand their choices and to weigh in on decisions, but if they are not interested, I don't push it.
   D. I make sure all my patients have information about treatment choices and that they express a treatment preference, whether they really want to or not.

<<If B, C or D answer 7 and 8>>

7. Using the 1-5 scale below, would you characterize your approach to SDM as:

   For this question, documented may mean that you follow a written policy, use materials from an officially published source, or have some tools or aids to assist you in the SDM process.

   1 = Informal and undocumented

   2

   3 = Somewhat formal and consistent in approach, but not formally documented

   4

   5 = Systematic, consistent, and formally documented

8. Indicate how much you agree or disagree with the following statements.

	Strongly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Strongly Agree	Insufficient Experience to Form an Opinion
Using SDM leads to **better clinical outcomes**						
SDM is **not worth the time** it takes						
SDM leads to						

increased patient satisfaction						
Patients are not qualified to participate in treatment decisions						

9. Do you *currently* use any tools or decision aids when implementing SDM with patients? (Check all that apply)
   A. Printed information (brochures, copies of articles, etc.)
   B. Worksheets walking patients through decision factors
   C. Websites
   D. Videos
   E. Other: _____
   F. No, I don't use any tools or decision aids

Physician Audio Segment

10. What **three** factors would you rate as the biggest ***barriers*** to increasing the practice of SDM? Pick up to three factors.
    A. Reimbursement is lacking
    B. Fear of legal liability
    C. Not enough evidence that SDM will produce increased patient satisfaction
    D. Not enough evidence that SDM will produce better clinical outcomes
    E. Lack of decision aids or tools to assist with SDM
    F. Lack of staff with the time to practice SDM with patients
    G. Lack of space in your office or practice setting to conduct SDM
    H. Other _____

11. Where do you refer patients for more information about their disease? Select all that apply.
    A. Patient web sites (e.g., Mayoclinic.com, Web MD)
    B. Crohn's & Colitis Foundation of America
    C. College of Gastroenterology
    D. American Gastroenterological Association

E. Your institution's website

F. Other: _____

G. None. I don't refer my patients to any information resources.

12. What types of decisions do you think are *appropriate* for shared decision making? Select all that apply.

    A. Routine, low risk medical interventions (e.g., prescribing antibiotics)

    B. Prescribing treatment for a chronic disease with several relatively low risk treatment options (e.g., blood pressure or cholesterol medications)

    C. Deciding on elective surgical procedures

    D. Selecting a course of treatment that may have significant risks and benefits (e.g., prescribing biologic medicines)

    E. Making critical, consequential decisions in life threatening circumstances when there are several options

    F. Urgent, life-saving interventions (e.g., emergency surgery)None of the above

13. Which **three** features would you rate as the ***most essential*** to creating a helpful SDM tool for physicians? Pick three.

    A. Could be used at home or in the office

    B. Appeals to patients and is easy to use

    C. Could be used by allied staff to help patients

    D. Summarizes information about the patient before their office visit

    E. Captures information about the patient's fears, values, lifestyle priorities

    F. Comes in multiple formats (online, DVD, print, smartphone app, etc.)

    G. Communicates treatment risk and benefit information in ways patients can understand

    H. Other: _____

14. Use the 1-5 scale to indicate the level of confidence you have in the following organizations' ability to provide useful SDM tools. 1=no confidence, 3=some confidence, 5=complete confidence

    A. Professional society/college (i.e., CCFA, AGA)

    B. Clinical centers of excellence (i.e., Mayo Clinic)

    C. A physician colleague with expertise in SDM

    D. Public sector (i.e., NIH)

    E. A health plan

    F. A pharmaceutical manufacturer

G. A program vendor

H. Other: _____

Demographics

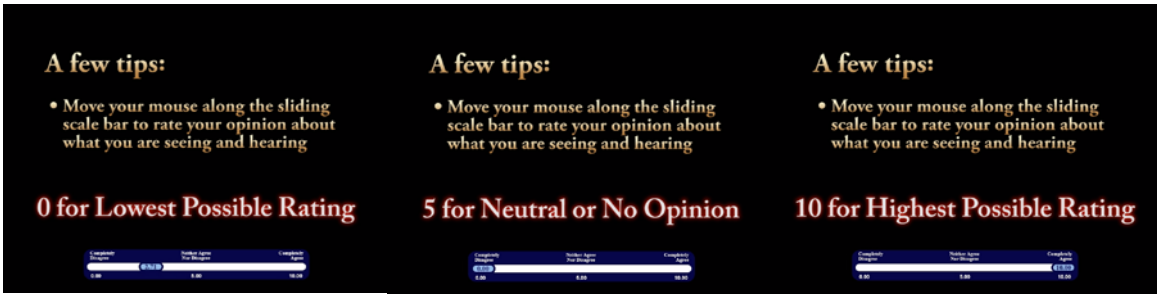
15. What is your age?
16. What is your gender?
17. What is your practice setting?
    A. Hospital system
    B. Integrated delivery system
    C. Community health center
    D. Private multispecialty practice
    E. Private specialty practice
    F. ER or acute care center
    G. Other_____
18. Do you routinely use anti-TNF agents for the treatment of IBD?
    A. Yes
    B. No

Media Rating Training Video Script and Select Screenshots

Media Rating Training Video Length: 50 seconds.

Welcome to the media rating system! Rather than just responding after watching a whole clip. Here you will move your mouse to rate what you are seeing second-by-second as it happens.

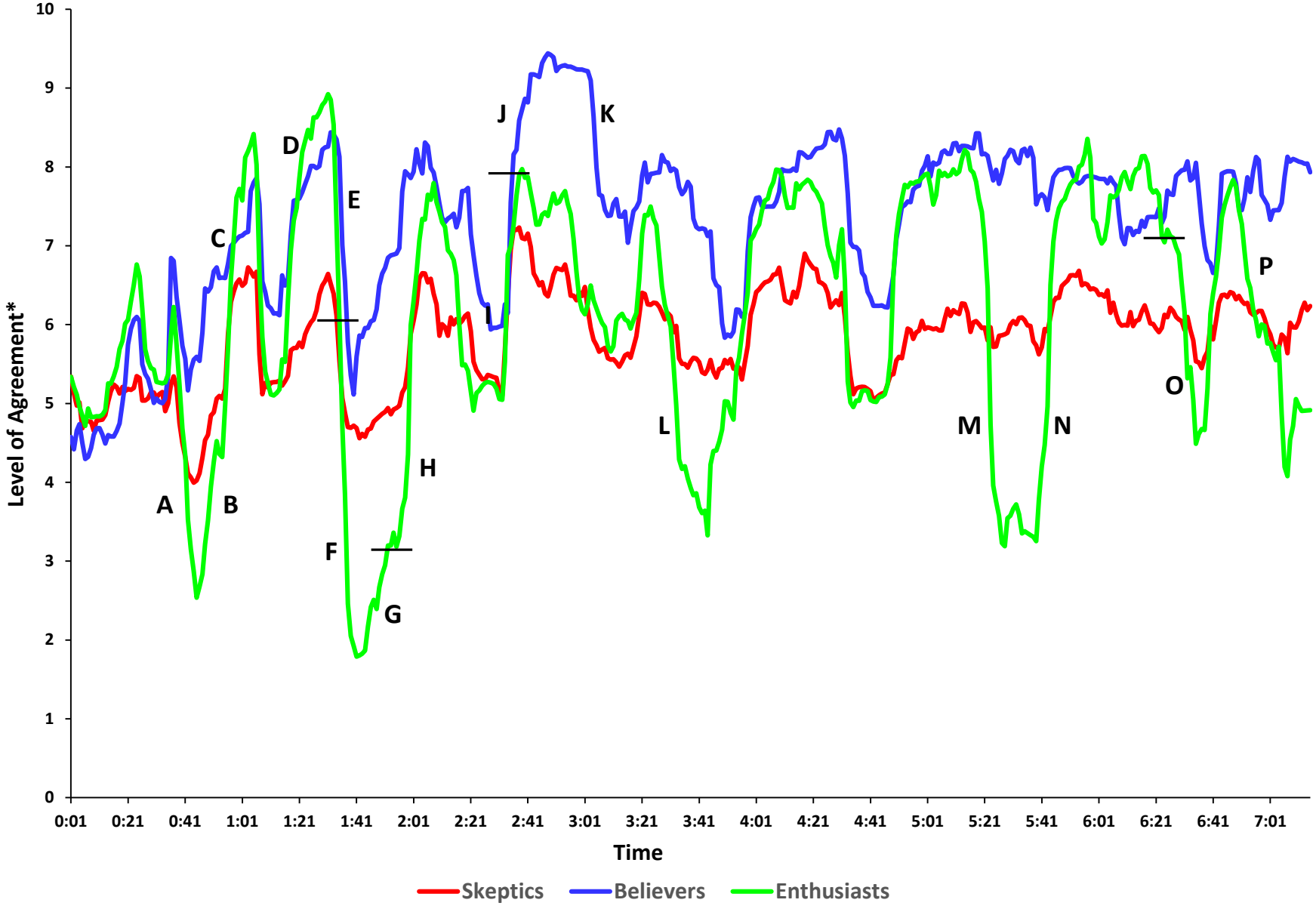
Move your mouse to 0 for the lowest possible rating; 5 for neutral or no opinion; 10 for the highest possible rating or any number in-between.



Please begin your rating at 5. When you hear something you agree with move your mouse towards the 10 on the rating scale. If you hear something you disagree with move your mouse

towards 0. You can return to 5 at any point during the rating to indicate no opinion or a neutral opinion.

Please remember you can use the whole scale from 0 to 10 to indicate your level of agreement at that moment.



*10 indicates complete agreement, 5 is neutral, and 0 is complete disagreement

Marker	Quote
A	Generally, no. It seems to me that patients appreciate the information, but that doesn't necessarily lead to higher satisfaction. At the end, they almost always ask, "What would you do if you were me?"
B	Ultimately, patients want guidance from their physician. That's what gives them satisfaction.
C	I think SDM does help patient satisfaction, because the patient knows their physician is taking his individual situation into consideration. Most patients want to be heard, and want to have a say in their treatment.
D	Absolutely. This follows what I was just saying. When patients feel heard and are part of the decision process, they are more likely to buy into the treatment protocol. And, when they have bought into it, they are more likely to do it. Better adherence leads to more effective treatment.
E	I would like to believe that's true, but I don't think SDM changes clinical outcomes.
F	I'm with you. Just because a patient feels good about his decision, or is confident in his choice, doesn't mean he's making a good decision.
G	I had a patient that wanted to stay on steroids. I advised against it, citing the risks. He was insistent, so I told him I could no longer treat him.
H	I respectfully disagree with that approach. The spirit of SDM is that patients have a say in their treatment. As long as patients understand their choices and the associated risks and benefits, we need to respect their decisions…even if we disagree.
J	Well, as they say: "What gets paid for gets done. It comes down to reimbursement. If physicians don't get paid for the time it takes them or their staff to implement a SDM process, it's just not going to get done…
K	We're not trained to "share" decision-making. The dominant philosophy is still "I'm the doctor; you're not. You should do what I say." We need a cultural shift in our profession that enables SDM to become the norm.
L	The real issue is that most physicians don't know the data well enough to walk to their patients through making a decision. Most physicians don't share decision-making with their patients, because they don't understand treatment benefits and risks well enough to really explain them.
M	Hang on…I'm not so sure I want my patients looking at this information out of the office setting. They get a little information, and that leads to questions, and if they're not in my office, they look to the internet for answers, and God knows where that will lead them. I would much rather have my patients look at these tools in my office, where I, or one of my nurses, can be there to help them.
N	The internet train has left the station. Whether we like it or not, patients are using the web to get at all sorts of information outside of our offices, and of course, they're going to use it. Because of that, I think it's important for patients to have some kind of tool that provides accurate information about options that are approved, safe and effective.
O	Most of the time, other patients are a terrible source of information. I don't think we want to facilitate the exchange of personal opinions about treatments.
P	You know, health plans have case managers to help patients manage other diseases, like diabetes. Maybe they could train case managers