



Shared Medical Decision Making: We're in This Together
Alliance for Health Reform
February 14, 2011

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ED HOWARD: Okay, why don't we get started? I apologize for the delay. My name is Ed Howard. I'm with the Alliance for Health Reform and I'm very pleased to welcome you to this program to look at efforts to help patients, and caregivers for that matter, better understand what their treatment options are and how to make appropriate treatment choices.

It's called shared decision making, SDM of course inevitably in this town. It envisions patients and their physicians exchanging information, exploring their comfort levels with the options being discussed and reaching closure on the treatment course to follow. Its proponents say that it can improve patient satisfaction, increase patient adherence to the medication regimens that are agreed on, and maybe help yield better results in the way of health outcomes.

Congress saw fit to include a program to promote shared decision making in the Affordable Care Act. There's even some hope that this technique could save money. The head of the Dartmouth Hitchcock Clinic told one of the conferences we ran a few weeks ago that the use of shared decision making in some specific situations had resulted in 30-percent of the patients going through that process changing their minds about the treatment option that they chose.

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SDM's often helped along by what are called patient decision aids, and in the show and if you didn't get one of these coming in, you might want to grab one. It's a sample of one of these decision aids done by the Foundation for Informed Medical Decision Making. There's a DVD in there. There's good information on how if you were in that situation for that particular condition, you would work through the options that were available to you.

Today we're going to examine what we know already about SDM including how it's being used in some of the best health care institutions in the country, what questions need to be asked about it, and what the policy implications of this initiative are. We're very pleased to have as co-sponsors of today's program the Foundation for Informed Medical Decision Making.

You'll hear from the Foundation's president, Michael Barry, in just a moment and the National Committee for Quality Insurance, NCQA, the nonprofit, Good Housekeeping seal of approval issuer in health care quality. I want to thank the Foundation also for supplying patient decision aids that you in the audience have available to you now.

Quick logistical review, I apologize for the repetitiveness of this for those of you who are regulars but the logistics are important and if you have not been to one of

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our briefings before, you'll find a lot of information about this issue in your packets.

I apologize, we actually I think miscollated these things so that the total biographical sketches that are available for each of our speakers are not in there. They will be posted online at www.allhealth.org so that you can take a look at them there along with all of the background materials that you'll find in your packets so that you can share them with others and review them at your leisure.

There's a web cast thanks to the Kaiser Family Foundation that will be available at kff.org starting tomorrow. You'll be able to look at a transcript of this event on our website, allhealth.org, in a few days, and a reminder that there are green question cards that you can use when we get to the Q&A part of the program and if you will, an early warning that I'm going to badger you to try to get you to fill out the blue evaluation form before you leave so that we can make improvements in these programs as we go forward.

As I said, Michael Barry is here. He is the president of the Foundation for Informed Medical Decision Making, formerly its chief medical officer as well. He's been the president of both the Society for Medical Decision Making and the Society of General Internal Medicine and, in his spare time, Dr. Barry practices primary care medicine.

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He's medical director for a primary care innovations center at Mass. General and serves on the faculty at Harvard Medical School. So I don't know how you found time to come down, Mike, but we're very happy to have you with us.

MICHAEL BARRY: Thank you Ed and thank you all for coming. Again I'm Mike Barry and welcome. Sorry, Mike Barry again. Welcome. It's great to have so many of you here today to discuss a topic that's near and dear to our hearts. Let me just start with a little bit about our foundation.

Our mission is conforming and amplifying the patient's voice in health care decisions. We think patients should be supported and encouraged to participate in their health care decisions, fully informed with accurate, unbiased, and understandable information, and perhaps most importantly respected by having their goals and concerns honored.

So why shared decision making? It turns out that for a lot of medical decisions, our research tells us there's one way to go. We should really get about that informing the patient about what we're doing but there may not be a lot of need for much discussion in those situations, but it turns out for many and probably most medical decisions, there is more than one way to proceed, more than one reasonable treatment or test that we might select.

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If we look on the left hand side and think about someone who's been having chest pain, angina from a blocked coronary artery, if the situation is stable, they're not in the midst of having a heart attack, they could reasonably consider taking medication for their condition or they might consider getting an angiogram, and perhaps having a stent put into a narrowed coronary artery. There's lots of research to suggest that those are both reasonable options.

Things can get more complicated quickly in health care these days. In the panel on your right, think about a man recently diagnosed with prostate cancer that appears to be localized to the prostate. There are many flavors of surgery, traditional open surgery, laparoscopic or keyhole surgery.

You might have a robot in the operating room with you. There are multiple flavors of radiation. You could even consider a strategy called active surveillance where if it was a low-risk cancer, you might watch it carefully to see if there's evidence of progression before you pull the trigger on treatment.

Now each of these paths the patient can take will have different outcomes in terms of both the therapeutic effects of the different strategies but also the side effects and patients will have different preferences for those outcomes.

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We think, without the patient knowing, what likely lies down that path in front of them with each of their options even to know that there are multiple options and to know what the side effect profiles are and for the clinician who's helping them make that decision not know something about the patient's preferences for those outcomes is a recipe for making a problematic decision.

So we've got a lot of evidence of the problem. briefly, many of you are familiar with the work of the Dartmouth Atlas that's documented for over 40 years, tremendous variations in the rates of medical care delivered in different parts of this country and in fact, around the world suggesting that where people live and what physicians they consult may matter as much or more than what they want and need in terms of what medical care has decided. Our foundation has recently, with our colleagues at the University of Michigan, completed something called the decisions survey.

You've got a copy of medical decision making where those articles have just been published. We think this is the first broad survey of the quality of decisions made by Americans in the United States for fateful things like undergoing surgery, getting a cancer screening test that may get one on the slippery slope for more treatment and more

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dilemmas down the line for the decision to take a medicine for the rest of your life.

What did we find? To cut to the chase, it turns out that patients tend to hear from their clinicians more about the pros than about the cons and potential side effects. They're not asked for their opinion about what to do anywhere near as often as they should be in our opinion.

Perhaps most important when we asked them some basic facts that our experts and patients who've been that road before think everyone should know before going under the knife or taking a medicine for the rest of their lives, they can answer very few of those questions. They often don't know basically what these key decisions are about. So if that's the problem, what does that lead to?

Well first we think patients making decisions in the face of avoidable ignorance and clinicians who are good diagnosticians of diseases but are less good, and we've got lots of evidence for this, in diagnosing patient preferences. That leads to decisions that are problematic.

Now a lot of our quality measures in medicine are about the delivery of proven effective care when there's one right thing to do. That's important but as I've said, lots of medical decisions, there are multiple options. What are the measures to know if we're helping patients make optimal

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decisions in that situation, decisions that are informed and consistent with their preferences, where they're asked their opinion. We think that's about decision quality and, at heart, our foundation is about working with you to improve decision quality.

So we think shared decision making is at least a pretty good partial answer to some of those problems in decision quality. There are basically four steps. It's a clinician and patient working together to start with. They might invite other people in, other members of the health care team, family members, friends, but it would be their decision but fundamentally it's at least that dyad of the clinician and patient.

An important step is sharing information. It goes both ways. The clinician, the experts on the option and the outcomes, shares that information with a patient but just as important, the patient shares information on their preferences and values for those different possible outcomes with the clinician. They both get informed through that process. Decision aids, as Ed said, are not shared decision making in themselves. They're tools that can make shared decision making practical in the busy world of clinical medicine.

Again I'd urge you to pick up a copy of the decision aid we've left. It's on herniated disks in case anyone's back

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is troubling them. We've produced them with our colleagues at Health Dialog who are here today as well but again at the heart of this, it's a different way of clinicians and patients relating assisted by decision aids to make it practical.

Having educated each other about options, probabilities, and preferences, they work together toward a consensus about the preferred test or treatment and they reach an agreement ultimately on the test or treatment to implement. This is not throwing the burden back on the patient entirely but really working together and if you will, democratizing that clinician/patient relationship.

So we think there's lots of evidence these days to support this concept. There are reviews, Meta analyses of randomized trials of treatments. There are also Meta analyses of the results of trials of shared decision making assisted by decision aids. The Cochrane Collaboration is a group that works worldwide to synthesize that kind of evidence. There were, at the last update, 55 randomized trials showing that this process, shared decision making assisted by decision aids, improved patient knowledge taking care of that big problem with informed consent, which is not really informed these days our decision survey tells us.

It also shows patients are more confident in their decisions. They get off the fence if they're not sure what to

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do and interestingly, at least for major surgery and decisions about screening for prostate cancer, it appears that patients are a little more conservative than their clinicians when they hear the full story. There's, for example, about a 20-percent reduction in rates of elective surgery when patients are fully informed and they can answer the kind of knowledge questions they couldn't in our decisions survey.

Now 10 years ago, there were conceptual problems from both patients and clinicians about this. People wondered were patients really ready to be involved and to have an active voice. Were clinicians willing to let them have that voice? Our survey data suggests that really patients and clinicians are there in terms of being ready for this.

The kinds of things we hear these days in terms of barriers are more logistical. I don't have time. I don't have the right tools. We can work with that because we think we're working through our demonstration projects and through our decision aid development to give them to give them that time and tools. We think, we'd love to build incentives into the system to have that happen as well and again that's what we want to talk about today.

Our Foundation is funding implementation models demonstrating that shared decision making can work in the trenches whether you're at a big hospital like Mass. General

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where I practice primary care or the Winding Waters Clinic in rural Oregon, part of demonstration network.

In fact, here's just a set of practices that are working with us to make good decision making supported by shared decision making the rule rather than the exception in American health care and very proud to have Karen Merrikin from Group Health, one of our largest demonstrations here to tell you about their experiences.

The Foundation has been laboring in this vineyard for about 21 years and we're really excited that we've got a lot of partners, many of who are represented here today. If I didn't put you on the slide, I was cajoled to leave plenty of space but whether it be professional groups, advocacy groups, lots of activity at the state level working with the Millbank Foundation [for Rehabilitation].

Groups like the American Cancer Society have developed position papers or statements around supporting shared decision making. It's great to have so many people involved and I hope we get some of you to join the effort today.

There are parts of the Affordable Care Act that address shared decision making. Section 936 has a program to facilitate shared decision making. As you see here, it's been authorized but not appropriated, which we think is an issue as far as moving this forward. The key aspects of 936 are to

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produce patient decision aids, set quality standards and certified decision aids.

We want high quality decision aids to be used. There are international standards for the quality of materials that we use to help patients make these fateful decisions, to create shared decision making centers around the country to help further work this into day-to-day clinical care, and to grant funds to providers for the development, use, and assessment of shared decision making techniques using those certified decision aids.

We'll also point out in the language around the CMS Innovation Center in terms of testing innovative models to reduce expenditures and enhance quality of care, one of the options is assisting applicable individuals and making informed health care choices by paying providers for using patient decision support tools and improve individual understanding of medical outcomes remembering that in the world where the payment system is more is better.

We'd love to move to a situation where better quality decisions are what's paid for. Also for quality measure developments, there's a language around developing the kind of measures that would let us know when there's more than one reasonable option heavily help the patient make the right choice.

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So in summary, we think shared decision making is at the core of ethical patient-centered care. We think shared decision making is at least a major appliance, if you will, in the patient-centered medical home. We think that as medical homes are aggregated into medical neighborhoods or accountable care organizations, the shared decision making is what can keep those organizations accountable to what patients need and want.

We also think there's a great marriage with meaningful use. What could be a better use of electronic health systems than delivering the right information to patients at the right time when they're wrestling with their clinicians about difficult decisions in real time. We think those are all trains we'd like to link to in terms of baking in shared decision making as the stripe in the toothpaste in health care reform. Thank you very much [Applause].

ED HOWARD: Good, thank you. Okay. Next, we're going to hear from Karen Merrikin. As Mike mentioned, she's a Senior Policy Advisor for Group Health Cooperative of Puget Sound. Group Health's one of those systems about which it is often said if only everyone did as well as in whatever it is.

Karen is in charge of getting Group Health ready for the reforms of the Accountable Care Act. Here she's going to share with us some of Group Health's real life experiences, as Mike referred to, using shared decision making and making

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treatment choices for some of their 650,000 members. Karen thanks for trekking across the country for us.

KAREN MERRIKIN: Thank you. Well I've been with Group Health now for well over 25 years and this is one of the most exciting times during our journey because there's so much innovation occurring right now at Group Health. Many of you know we're a member governed nonprofit organization that integrates care and coverage. We now have over 650,000 members in mostly Washington state and a little bit of Idaho.

Our members come from all lines of coverage. We do Medicare. We do individuals, small group, employers, self-funded, Medicaid. We do it all and we have two primary models of care. So we have both group practice model, which is very ACO-like in its setting and orientation and we also use an extended network of providers. So we really combine both but our consistent theme throughout is to try and get the care as patient-centered and as patient-oriented as we can.

So this just shows you a little bit of our implementation timeline and journey as it relates to patient-centered care and shared decision making. So we had work going on around shared decision making early in the 90s. Dr. Barry referred to that but where things really took hold is when we put in our electronic medical record because that really gave us the opportunity and the power to move into much broader

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applications with shared decision making and many other things as well.

In 2007, we had a medical home pilot that we started in one clinic. We radically changed the way care is delivered to make it much more patient-centered and actually less expensive in one clinic. We rapidly moved that out into practice in the rest of our primary care settings. In 2009, we really began our latest journey with shared decision making although that had been in the works for a couple years as well.

In 2011, we're now in the evaluation of the decision aids as far as our research project because one of the things we like to do as we move things out into practice is we want to respect our evidence-based heritage and try and be as systematic as we can and measure the results of big initiatives that we put into place so we can see the impact on patient care, cost, and quality, and efficiency across the organization.

So why focus on variation? This is actually one of those maps that we were talking about earlier. This is a Dartmouth Atlas distribution map. Each one of those blue dots is a different hospital referral region in the country. This shows you the variation in the rate of knee replacement across the country.

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So you can see there's incredible variation in the rates that people in various communities are experiencing knee replacements as a result of knee osteoarthritis. Those red dots show the variation just in Washington state alone. So for example, if you live in Spokane, Washington, you have almost a two times higher chance of getting a knee replacement than if you lived in Seattle. There's good reason to think that most of that is not relating to underlying osteoarthritis. So we began to really ask a couple of questions. Why is that? Do we have that same level of variation within Group Health?

Well this is some data that showed when we looked, to our surprise actually we did have variation within Group Health. This is just a different look at the statewide map of knee surgery. We are very good at Group Health. We have always been very good at getting consistently preventive care services out to individuals.

We've been very, very good and very focused on effective chronic care management but these discretionary surgeries were something that we hadn't focused on anymore. So this was a really interesting finding for us. So being Group Health, what we did was, okay so what are the evidence-based solutions that we can apply to this problem? So we harkened back to some of the work that we remembered around shared decision making and in fact, we had had two Group Health

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studies looking at the use of decision aids to reduce variation, unwarranted variation, in these preference-sensitive areas.

Primarily in the 90s, we knew there were other really good randomized clinical trials saying that decision aids used in the context of a really good shared decision making process could really help reduce unwarranted variation in these areas. We also recognized there were really good health policy rationales to do this.

This is getting care that is centered on what the patient wants when there are reasonable patient choice options is the right thing to do. Getting them better decisional quality that Dr. Barry talked about is absolutely the right thing to do. Actually when you give patients better information about what they're coming up on and what they might experience and engage them more, there tends to be lowered malpractice exposures, one thing that's coming out through the research and it can also help this process in reducing health disparities. Generally, you do see more conservative utilization of surgical procedures but that is not always the case.

So for example, some women when you present them with their options around breast cancer treatment might prefer a mastectomy over a lumpectomy for their own personal reasons

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that have to do with where they are in life, what they want, what they want for their body, what they want for their lifestyles. So that's what we're really trying to get at is the right treatment for the right patient.

So we wanted to do more than just do this at Group Health though. We wanted to engage our community in this effort. So in 2006, we had an opportunity through state process looking at health reform focused on delivery system reform to come up with a series of recommendations on how our state could work together to address some of these problems around unwarranted variation.

We made two recommendations. One was that we have a state Dartmouth Atlas of Health Care that would help us identify where our low-hanging fruit was and what we really needed to address. Number two, we really suggested a focus on shared decision making because we knew there was this variation in our state.

So we decided to put in legislation as part of an omnibus bill that did two things. It established a statewide collaborative that focused a number of multi-disciplinary group practices in the state with state government on some of our highest variation types of discretionary surgeries and we also elected to throw in a carrot to make this more interesting to the provider community, engage the provider community.

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We raised the bar in informed consent and the standard so that if you use a high-quality decision aid in a shared decision making process and you document that, you've got better protection from exposure for failure to provide informed consent than you otherwise would. It's a little carrot but it's really there, in part, to make the statement that this is important and if you do this the right way, you are providing better information to your patient and that should be reflected in our standard of care in our state. So that's my little symbol.

This is just a map that's in your material of our collaborative infrastructure. I won't go into it except you'll see that there are multiple parties from the University of Washington as an evaluation site, the three other specialty care clinics, and two government entities, our State Health Care Authority, which is the lead purchaser for public employees and some low-income programs, and also our OFM, Office of Financial Management and at the time, they were gathering data on variations in care in Washington.

Our collaborative decided to focus on six different areas because these are the ones that we mapped in Washington that showed either high levels of surgeries or high variation across the state. Group Health's approach was really very

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systematic. We decided to go after the whole spectrum of conditions.

So we did a system wide implementation, combined it with a two-year research project with considerable foundation support including from the Commonwealth Fund, the Foundation for Informed Medical Decision Making, and another one that I'm forgetting right now but that's okay. We decided to go and use shared decision making tools for 12 preference-sensitive conditions, the one you see here. The DVDs can be ordered online and you can get the disk mailed out to you or you can view it on the web, which is really fantastic.

So all of our patients, if they want to see these streamings on the web, they can. We're learning a lot in the process. This just shows you the rate of ordering of DVDs and tools across. You can see they really shot up in June. That's because we had an intervention in June as we sometimes do when we want to do system wide learning to really encourage broader use of the decision aids and they shot right up again.

We're measuring the lack of the decision aid before surgery as a defect now. So we're keeping track of patients that don't get decision aids, which is a really important thing to keep your eye on if you want to have cross-system improvement.

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I'll just briefly show you these patient assessment, these patient scores for how patients value getting and using these decision aids are really quite remarkable, I mean just really high, excellent, very good ratings on do you understand your treatment options, did this help you prepare to talk to your providers, and this one, which I think is really critical, how important is it that providers make programs like this available? You can see that we've got well over 90-percent saying it's extremely important or very important.

So we have a lot of research that we haven't done yet. Our preliminary findings from our two-year evaluation, the findings likely will be complete in late spring 2011 and then they will be published after that. Those will look at things like the cost impact, more data on patient satisfaction and strategies to improve usage rates but we are not waiting for the formal results for this.

We are really escalating our efforts around shared decision making within Group Health and within our network because we really think this hits that real sweet spot. We want to do this because we care about better value for our patients and because care should be centered around patients' value. With shared decision making, you can get both of those things and in the process, particularly if you're engaging as a community, you're learning about working collaboratively, which

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is one of the best ways you can learn about how to tackle some of these other bigger, broader problems of reforming our health care system as a whole and getting better value from our delivery system. Thanks [Applause].

ED HOWARD: Terrific, thank you. Next, we're going to hear from Helen Darling who's the president of the National Business Group on Health, which as the name implies is, an organization in search of practical solutions for its employer members health care problems. From her post at the Business Group, she's been an important voice in the reform debate.

Before her tenure there, Helen directed the purchase of health and disability benefits at Xerox, served a stint in Senate halls as well as a health care advisor to then-Senator Dave Durenberger. Helen can tell us about the interest in shared decision making among her group's members who offer health benefits to 55 million Americans. So Helen, thank you for bringing that point of view to us.

HELEN DARLING: Thank you Ed very much and thank you all for the opportunity to talk about shared decision making. We large employers on behalf of our employees, retirees, and dependents, think that shared decision making is an essential resource if we're going to have patient-centered, not provider-centered, patient-centered care based on science.

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There's almost no other way to do it for a whole complicated set of reasons and if we want to talk about that, we can maybe in some of the question and answer. We are headed towards a world of highly personalized care and it really means that the decisions that are made by a patient with his or her doctor have to include science, evidence related to some general populations and then a subset of the populations that the patient might be a part of. So it's a very complicated transaction and you can't do it without a lot of help. I think that's one of the things we've all learned more and more.

Every day, millions of Americans, literally every day, make choices that affect the quality and length of their lives and the likelihood of their survival, and avoidance of serious disabilities and suffering but most make those decisions with little, if any, information about the risks they are under or the harms that they might suffer. They are usually pretty well informed about benefits.

There's actually a journal out there, which I hope you picked up, *Medical Decision Making*, and I'm just going to read you one thing from it because I wrote this. It said participants felt, this is a study, where screening had been well explained by the provider. They also said the discussions for each of the cancers consistently addressed the pros of screening more than the cons. Participants reported that 70-

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percent to 80-percent of discussions failed to address the cons of screening.

How many people in this room, sometime today either already or before you go to bed tonight, are going to take a pill of any kind? Well I'm surprised it's that low. Are you confessing [Laughter]? How many of you, say in a 12-month period, are going to have some kind of screening? How many, any kind? Okay. I'm surprised it's not 100-percent.

Now you probably know a lot about the benefits. You've probably been told all your life that you ought to have that. My guess is that you know next to nothing about the risk and nothing about the harms, maybe a little bit but you really don't know the probabilities. I can tell you, as someone who has mammograms over many, many years, I didn't know the harms until I had one of the harms. Then suddenly you start talking to the doctor and you say what do you mean, could this be? You need to have a biopsy.

Well 50-percent of all mammograms, at least at the time, this is a few years ago, resulted in a false positive, 50-percent. Now if you know that and you may be a low-risk and you're talking to your doctor and you have this conversation, depending on the age you're in, the size you are, a whole bunch of variables, you might decide to have it more often or less often but you would do it understanding the harms and the risk

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and the probabilities of whether or not you have underlying disease or an underlying condition that needs to be detected is highly variable itself and very much related to your risk factors.

Most of us go through life having none of that information. It hurts us. There are people who literally die from it. Sometimes you will go into a hospital maybe for a reason that started out in a trail of false positives and then you get a hospital-acquired infection and nobody tells you about those until you look at some of the national statistics.

So shared decision making is, among other things, to help each and every one of us as an individual talking with his or her doctor, with the right decision support tools, with the right science, with the right understanding about you and your risk. Then you, as an individual, can decide are you willing to take those risks or do you want to take those risks because you're very concerned.

I mean a better example would be someone who's at high risk for breast cancer. They should be screened more often. So it's about the individuals. So if it's going to be patient-centered care and it's going to be on science, it really requires shared decision making.

As we have more evidence about genetic components of everything, this is going to become even more important. So we

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certainly hope that we will have more tools and that's one of the good things about the Affordable Care Act because there is support for that.

Most of us think, by the way, when we go into hospitals or we go and get any kind of care that we're actually going to be fixed. We really do. I mean we think that somebody says you need this treatment and we think that's going to fix whatever the problem is. The probabilities are not that great that that will always be the case. We just need to understand that.

So one of the things that we're hoping is that all research including comparative effectiveness research and the research at NIH and other places around the country will build in when they're doing the research, the information they need so that as they come out of the pipeline, we don't have to go back and do shared decision making aids and tools based on research.

It will be from day one when a decision is being made about what is going to be funded and how it's going to be designed. The information will be collected at the same time and again that's something that certainly could be much more possible with the Affordable Care Act.

We do have lots of examples. I've talked about mammograms. Another one for those of you slightly older might

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remember hormonal therapy. Most women in this country, for about a 20-year period, were told to take a drug and most of them felt that it was good for them and by the way, it does have some benefits so it's no question that it was beneficial but it also turned out, we learned many years later, about 20 years later, that in fact it was also very harmful.

Today, women can make a decision. They can know what it's harms are. They can know what its benefits are. They can decide whether or not they want to take it because the benefits, to them, outweigh the harms, and for how long, which is another example. A lot of these things, if you know the benefits and harms, you can then decide how long you do it if you do it at all.

Actually, Karen already mentioned mastectomy and lumpectomy and you all know last week, there were a whole bunch of stories about lymph node surgery, perfect example of how much we know now that we didn't know even until quite recently and of course that's surgery that is very debilitating in lots of ways but there's new evidence out of comparative effectiveness research that tells us what the benefits and the harms and again you have information.

Men have the PSA test and I won't ask anybody to raise their hands on that one but you can be sure that that is a very good example of a test where it is not an unalloyed benefit to

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take that test. Men ought to understand and frankly the women who live with them ought to understand the consequences of a test that may lead to a series of interventions that can be life altering. That's not very well understood. In fact, we have a few official organizations that say every man should have a PSA test. I don't think that that's universal but that's what's being talked about.

Some of the most overused procedures, you heard Karen talking about those as well and Dr. Barry as well, one of the things that as employers, we would like to see is what we call prior notification. This is something very easy to do for those of you who are thinking about policy. In the days of managed care, we had prior authorization.

Well that was very unpopular with some people maybe for the wrong reasons but it was unpopular. Now what we're putting in is something that says we're going to let you do anything you want with your body. We'll pay for it. We'll even pay for it 100-percent but we only ask you that you notify us, us being the health plan in this instance or the organization like Health Dialog that's working with, that you would say I have been told I should have back surgery, hip replacement, knee replacement, C-section, and I just was told to call you.

So all you have to do then is go through a shared decision making process about that. So you're fully informed,

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one that has got all the evidence, all the science, all the personalization that you could have and then you, as an individual, can decide.

If you want to do it still when you're done, it will be paid for 100-percent, no deductible, no cost sharing. We know for a fact that an awful lot of those things don't happen once people understand the consequences but there's no barrier to care. It's just you have to be informed. We think that's really important.

So one of the things that we think this is all about, is better care for every patient. So some of the most important values of shared decision making and patient decision support tools are the following: First, they remind people, patients, those of us in this room, every day that we have a lot more control over our future and what's valuable for us in terms of health care, screening, and those kinds of things than we realize. We need to be reminded of that every day.

They also remind physicians and nurses and other health providers that they have to provide a fair objective balance review of risks, benefits, and harms for all of treatment options. Well meaning as they are, they do not do that. The evidence has come up over and over and over. Unfortunately without all of that, with the right conversation with the patient, the reality of informed consent is almost laughable.

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We don't really have informed consent. We have consent but it is not informed and shared decision making will make that possible. Thank you [Applause].

ED HOWARD: Thank you so much Helen. Finally, we're going to hear from David Shern. He's the president and CEO of Mental Health America, which is as many of you know an advocacy organization addressing mental and substance use conditions and their effects.

Dr. Shern is a respected researcher who has headed projects funded by almost every major actor in the mental health and substance abuse field. He's here to share with us how consumers, especially those with mental and substance abuse conditions, are affected by shared decision making. David thanks for being with us.

DAVID SHERN: It's great to be here and I certainly have enjoyed the panel to this point. What I wanted to do is to try to put a patient face on this. I want to start by talking just a little bit about our organization. Mental Health America used to be called the National Mental Health Association and we're actually going to be 102 years old in five days.

We were founded by a person who had bipolar illness who was unsuccessful in his attempt to complete suicide in Connecticut and spent the next two or three years in both the

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public and private psychiatric system in that state, came out with a tremendous desire to reform the mental health system, wrote a book called *A Mind that Found Itself*.

It was a lot about his working through the treatment system in Connecticut in spite of what happened to him to get better. He ultimately ended up partnering with William James and Adolph Meyer and other sort of **luminaries** at the time to found this organization, which has traditionally focused a lot on issues of patient involvement and patient voice.

So what I want to do is to sort of start to build on that theme, talk about people with psychiatric illnesses and also introduce something that hasn't really been discussed too much today and that's this notion of chronic illness. As you know, we know that chronic illnesses account for the vast majority of health care expenditures and we also know that the prevention and treatment of those illnesses is very, very uneven.

So it's very important that we think about what we can do to better engage people in their own care, to foster relationships, which are information-symmetric. I mean a lot of people have talked about that but also that reflect true alliances between providers of care and persons who are recipients of care.

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As several people have mentioned that's an important move away from what has traditionally been a much more prescriptively oriented system, I think really coming out of the enormous success we had with germ theory and with the treatment of infectious illnesses where literally physicians and others had special knowledge about the particular agent that was causing your particular problem or at least that was believed to be the case and therefore had special power to prescribe medications to do that.

We're thinking about chronic illnesses and we're thinking about the things that Mike talked about where we've got multiple decisions with multiple potential tradeoffs involved. It's more important than ever that we truly have a reciprocal process that everybody has been speaking about.

So I thought that it would be good to think about people with severe mental illnesses. In some sense kind of a paradigm case for what we need to talk about and we're talking about building a true relationship and really understanding people's preferences.

I think Mike talked earlier about the fact that there was a time not that long ago when people were felt to be incompetent to participate in their own treatment decision making and think about that germ model and what would you know

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about that bacterial agent. That has been particularly true for persons who have severe mental illnesses.

When the illness affects your cognitive abilities, your perceptual abilities, etc., etc. it's very easy to discount your ability to truly participate in care. What does that lead to and again this is true for people with severe illnesses but I would argue it's true for people in general, at least on objectification. So the person is treated more like an object than as a human being.

It leads to lack of engagement because again it's not a dialogue. It's a monologue. It's prescriptive. So patients don't feel as though they own their treatment plan particularly important when we're talking about chronic illnesses and it leads to a lack of full participation in planning. That treatment course, again critically important when we're talking about people with chronic illnesses.

As Helen just pointed out, it leads to poor quality care. Lots of times, we talk about what we call the demand side push for quality. A great example is direct-to-consumer advertising, which has people asking their doctors about medications, which sometimes the ad doesn't even tell you what the medication is for but it's important to ask your doctor if you should be taking this medication.

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That's an example of how we can motivate individuals to become more actively involved. I know there are concerns and downsides with DTC advertising but if we just think about it as a mechanism to better empower people to participate, there probably is a moral to that story that we should build on.

We talk about people with psychiatric illnesses, we have lots of problems in terms of the care of those people. First of all, there's a high rate of failure to engage. We hear about this particularly when you're talking about people with severe illnesses, psychiatric illnesses all the time. If only he or she would take their medication, everything would be fine.

If only they had insight into their illness, they would realize that what I'm telling them, as the provider, to do is in fact the thing that they should be doing. So you can see how those kinds of mindsets lead to an objectification and a lack of engagement in very important treatment decision processes. Of course they lead to non-adherence in part because people aren't informed about the side effects. Major psychiatric medications have very serious side effects in terms of either movement disorders or endocrine conditions that lead to obesity and diabetes.

So people might choose not to take their medication because they prefer or value other things like their physical

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appearance, avoidance of diabetes, the lack of sedation, etc., etc., and all those things are really important to be involved.

As a result of that and the fact that we still have under treatment for people with mental illnesses, the rates at which people receive adequate care are really disturbingly, alarmingly, and outrageously low. So one of the strategies for starting to improve that again is trying to stimulate this demand side involvement. We talked about lack of information. We talked about inattention to a person's goals, the research shows that not only do people not talk about the downsides of certain treatments, typically they don't know an awful lot about the goals, what's important in that person's life, what are they trying to achieve? Like Helen said, there's this sort of fix it notion that there's something specific wrong with you and again I always come back to the sort of bacterial infection and if we could fix that, everything will be fine without considering the whole life space in which these decisions have to be made particularly important for people who have chronic, long-term illnesses.

Typically, we're getting better at this. There's a failure to empower the person, again we're more prescriptive than we are participatory and a failure to provide effective services, which harkens back to a lot of the discussions we've had here about decision aids in general and trying to do things

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to intelligently codify services so that we're more likely to reduce that variability that Karen was talking about while maximizing quality and efficiency of the system.

We talked a lot about what your decision making is, I won't spend much time with it except that when you think about chronic illnesses, it's important to start with these information supports, their technologies.

We're working with a group that, at Dartmouth, a psychiatric research center had developed shared decision making technologies in six areas that are really important for people with psychiatric illnesses, to help get information to people in a meaningful way to help ask them about their preferences in a way to which they can genuinely and effectively respond.

It's not as easy as one might think to really elicit preferences always particularly with people who have low literacy and for individuals who might be experiencing cognitive issues or problems related to their illness but anyone who's acutely ill could easily find themselves in that situation as well.

Through these structured processes, we start to do what Michael was talking about earlier and that is start to balance some of these power relationships, get to a more reciprocal

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relationship or more genuine dialogue occurs between patients and their providers.

There have been seven randomized trials taking a look at shared decision making for people with psychiatric illnesses. They've shown, and this is very similar to the results that Mike reported from the meta-analyses, that they're effective in increasing knowledge and real participation and planning, very important if you want to increase adherence.

You're much more likely to adhere to a treatment plan that reflects your goals and aspirations and one that helps you measure how you're doing in terms of the achievement of those goals, which is part of that sort of self-reinforcing process that Karen talked about a little bit that people who are engaged in this report greater satisfaction with care. There are fewer unmet needs.

So when you understand, again for a person with a chronic illness, is that there's a housing issue that should be addressed, there's perhaps an issue around supported employment and if that's not on the practitioner's radar, there will be unmet needs in those areas. They improve adherence. So that's important. I've been told and I believe it's true that 50-percent of all prescriptions for antidepressant medications are never refilled.

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That's an enormous waste since we know those prescriptions don't even start to take effect until after 30 days and that means that people aren't adhering and understanding basically what that medicine should do for them and when it should. There's evidence that it actually is effective in terms of decreasing symptoms of depression and alcohol abuse.

Practitioners report that they very much got increased insight into what the patient was talking about, again this sort of asymmetry of focus on procedures and benefits. This gives them an opportunity to really understand more about people's preferences. When this is done correctly and again we used peers in waiting rooms to capture some of the information about people's preferences, it actually improves the efficiency of care because the dialogue can actually be more to the point and more targeted at sort of the key elements in that treatment encounter. There's some age- and discipline-related reluctance to participate on the part of physicians and I'll let you all fill in the blanks there.

So SDM, in conclusion, reflects patients' desire for more trusted organized information on treatment decisions. There's no shortage of information but there's a shortage of edited, trusted information, enhances a sense of real participation and alliance, and overall sense of empowerment

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around your own health and well being, and if it's efficiently designed, providers report that it increases efficiency and that they get important new insights into what their patients need and want in designing an effective treatment program. So thank you [Applause].

ED HOWARD: Thanks very much David. Now we are at the point where we give you a chance to ask some questions, give our panelists a chance to react to anything that they've heard that they would like. You can either fill out a green card and hold it up as that person there is doing. There are microphones in the back on either side.

Let me just kick things off by picking up on something that you said, Michael Barry, that you can demonstrate in some of these instances a 20-percent reduction in certain kinds of surgery if folks have gone through this. It raises the question, at least in some people's minds I would suspect, that this is perhaps described as a backdoor way of rationing rather like the end of life counseling sessions that were in the ACA that got described as death panels.

So the question is, is this a sort of near death panel experience that we're describing?

MICHAEL BARRY: Well when I look at the data on the practice variation phenomenon, it cries out to me what's the right rate of these procedures? We've sort of begged that

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question for 40 years. We've been studying practice variation and the best answer I can come up with, well what's the rate that fully informed patients, working with their clinicians would set. I think that's the reason to do this that I don't care whether the rates are higher or lower at the end of the day. I want to find the right rate of care. We can't do that until we involve patients in those decisions.

ED HOWARD: I'd be interested in what Helen has to say about this because obviously some of your members would be happier with lower surgery rates.

HELEN DARLING: Well actually certainly we would be happier with lower surgery rates and lower other rates if it's not necessary or appropriate and not right for the individual. In fact, the sad thing is we pay for now \$2.7 trillion worth of health care, which every expert looking at it from every possible angle says somewhere between 20 and 30-percent of that is either misuse, overuse, or harmful. That's a huge amount of inappropriate care.

So what we'd like to do is to buy much more health not just more health care. Almost everything we do, unfortunately at least in the past, has moved towards paying for more health care and not paying for health.

So one of the many good things in the Affordable Care Act, is this idea of the personal prevention program that a

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doctor works with the patient to develop and among other things, anybody who does that is going to be focusing on getting more health not just more health care.

ED HOWARD: Yes sir, you want to identify yourself and I would ask all of our questioners to be as brief as you possibly can.

NEIL KIRSCHNER: My question's an expansion of what you were saying.

ED HOWARD: You want to identify yourself?

NEIL KIRSCHNER: Yes, I'm Neil Kirschner with the American College of Physicians. 135,000 physicians and students are very supportive of shared decision making. Most of the statements here are put in the same category as motherhood and apple pie, it's all good but we would all agree that the foundation for good shared decision making is good information and good data.

There are aspects of the Affordable Care Bill, for example the comparative effectiveness entity which helps produce that information and unfortunately doesn't have that reputation in a lot of the mass media and even here on the Hill. It's seen as this information will get in between you and your doctor even though most physician organizations are very supportive of it.

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What I'd like to hear from the panel is your comments on this view and how this view of the foundation for shared decision making can be made more realistic or practical based on the information produced by this entity.

ED HOWARD: And I assume you mean foundation with a lower case "f."

NEIL KIRSCHNER: Yes.

ED HOWARD: Okay, Helen?

HELEN DARLING: What we need is more and more examples where more information from comparative effectiveness research and clinical research through trusted voices like physicians demonstrate over and over that more care isn't always better and more expensive care isn't always better.

So for example, Vioxx, hormonal therapy replacement, or hip replacement, I mean there is example after example where you can document that having something done to you or for you is actually harmful. We should be able to document the same thing for those things that are beneficial. We have those too.

I think the more that we get those stories out and done in ways that are trusted by the public, and it's only going to be trusted by the public if it comes from groups like yours, for example, and the American Academy of Pediatrics, and all the data and we've got lots of it, they trust doctors. They trust nurses. They trust sometimes, hospitals, a little less

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so but sometimes and then it quickly falls off beyond there. So we've got to get the information out and the evidence that demonstrates when harm occurs and then when it doesn't occur so people will begin to understand there's just as much evidence on both sides and what we ought to do is all one evidence.

DAVID SHERN: Could I sort of tag on that from kind of an institutional perspective thinking about the role of PCORI, the Patient-Centered Outcomes Research Institute, which is going to be funding this. I think there are a couple important points. Number one, it's really important that we, the advocacy community, continue to push on the PCORI board to develop into research methods for better communicating and codifying information so it is more accessible number one. Number two, their methodology committee was one of the things that's initially established in statute for PCORI.

I've actually been very heartened in, I recently was on the AHRQ National Advisory Board with Helen, and I've actually been very heartened to see the degree to which these methodologies focus on trying to understand heterogeneity in response. One of the potential problems with comparative effectiveness is oftentimes you're looking for average between group differences.

Everybody appeared today has talked about patient-centeredness relating to the unique idiosyncratic conditions of

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a particular person. The more we can start to unpack heterogeneity in trials and understand why some people respond and other people don't rather than just looking at averages between group differences we'll be better able to make that information available and meaningful for patients.

ED HOWARD: Yes, go ahead.

BARBARA TOMAR: Hi, I'm Barbara Tomar from the College of Emergency Physicians and while Mr. Howard almost stole my question here, I was wondering particularly for you Dr. Barry if you've had some good experience with shared decision making on end of life care since we hear from our members, emergency departments, really become revolving doors and this shared decision making not just with the patient in that case but with the family is a huge issue. I know it's a political hot potato.

MICHAEL BARRY: Well it is a political hot potato, but it still feels to me that patients really being informed about what's on the path. We may not know how many exits up the road that path will lead but we hear those basic questions of where are they most comfortable dying, what are the support systems that are needed to make them comfortable with the one option versus another?

That's all an issue of informing patients and respecting their input into the decision making not that there

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is any external panel, death panel or otherwise, but they're the panel and the people they love and care about are the panel. I love to keep working in that direction. Our foundation supports a fair amount of research including research in how to make that kind of end of life care real.

HELEN DARLING: There are also some important policy issues that if they are fixed, would help. So even in the private sector, we are saying that you don't want to have, there's no reason to have a limit on hospice if people want hospice however long they want it.

When I was the Senate staffer, we actually worked on that so I know the history and why we had limits because they were dealing with a different set of problems but those are not applicable anymore. We need to be sure that it's clear because most people don't understand this. You shouldn't have to give up rescue treatment if you want it just because you've chosen hospice and palliative care. If we fix those two things, essentially in the private sector and the public sector then people would stop thinking of it as one or the other.

What we want to do is to make sure everybody is comfortable, their symptoms are managed as much as humanly possible, and they as individuals or their loved ones if they're not able to make the decisions, feel like they have flexibility and freedom to move back and forth between rescue

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care and non-rescue care if they feel that and then they understand the benefits of managing end of life in a way that's supportive of the individual patients, the patient's values, and the family's values. If we get all that across then some of these problems will go away. Unfortunately we've created some of the barriers ourselves.

ED HOWARD: Yes, go right ahead.

RHONDA OZANIAN: My name is Rhonda and I'm a Robert Wood Johnson policy fellow. I heard the Winbergs talk about shared decision making about three years ago and at that point I was frankly a little bit, I had some concerns and I'm so excited that you all are here today and the way in which this notion has been embraced by the policy community.

There's still something bothering me though about this. I think it has to do, I love that it's about patient preferences and that we're beginning to understand what patient preferences and tradeoffs are. However, there's a time horizon involved with decision making.

I think that we may be thinking about this in a very linear kind of way, patient's sick, patient go to the doctor, patient go to the decision making aid, patient make decision. I don't think it happens that way with some conditions that they're either chronic or such as a knee problem, they can be

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delayed for years and during that time, the impact that those decision making aids have are going to be different.

They're going to change. You're still going to have the patient going back to the doctor saying what do you think? Medical evidence about what the best treatment is can change over time as well. So I just wonder if you could perhaps comment on that. Thank you.

KAREN MERRIKIN: So this is Karen Merrikin from Group Health. So I think your observations are very, very good and Group Health patient engagement doesn't stop or start with a particular tool number one. It's about a relationship and a home with a clinician that can help guide you through your health conditions as they develop over time.

One of the things that I think is really kind of cool about the way we've use the decision aids at Group Health is they are right on the web where all of our patients can get access to them.

So for example for me, with my dad who's thinking about going through with knee replacement, I can go out and look at that decision aid too and think about it from my perspective as a family member or he can think about it from the very beginning of his journey on osteoarthritis so when he's just beginning to think about it, he can have access to it but definitely it's there as something that is to help him guide

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his decision choice at the time when he's trying to make that decision choice too.

The other great thing is that the decision aids and the tools are updated fairly regularly so that if the science changes, if the evidence changes, or even we learn more about the best way to present the information to patients so that it is understood in the best way. The decision aids can be updated and those can be incorporated right into our processes too. So at Group Health, they're part of our strategy of patient engagement and a really important one but they're not the only tool we have in our toolkit.

ED HOWARD: Mike?

MICHAEL BARRY: Perhaps I just add that as I tried to focus on the tools on shared decision making, the tools makes your decision making practical but it is a new way of relating between clinicians and patients. I think it does have a longitudinal record over time.

I think in many ways like we've learned that chronic disease management isn't readily managed in the occasional short office visit and [Dr. Ed] Wagner and others at Group Health have shown the way there, that good decision making unfolds over time. It can't be rushed in many circumstances.

That's why we think that the marriage between the medical home concept and shared decision making is such a good

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one because it emphasizes that longitudinal relationship remembering that in our health system, there are lots of people with a stake in whether people pick treatment A or treatment B. We have to think hard about how we keep those influences to a minimum in that decision making.

ED HOWARD: Yes? Go right ahead.

DEBORAH ROSEMAN: My name is Deborah Roseman. I work at George Washington University at the Aligning Forces for Quality National Program Office. I wanted to ask about incentives because you spoke, Dr. Barry, about the fact that there is broad based support, it seems, on both the patient and the provider side for shared decision making but that there are structural barriers in place in terms of the payment structure for example. There was mention of patient incentives or payment structure forces in terms of the prior notification but on the provider side, can you speak a little bit to what incentive structure might look like, some options for that?

MICHAEL BARRY: Well sure, I'll start. My colleagues will have additional ideas. First I would say it's really important to think about interventions that deal with both patients, helping them know why it's important for them to be informed and involved, but also to make our hospitals and clinicians better receptor sites because in my mind, nothing would be more frustrating or in fact tragic than having

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informed activated patients going in and hitting brick walls when they see doctors or hospitals.

So first there is a hearts and minds strategy and I think we're winning there because I think clinicians are seeing why this is a good idea. They want informed patients. They want to be good diagnosticians not only of diseases but of patient preferences but we know incentives could be effective and one could build in either direct incentives for some kind of giving patients a shared decision making experience using a certified decision aid for example.

For those in primary care, you know that in terms of payment in the usual payment for piece work system, it turns out whether you do something called an 11-item review systems in an office visit, largely determines whether you can bill enough to make a primary care practice float.

There's absolutely no evidence that that does more good than harm. There are no randomized trials but it essentially drives reimbursement for cognitive care. Could we just shift that to a shared decision making experience? Alternatively one can build an indirect incentive to maximize the health, not health care, of the population using an accountable care organization framework. That would work too. I think those are two basic strategies that could be thought about.

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ED HOWARD: Anybody else want to weigh in? You've touched on a theme that has been picked up in a number of questions that have come forward on the cards. The basic notion is encapsulated in the following question. If you're a gastroenterologist who makes your living doing colonoscopies, will you freely share information on the risks or for that matter on the benefits?

So what do you do and in that connection, Karen, you talked about the two models of care in Group Health, is there a difference between the reactions and the results of SDM in your integrated system versus in the system that involves contractual relationships with providers?

KAREN MERRIKIN: Let me talk a little bit about that first because we're not as far along into our implementation in the network strategy but I would say physician culture is very similar across organizations. Physicians, for the most part, really deeply care about making sure that they're getting the right care to their patients. I think most clinicians, regardless of what their starting place are, are convinced they're doing good informed consent already.

I think when you start showing them some of the data about what's actually retained or patient decisional quality and when they start seeing how much better informed patients are when they get to the office, that's been one of the chief

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advantages for most of our physicians that we've been working with regardless of how good a job they thought they were doing at the beginning.

They now can see patients that are coming in their office that are more ready to have a deeper conversation with them about the nature of the procedure and move to decision more quickly, which is a real benefit. I think this is culturally something that is easier to do in an integrated group practice setting, an ACO-like setting, which is where we are today because some of the financial incentives aren't there the way they might be otherwise but really I think more than anything else because remember we saw this variation in Group Health too.

This is a matter of physician culture and physician practice patterns. I think it's really not something that can only be addressed successfully in integrated settings.

All of the research that have been done in other settings demonstrate that with the right interventions and the right incentives and strategies, we really can get to decisions in these areas that are much more patient-centered and focused on the actual choices of patients after they're fully and effectively informed.

ED HOWARD: Okay. Go ahead.

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ANN O'MALLEY: My name is Ann O'Malley and I work at the Center for Studying Health System Change. This is a question for either the panel or legal experts in the audience. As a physician, I know myself and have a lot of friends who really buy into the kinds of shared decision making, engage with it in their patients, and have some close friends who still, when a patient has been found to have prostate cancer in an advanced stage after being advised about the risks and benefits and the patient decided not to engage in PSA testing five years ago, sues the physician and the hospital and often the hospital ends up paying \$1 million in payment.

So my question is how do we overcome the legal obstacles so that nationally, we have liability protection for physicians, for hospitals, for nurses to engage in shared decision making where we've got good evidence, that we have tools for preference-sensitive treatments and PDAs similar to what Washington state has done. How do we overcome these legal, political, and other stakeholder obstacles?

KAREN MERRIKIN: Ann, I'm really glad you asked that. I'm going to ask Ben, if you might come forward to the mic too to speak on this, Ben Moulton, who's one of the foremost experts on this in the country but one of the things that we did in Washington state is, as I mentioned, we actually changed

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the standard of informed consent to give a little bit of extra protection.

So you have to overcome a higher standard if you're going to bring a case of failure to provide informed consent if you got a good documented trail of using a shared decision making process with a credential decision aid. The piece that's missing right now for us to be able to effectuate that law is the national credentialing standard that was built into the ACA.

That's something that's still on the books and that's one more thing that we really need as a community to get into place because then I think that, it's not going to solve world peace right but I think it will provide one additional bit of protection that practitioners can look to, to really rely on the fact that if they're providing state of the art clinical evidence in a good effective procedure that they've met the standard of care. Ben do you have anything to add to that?

ED HOWARD: Do you want to identify yourself?

BEN MOULTON: I'm Ben Moulton. I'm the senior legal advisor at the Foundation and actually Dr. Barry and I did a series of focus groups where we replicated the Marenstein case, which I think is the case you may be referring to, the fact pattern and did usual care, which is informed consent sort of mentioned in the medical record risks/benefits explained and

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then we used the decision aid as part of the informed consent process.

When we did that, juries could understand, there was almost looking at the tapes of the mock jurors, sort of an epiphany as to why it would be a reasonable choice for a particular patient to decline to have a PSA test. In that situation, there was a 98-percent finding for the physician.

So I think what Karen's alluding to is you could use shared decision making as an adjunct to informed consent, strengthen it, and also give providers probably better protection against malpractice suits. That particular case, that study, is actually on the website, part of the materials that's available to you.

KAREN MERRIKIN: So we need malpractice reform in this country not just for this reason but for a lot of other reasons. So we have a window right now, perhaps, and it's probably a very good time for everybody to get behind medical liability reform. We may not have a better time.

BEN MOULTON: Mike, do you have anything you want to add to this?

MICHAEL BARRY: Yes, just to add as a primary care physician, I have had patients in my practice who've decided not to have a test and had a bad outcome. I've had patients in my practice who've made an informed decision to get a PSA test,

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one who died during his prostate surgery. It's rare but it happens.

Another who is euphemistically called by my surgical colleagues sometimes as gravitationally incontinent. When he stands up, his urine all drains out. Bad things can happen no matter what you do. What helps me look myself in the mirror each morning and say I'm doing the best job I can is that I worked hard to make sure they made an informed decision. I can't control the outcomes but I can control the process.

ED HOWARD: Here's a question that actually was touched on in one of the presentations, how much variation, this person asks, do you see across ethnic and cultural groups in accepting and using shared decision making with the observation that some cultures are coming from a belief that the provider can do no wrong?

MICHAEL BARRY: There are a couple of variations to that question. The broad theme is how do we design these strategies and decision aids to be accessible to the broadest number of people whether across literacy, education, numeracy, race, culture, and in my role at the foundation where we develop decision aids, it can really keep me up at night but then I think, in the middle of the night, compared to what? Compared to how we, as clinicians, are handling those problems behind closed doors?

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I can often get back to sleep at that point because we can show these to multiple groups of people and measure accessibility. What we're finding, for example, on the literacy issue is that more vulnerable populations often with lower literacy start with lower knowledge levels.

They have more need in this area and appropriately constructed tools that can get them up to the level they need maybe by using video testimonials to get around the issues of reading, using the research on pictographs to communicate the probabilities can actually have a larger effect in those populations than in the well-educated populations that may need them less. So there's lots of work to be done here but that's not an excuse for not to get about doing it from my perspective.

HELEN DARLING: I think we have a lot of differences in this country about doing something everything for somebody what it means and doesn't mean and we have enough data and experience in this country about subgroups of the population who've not been given the same services as others and it can be socioeconomic status.

It can be race, ethnicity, language, anything but the misunderstandings and the belief that if you are low-income or uneducated or something that you're going to get less, at least if you have coverage is going to drive an insistence that

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getting more is the right thing just as many of us believe that if it costs more, an MRI must be better than something else because it's the most expensive. If somebody says to you I can do this for you.

It's \$1,200 and this other's \$500, most people in this country would say I want the \$1,200 one. We assume, just like cars and everything else, the most expensive is going to be the best. That'll come up over and over. I mean that's a major national phenomenon that we have to deal with independent of all these other things.

ED HOWARD: Let me just ask in that connection and voicing the question that a Congressional staffer has asked, what role, when you put these aids together or have the conversations, does cost play? In other words, do you let the cost of the treatment option enter into the patient's decision and does that get affected by whether or not you know they have insurance or not or the kind of insurance they have.

HELEN DARLING: Well I can tell you what we recommend. As the comparative effectiveness research be done completely on clinical grounds solely, that all research that has to do with whether or not something is effective for individuals, groups, the whole thing be done in a way that looks only at the clinical evidence.

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If someone else, another group and this should be no connection, should not be the same people, should be no connection, if another group, those who are making decisions about coverage wants to take clinical evidence and decide how they do it fine but they should not be mixed up.

ED HOWARD: How about the patient level when these encounters take place? David?

DAVID SHERN: Well again, a couple things. Number one, in terms of the cultural, the question we just had a minute ago, I think that if you start to think about measuring preferences and doing it in a way that people can meaningfully respond, you start to deal with some of the issues that others were talking about, I think the cost issue is a very tricky one. I agree with Helen that we should separate these functions. On the other hand, I think it's important that people realize that the decision they're making does have cost consequences and that those consequences, in some sense, have some sort of public health impact.

I don't think they should be determinative but I think it should be part of the discussion just like Helen said in a way, you have to inform people about the fact that simply because something is more expensive doesn't mean it's going to be more valuable in this instance but also the fact that if you're making choices that should be part of the consideration.

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One could argue that part of the reason that we've had the health care inflation that we have had for such a long time is that cost considerations, both from a sort of a clinical practice model as well as from a consumer being insulated from the effects of their decisions vis-a-vis your costs, has contributed in some sense to that cost inflation. I think it's tricky but I think that people, when they're making these decisions, should be thinking about the resources that are going to be used in making them.

HELEN DARLING: I want to give you an example how you can do this. You take the clinical data and you say for those people for whom this is clinically appropriate and effective and which there's no other, then that's a covered benefit. If you want to have that and you're not in that group, you're welcome to it but you'll pay for it for yourself.

If we stuck to that again it's all clinical but if you have something that's equal, right now we have it in benefit packages all over the country including actually probably in Medicare, if something is clinically appropriate and effective for you as an individual and there is a generic available and it's available by mail or if it's something you take then employer plans will pay that.

If you want to go to the local drug store because you don't want a three-month supply or whatever and you want to

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have the brand name that's exactly equivalent, you're welcome to that.

This is the United States of America where you're going to pay the full difference but again if you stick to what's clinically appropriate, evidence-based then this will all sort out but the problem is we didn't and we don't. That's why we have all of these sort of overruns. I'll give you one other example.

A drug that was recently evaluated and I was part of the panel and it was public information, so this isn't anything. It was found to be effective for a very special and relatively small population. We basically said it met scientific criteria. It had been approved by the FDA for this very tiny population.

Now legally in terms of FDA, it can be once it's approved, can be off-label use. We just say okay the evidence is on the on-label use. If you wanted it to be a covered benefit then you have to prove it and until that happens, it isn't going to be paid for any other circumstance. That's the way we can have the best of both worlds.

ED HOWARD: Well forgive me for pressing this, assuming that the system works exactly the way Helen Darling's describing. To what extent does cost enter into the

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conversation between the provider and the patient when they're making a decision using the decision aid if at all?

MICHAEL BARRY: I would start with that concept of appropriateness but highlight that appropriateness is more than what an X-ray shows. So to illustrate, I mentioned the choice about medication versus a stent for a blocked coronary artery. So 10 years ago there was a survey of patients at Yale, not Harvard but a pretty good place that asked people who'd had a revascularization procedure why did you do it?

Seventy-five-percent of them said it was to prevent a heart attack. We've added to this evidence base, over the last 10 years, there are over 50 randomized trials of putting stents in that circumstance versus medicine involving almost 70,000 patients that show for the great majority of anatomic patterns of blockage, you're not preventing heart attacks. There are other reasons to do it. It might reduce the frequency of angina, let you do a little bit more but it's not about preventing heart attacks.

Ten years later, after all that evidence, that same study gets done at U. Mass, 75-percent of people had it to prevent a heart attack. So is that appropriate? They had a blockage. It was reasonable to put a stent in but I think if they were fully informed, many of those patients would've decided that medicines would've been okay without even raising

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the question of cost. So I'd like to get rid of the avoidable ignorance, see where we're at and whether we need to introduce cost into the equation at that point.

KAREN MERRIKIN: The other thing is I think when you start off, for example, if you're contemplating having a knee replacement, if you really know what the costs are that are entailed in that but not only the cost of the surgery, the cost of the PT, the cost of whoever's going to maybe help you at home or help your spouse at home while you're recuperating.

I mean the decision aids won't give you the cost information as part of the decision package but it does begin to help you frame up those thoughts so you can take them home and talk about them with your family members. I mean this is a conversation that's been going on in my extended family of you know what? This might not be the right time for knee replacement.

We've got these other things going on. We've got these costs going on this side. Medical management's looking pretty good for right now but maybe in a while it'll be a better time. So it at least sets up the foundation for those kind of bigger costs, family budget issues to come up in the longer term.

ED HOWARD: Go ahead David.

DAVID SHERN: I want to follow up sort of what I said earlier and maybe clarify it a little bit. We had a big

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practical trial in psychiatry comparing new antipsychotic medications with the first generation antipsychotic medications and it's a very controversial study but one of the findings was that you just looked at psychiatric symptoms or you just looked at discontinuation rates of use that really there was no difference between older medications and newer medications. New medications are much, much more expensive than older medications.

That caused the state mental health program directors, medical directors' group, to really sit down and think hard about how do we go about making decisions about, this is a little bit out of the SDM framework, about what the physicians might want to do.

What was interesting after they reviewed the literature again and developed their own sort of decision algorithm, cost was there but it was the last thing that was considered and not the first thing. I think this relates very much to what Michael's saying. The first thing you think about is what's appropriate for this person.

So if they have, in this case, if the side effect profile is such that they are particularly sensitive for certain kinds of extra-parametal effects, movement disorders associated with the, you would definitely want to stay away from the first generation agents.

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What their preferences were, certainly what their experience had been and if all of those things are equipotential then cost should enter into the decision. So I think it really just reinforces what Michael's saying. It's not that it shouldn't be there but it should be at an appropriate place in the decision making algorithm.

ED HOWARD: Okay. Helen?

HELEN DARLING: Yes, David's comment reminded me of something else, which is we talk about cost and we're the first to talk about cost, so the fact that I'm saying this is significant but we have to look at productivity consequences. So if we've got people not able to go to work or in some instances not able to recover and ever work again or they're going to be a burden to their family.

So we're not paying something on the narrow medical costs but we're essentially depriving the country of productivity that we desperately need because we're in big trouble as a country. If we don't have the investments that are the right investments, more health and productivity instead of just more health care, and that may require some higher costs for certain things but if the productivity evidence is substantial that's exactly what we should be doing. By the way, if on balance we did all that right, we would be saving money.

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ED HOWARD: Let me ask you to pull out the blue evaluation forms as we come to the last few minutes here and give us some feedback. I've got sort of a broad gauged question that might be an appropriate way to give people a chance to make some final comments. What's the best way to teach shared decision making? Should you go to consumers and patients first? Should you go to clinicians first? Should you do it the same time? Is there anything in your experience to inform this decision?

MICHAEL BARRY: Well if anything, I think our foundation may have been a little bit guilty of focusing more on the patient side in part because I think we saw the relationship so dominated by the clinical side and I won't to apologize too much for that but again, I'll come back to the point that has been made in a number of articles. Here it takes two to tango and again I'd hate having the activated informed patients hitting the brick wall in the clinical encounter. So I think we're more convinced than ever we need to work both sides of the aisle because if they're not working together, you won't get the best decisions.

KAREN MERRIKIN: I would echo that and bring in the rest of the clinic staff as well. Nurses are critical in this process but one of the things that we had the good fortune to do at Group Health is we actually have a group of our

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longstanding members who've been with us, sometimes, for many, many years, it's called our senior caucus, and we previewed some of these decision aids for the senior caucus.

They, almost universally, loved these. That's one of the ways to sort of stir up demand. So again we don't want the demand hitting the brick wall. So it's been a matter of really engaging the clinicians including the nursing staff and the other office staff with the patients and really building towards a shared understanding that this is part of Group Health culture and something that we really want to incorporate in our patient engagement strategies.

ED HOWARD: Helen?

HELEN DARLING: Yes, so we really need to reach the public broadly. We don't want to wait until somebody needs knee replacement to think about this. We want people to know almost from the day they're born, to understand that they need to understand everything about what could happen to them and what power they have.

This is really about empowerment for everybody and you want every individual, whether they're getting immunizations or they're making decisions about women with making birth control, which ones, things like that. They know they have to think about it. They have to understand the benefits, the harms, and the risk.

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DAVID SHERN: I think that resonates to what Karen and Michael said as well as the report about full participation. I mean our experience has been that it's critical that both clinicians and patients be involved in this. In psychiatry, it has been, in some areas, a heavier lift in terms of the traditional way that psychiatric patients have been considered in terms of their competency but what people uniformly report is that it adds another dimension to their relationships with the patients that they feel is extremely important and makes a big difference.

I mean the trial data shows that it makes a difference in terms of adherence and participation over what can be long-term illnesses but it's really important that we talk about this reciprocity of communication that they don't hit a brick wall after having been charged up.

In fact, the interventions that we use typically occur in clinic settings where the physicians have been primed although there's some initial reluctance, typically that goes away like Karen said, immediately and the physicians and clinicians wonder why has it taken so long to start using these techniques.

I think it's consumerism and health and active involvement in staying well speaks to a broader move in our culture that's critically important for all of us. I think

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that shared decision making really can be the engine to help drive that true planning around costs and benefits.

ED HOWARD: Okay. Pretty good discussion of a very much discussed than I think less well understood tool for improving our health care system. I want to thank our friends at the National Committee for Quality Assurance and of course, at the Foundation for Informed Medical Decision Making for their co-sponsorship, the Foundation particularly for its participation and support of the briefing.

Thank you for sticking with it and asking good questions and as you, use your third hand to fill out the evaluation, could you join me in thanking the panel for a very enlightening discussion [Applause].

[END RECORDING]

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