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Session: The Basics of Shared Decision-making  
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Angie: Let’s see into this webinar. Why you have chosen to spend this hour listening to me talk. So if you could please just indicate why are you entering this webinar whether your interest is primarily research interest, clinical interest or some other kind of interest. If you could please just click your responses that would be great. Okay, I think central office is closed today and a lot of people are…the person who is helping me run this webinar is at home and we are not going to be able to see the graphs today so I apologize for that. So what I am going to just do is just help that there…assume that you are here for both interest.

So I want to start off by talking about what \_\_\_\_\_ [00:00:47] decision making is. To give you a definition we are going to be using throughout this talk. So it involves at least two participants so that would be the physician and the patient but it could also be the physician and a target decision maker to there could be more than three participants. The physician, the target decision maker and the patient. All parties…

Heidi: I apologize everyone. This is Heidi \_\_\_\_\_ [00:01:15]. I am in Boston. We are getting a snow storm and I am just a little \_\_\_\_\_ [00:01:20] is a little bit not working right now. I just on the call. I apologize that I was not here right away and \_\_\_\_\_ [00:01:28] like you started already, I have the screen up so everyone is able to see your slides now. \_\_\_\_\_ [00:01:34] screen and I will let you keep going. Thanks everyone and I am sorry for the slow start here. Back to you Angie.

Angie: Okay, thank you. So \_\_\_\_\_ [00:01:52] participate and that is different than other models where the physician primarily is the decision maker or the patient the primary decision maker. In addition there must be this atmosphere of information sharing. So the physician must create the atmosphere. That is the first job is to make sure that the patient understands that this is a collaborative decision, that they are going to work together and so that the patient knows that their questions and values and goals are a part of this decision making process.

The physician’s primary responsibility after that is to explain the medical technical aspects that they patient needs to be able to understand their new diagnosis and the risks and benefits of the potential treatments. Then the patient also has a responsibility to share information and in that case patients need to share their preferences and their values and their goals and then together they decide on a treatment that they both agree with. This is a key component because if they do not both agree with a treatment decision then it is no longer considered a shared decision it is a different type of model of decision making.

So next I would like to talk about the concept of clinical equipoise. This is a case where shared decision making is especially relevant. So here decision making is most relevant in clinical situations in which there is this clinical equipoise which means that the treatments have similar benefits and risks in terms of survival or recurrent and so they tend to be perceived as similar in terms of those outcomes, but other things, other risks that are associated, potentially other benefits are different. A lot of those are more value driven. This is also called preference sensitive decision. Examples for this include therapy for early stage breast cancer or prostate cancer, lipid lowering medications for prevention for coronary heart disease as well as genetic and cancer screening test.

So what would a high quality preference sensitive decision be? How do we define that and how do we know if the shared decision that comes about and the patient’s decision making process is of high quality? And \_\_\_\_\_ [00:04:22] that patient has a high level of disease specific knowledge. The idea here is that in order for patients to really be able to make an informed decision they need to know and understand the risks and benefits associated with their treatment options as well as key components of their treatments and their disease. Similarly, for a high quality decision to be made the decision actually has to reflect the patient’s values for different outcomes associated with the options. So when people say the most important thing for me is X, that their decision reflects that.

So let me give you an example. So imagine a women who is diagnosed with early stage breast cancer and she says one of the most important factors in her decision making is for her to be able to keep her breast and she chooses a breast conserving surgery. Then she has demonstrated at least one part of the high quality preference decision. Her values are reflected in the decision that she makes. Similarly for a woman with breast cancer who wants to avoid radiation who chooses mastectomy is making a decision where their decision is concordat with their preferences. Now that is half of what makes quality decision making. The other half is being able to actually understand all the risks and benefits of the disease. There are many cases in which patients will say one of the most important things to me is for example, not becoming impotent with prostate cancer treatment and then chose surgery which is most likely to result in impotence and that would suggest that, that was not a high quality preference decision there.

So for shared decision making to occur in practice there are five main steps. One is to identify those situations in which shared decision making is critical. So there is some debate in the field about whether or not every decision out there should be shared decision making versus the other perspective which is while the idea to do shared decision making for every decision possible that given the constraints of time and patient desire for involvement and frankly physician desire for involvement that it might not be a case which every situation shared decision making is not critical. So we first have to decide which of those situations, which decisions is shared decision making especially critical for.

Then the next thing is to acknowledge the decision to a patient. By telling them that they really do have a decision between two different treatment options and making sure that they understand what the decision is and what those options are. It is interesting \_\_\_\_\_ [00:07:08] had published a paper in the New England Journal in about 2012 which showed that I think it was around 50, 60 percent of patients who were getting palliative chemotherapy actually thought that they were getting curative chemotherapy. So in that case that is an example in which the patient actually did not know what they were making a decision about. So that decision might not have been acknowledged either that they had a role in the decision or what actually the decision was that they were making.

So the next step though in shared decision making is describing the treatment options including the risks and the benefits of those options and also being honest when there was uncertainty about the risks and benefits. Sometimes there is not good data on those. Sometimes there is something about the patients that make the risk models not fit for them and so acknowledging where there is uncertainty. And also acknowledging the risks and benefits of not picking a treatment or not having a treatment or not doing a screen test, et cetera. The next step is for the physician to listen to the patient’s preferences and values and also similarly the patient has to construct their preferences and values. A lot of people especially when they get diagnosed with a disease that they may have never heard of or do not have much experience with they do not automatically have a preference about what treatment is best for them. Therefore…

Heidi: Angie, I am sorry. Just wanted…for a second you are talking really, really fast if you could slow down a little bit it would help the audience a bit.

Angie: Okay. Sorry. So the patient does need to construct their preferences and values and determine what is most important to them and then they need to be able to communicate that to their physician. Next the patient and the physician each agree on the plan for the next steps. So the question is and that has been being asked for over a decade is are we there yet? Even though we have been talking about this for a good 20 years are we there yet? Many clinicians will say yeah, we are there. We do share decision making all the time. This is what we do every day in our clinical practice. But let’s do a reality check based on some work by Dominic Frosch who asked patients how comfortable would you be to ask your physician questions about your diagnosis or treatment preferences and how comfortable would you be in discussing preferences? Would you be willing to discuss your preferences there risks and benefits? I mean, the preferences you have for the treatments? What you can see here most people would say absolutely. I would feel comfortable asking questions and discussing my preferences.

In terms of when physicians make recommendations very, very, very few patients would disagree with a physician’s recommendation for treatment even if they had a good reason to do so. One of the reasons that patients indicated that they were worried about this was that they feared being labeled a difficult patient. Again, even 12 percent of patients thought that by asking questions they might be labeled a difficult patient especially when their physicians are especially busy that their physician would get frustrated with them. Again, it is a minority. Similar \_\_\_\_\_ [00:10:25] preferred discussing preferences and then finally almost half feared that they would be labeled a difficult patient and not a patient that the physician wanted to work with if they were to disagree with a physician’s recommendations.

So even though a lot of physicians feel that they are doing this, a lot of patients are fearful of really engaging in all aspects of shared decision making which part of may include disagreeing with a physician’s recommendations. But there are many benefits of shared decision for clinicians. One is that it improves…the research has shown that shared decision making actually improves informed consent procedures. So patients are more likely to be able to give informed consent. Additionally, shared decision making can save time and make consultations more efficient and satisfying. This can be done in a couple of ways. Some ways is through counseling beyond the busy office visits so using physician extenders to help do some counseling either before or after visits. It can save time by proving patients baseline knowledge and by doing that for example, you could give patients decision aids or other educational materials before they see the physician which makes the conversation much quicker. Then also by focusing the discussion on key issues for the decision rather than basic education.

If patients already know a little bit about their disease and the treatment options then the physician can focus in on the most important points rather than just giving a general spiel. There is some suggesting that they could reduce malpractice claims or the success of malpractice lawsuits particularly if patients are given decision needs before they make a decision. There is actually a law in the state of Washington to do so. Even though there are all of these benefits, there are many challenges to share decision making and today I want to discuss three challenges to shared decision making on the patient end. There are also challenges on the physician end but today in lieu of the time that we have I am going to focus on patient based challenges. One is when patients are being diagnosed with a new disease they do not have a lot of knowledge about the disease, about the treatment options. Some of this is compounded by the fact that patients may have low literacy and low \_\_\_\_\_ [00:13:01] skills that makes learning about their disease and understanding what their physician says.

The second is that from about 25, 35, 40 years of decision psychology research also sometimes referred to \_\_\_\_\_ [00:13:16] now. There has been lots of \_\_\_\_\_ [00:13:19] decision making processes that can make it difficult for patients to share decisions in the way that we would want. Then finally there is often a lack…of patients of their values and goals and preferences or how to communicate them to their physicians. I am going to take each of these in turn today and then also talk to you about some potential solutions for each of these challenges. So let’s firs start with patient literacy. As you may know the average person reads at a seventh or eighth grade reading level. In some cities between 26 and 60 percent depending on the question patients could not understand medical directions, a standard informed consent \_\_\_\_\_ [00:14:00] or basic healthcare materials. Additionally, approximately 80 million adults have limited health literacy skills and these rates are higher especially among the elderly, minority populations, people with lower income and those with less than a high school education.

I recently conducted a study in four VAs and in that city about a quarter of the veterans had…could be termed as inadequate health literacy. There is also a lot of impact of health literacy as you might imagine. People who have lower literacy tend to have more hospitalizations ratings of emergency care, lower mammography screening, lower influenza vaccines and overall poorer health status and higher mortality rates especially among the elderly. They can also have the impact of lower health literacy can also have an impact on health interventions. For example, a lot of interventions use written materials, websites, decision aids, patient brochures and those are often inaccessible to the very people who would benefit from them the most. I published a paper in the early 2000s which showed that almost all of the highest quality decision aids for prostate cancer were written at a 10th to 12th grade reading level and some at a college reading level. Again, making these interventions inaccessible.

The impact of low health literacy can also have an impact on what patients can understand from their physician if the physicians are using a lot of jargon or terms that they are not familiar with. Their ability to understand the physician’s description of the diagnosis treatment options will be impaired. There are some solutions for this. There is a number that we could go through but the two I want to highlight today is just the use of plan language and I mean this both in terms of physician, or clinicians, nurses, physician extenders, et cetera will communicate with a patient the importance of not using jargon, discussing things in the most common everyday terms as possible. So instead of risk maybe the risk of something happening, talking about the chance of something happening. Similarly, you can see the same thing in written materials that using this more common language is much more effective in helping people understand. In written materials it goes beyond just low literacy. Words or more simple works but also the use of white space, use of bullets instead of long sentences, et cetera.

Another thing that has been found to be really useful, especially when working with patients is to do what are called teach facts. The idea of this is after you have talked with your patient about the diagnosis and the treatment options is you might want to ask the patient to explain back to you what they understood from you. You do this in a self-defecating which seems to be the most effective which is to say, I know I just said a lot of things and I know you are going to want to take this back to your family and I know you are going to want to take this back and think about what is best for you. So I want to make sure that I did a good job of explaining everything because I know sometimes when I get talking I talk fast, or I use a lot of words that you might not be as familiar with because you are not a physician. So tell me what you think I just said so I can make sure that I explained myself well. A lot times that will give a really good idea of what the patient might be misunderstanding or if they are not repeating back come of the key things that you think is really important for him to know that you can repeat those kind of incidents or clarify or correct any incorrect understandings.

The next thing that I want to about is patient numeracy. So first of all, let me start off by telling you what is numeracy. Numeracy is the ability to comprehend, use and attach meaning to numbers. So if you think of words are to literacy as what numbers are to numeracy. Similar concepts. So to make this clear let me put numeracy into context. So I could ask you either of these questions. What is a bigger risk? One percent, five percent or ten percent. And most of you can answer this question very easily. You are probably wondering why I am wasting your time giving you this question. Well, the fact of the matter is that I have a study in North Carolina around Duke, UNC area that about 25 percent of college educated adults––so these are people who have a bachelor’s degree––about 25 percent of these participants were not able to answer either of these questions or at least one of these questions correctly.

So what that is saying is that if we think we can just give patients numbers and they will understand it and they will be able to use them and they will be able to make good decisions out of them we are wrong. Where giving people numbers is necessary, it might not be sufficient in making sure people understand the risks and benefits of treatment or of screening options. So I just want to quickly discuss with you today why is numeracy so important in medical decision making. So one thing is that there are every day decisions that people have to make and that they have to be able to use numbers. A really good example that you might not have thought of is, what is a teaspoon of medicine?

Many of us have children and we have gotten up in the middle of the night to try to give them medicine. A lot of people do not recognize that a teaspoon of medicine that you would use with a syringe or your measure spoons can be very different than with a teaspoon or some cases a tablespoon of medicine is. There has been a lot of discussion of children, babies being overdosed because parents do not recognize that their teaspoon they grab out a draw is very different than necessarily to be double what an actual teaspoon is. So there has been harm to children based on that. Similarly, being able to understand how many pills to put in each days pillbox when you have a number of different medications and you are supposed to take some twice a day and some three times a day can be very difficult for people to do if they have low numeracy skills.

In terms of cancer screening, there is a lot of decisions where numbers become very important to people. For example, what is a benefit of PSA test? What is the benefit of a lung cancer screening test for me? How do I weigh the benefits versus potential harm including false positives, unnecessary test, unnecessary treatment? Should I get a mammogram before I am age 50? Then when should I stop screening? At what age is screening no longer beneficial to me and that could actually cause more harm than good? These are all questions that people have to consider as they age and think about screening for cancer and all require a really strong understanding of numbers.

Then finally, treatment decision making. I have just been diagnosed with cancer what treatment is best for me. There has been research that has sown that people who have low numeracy skills, if you show them the risks and benefits of two treatments that a lot of people actually cannot determine not even just what is best for me but what is the best treatment. These are in cases where there was a dominant choice. There was one best treatment and people often with low numeracy skills cannot make that judgment.

So what are the solutions? So one thing I want to talk about, there are some different examples of how you can discuss numbers to patients that will improve their likelihood that they understand information you are trying to communicate and can make informed decisions. The first one I want to look at is absolute versus relative risk presentation. So first I want to ask you, what if I told you that I could reduce your risk of breast cancer by 50 percent. How interested would you be in taking that drug whether it was prostate cancer or breast cancer? Now what if I told you that a drug could reduce your risk from two percent to one percent and I am using an absolute risk presentation method. They obviously have the same affect, the same benefit but the first description sounds much better, much more persuasive. You will see this a lot where people will use the relative risk presentation to make drugs sound better. This is a fact. This concept is one of the most proven areas where there is one way that is much more confusing to people than others and in this case using absolute presentation makes it much clearer to people what the actual benefit would be from this treatment is.

As you know, this is not just important for patients but also for physicians. An article published in the Journal of Cancer Oncology shows that when physicians are randomized to two groups, one where they received…oncologist were randomized to one of two groups. One group reading an article about the benefit of a chemotherapy agent using relative risk presentation and one reading the same article but just with an absolute risk presentation that clinicians who had received the relative risk presentation were much more \_\_\_\_\_ [00:23:31] want to prescribe the medication, the chemotherapy and thought it was more successful. So even clinicians are affected by the presentation of absolute versus relative risk information. So if you are trying to inform a patient and not trying to persuade the patient but just having them understand what the risks and benefits are then you absolutely should use absolute risk presentation.

Another factor which could be helpful to people is to present information in graphical format. This is often widely recommended but there are so many different graphic formats that it is hard to know which one is the best for communicating health information. Just look at USA Today. You see many options on any given day of \_\_\_\_\_ [00:24:14] format that you can use to present numbers. So what we wanted to do in a study was to look at the five different graphical presentations to use and because pictures are worth 1,000 words instead of describing them I am going to show you what they look like. So this is your typical bar graph. Zero to 100. You will see that there are no numbers on here. That was purposeful. We wanted people just to be able to see what people were able to determine by looking at the graph. So here is a bar graph. Here is your typical pie graph. Because we chose not to use numbers, we were worried that we were making pie graphs definitely an unfair disadvantage so we also created what are called clock graphs which is kind of a mix between a bar and pie graph that you can give to people more likely being able to interpret the information correctly.

These are pictographs, these are sparkplug which is the same. In both cases, you will see the color is to indicate the number of people who are affected. So these are the number of people who would need bypass surgery and these are the number of people who would experience a side effect. It is a 10x10 matrix with each person representing one percent. And a sparkplug is just similar but just slightly visually different. What we wanted to know was which of these methods were most appropriate and lead to the best knowledge. Using \_\_\_\_\_ [00:25:47] terminology I wanted to look at both just knowledge and verbatim knowledge. By just knowledge what we mean here is people’s understanding of what the key purpose we were trying to get across to them. In this case, which pill was going to decrease the need for bypass surgery and which pill would have the highest likelihood of a side effect.

Then verbatim knowledge is people’s ability to pick the numbers out of the graph and report the number to them. So just out of communication what…I mean, just out of curiosity I would for you guys to…and we will see if the poll works this time is what graph do you think communicates just best? The actions are bar graph, pie graph, the clock graph, pictograph and sparkplug graph. So if you could please just enter one of those five letters on your keyboard we will take a quick little vote and see what you think.

Heidi: We will give everyone \_\_\_\_\_ [00:26:52] the responses are coming in and I will read you them as soon as \_\_\_\_\_ [00:26:57]. Close that down. And the results we are seeing is 33 percent saying bar graph, 23 percent saying pie graph, 10 percent saying clock graph, 33 percent saying pictograph and 0 percent saying sparkplug graph. Thank you everyone for participating.

Angie: Well, congratulations to the people how chose pie graph. I think about a quarter of you got that and in fact for just knowledge, pie graphs were the most effective communication method. However, as you can see so the \_\_\_\_\_ [00:27:42] number…those are the correct responses out of two questions. As you can see they were pretty close together. The bar graph was actually the least effective in communicating just knowledge but they are very similar. Now I want to ask you one last question today which is, which graph do you think would communicate verbatim knowledge best? And again, it is the same options as before. Thank you. If you couple please just enter A, B, C, D or E.

Heidi: Sorry, it was a little slow on \_\_\_\_\_ [00:28:35] but responses are coming in. \_\_\_\_\_ [00:28:38] just a few more moments and I will read you those results. It looks like we have slowed down. I am going to close that out and share the results. So we are seeing 36 percent saying bar graph, 11 percent saying pie graph, 4 percent saying clock graph, 43 percent saying pictograph and 7 percent saying sparkplug graph. Thank you everyone.

Angie: Thanks everyone. I do appreciate that. We are a little surprised by this finding but bar graphs slightly one. “Had the best verbatim knowledge compared to the others”. But as you can see there was much more variability in this knowledge and pictograph was very similar to bar graph. So what we found here actually is that people just \_\_\_\_\_ [00:29:33] verbatim understanding of risk very significantly across the graph. For just knowledge, questions of \_\_\_\_\_ [00:29:40] were most effective but very ineffective for the verbatim knowledge graph questions and then the reverse was true for bar graphs. So one thing we did see that in both cases pictograph both for verbatim knowledge and just knowledge pictographs were the “second best graph in communicating that type of knowledge and not significantly different than the top winner”.

So pictographs were the only graphs that consistently lead to more accurate risk knowledge across just and verbatim knowledge question. If this is something that looks interesting to you and you wanted to create a graph, we have a website called \_\_\_\_\_ [00:30:19].com to create your own pictograph in about one minute. So you might wonder well, you just use these really boring rectangles. How interesting is that? What if you used something else like a smiley face? Well, we were interested in that too and we wanted to look at a whole bunch of different options for to use as an icon and we tested all of these.

Rectangles, ovals, pictures of real human beings, your cute little smiley faces, then red and green, restroom sign pictures as well as head outlines. What we found was that the bathroom signs were the most effective whether you use men or women or a combination of men and women. Their recall was higher, they were most preferred and they resulted in the highest correlations between perceived and actual risk a more \_\_\_\_\_ [00:31:12] and graphically literate participants. But there were no differences between lower numeracy and lower \_\_\_\_\_ [00:31:20]. So we would recommend the bathroom signs if possible.

My last thing that I want to talk about in terms of risk communication and communicating numbers but it also goes a little bit to the literacy concern is using…keeping things simple. So you can see this is a common graph that is used with breast oncologist talking to patients about their decision making. What we show here is that there is a lot of information, a lot of people have difficulty interpreting it. As you can see there is four treatment options showing previously, but for any one patients only two options tend to be relevant to that patient. So for example, if they have an ER positive breast cancer hormone therapy is really strongly recommended and so it probably would only be useful to compare hormone therapy only versus hormone therapy and chemotherapy. Similarly, if it is an ER negative breast cancer hormone therapy is not recommended so then the decision is only \_\_\_\_\_ [00:32:14] therapy versus chemotherapy.

So we wonder whether including less information can help comprehension of other critical information. So randomized people to either receive all four aligns or treatments as typically used \_\_\_\_\_ [00:32:31] online by breast oncologist or just give the two that was most relevant to patients in our scenario. What we found using hypothetical scenarios with an internet panel is that, when we gave only two options about almost 15 percent more patients were able to understand the incremental benefit of chemotherapy. So we asked them how much more likely are you to live with…to not have a reoccurrence if you were to have chemotherapy and about 15 percent more people were able to answer that correctly when they are only given two options. So less can be more. Showing fewer options can be better. It leads to better comprehension and also when we timed the…it takes people less time to understand and to process which can be good.

We do have one other website that we would refer you to. This was \_\_\_\_\_ [00:33:27] Robert Wood Johnson Foundation Award to look at a whole bunch of different types of risk communication methods for everything form a health risk appraisal to discussing disparities in treatment to discussing risks and benefits of treatment in screening. So feel free to check that out if that can help you. The next I want to talk about are biases in decision making that can make it difficult for the patients to make informed decisions. I am just going to go over a couple of common ones. One is availability bias which means the easier that something is to recall from memory the greater the perceived prevalence. So with those results then is a probability of recent salient events is overestimated. But as are the probability of rare \_\_\_\_\_ [00:34:15] events. So people are really influenced by what just happened. You see this when celebrities have a treatment or get cancer you see people get screened more for cancer, et cetera.

The other problem on the other hand is that the probability of remote less memorable events is often underestimated. Similarly, the probability of \_\_\_\_\_ [00:34:40] and ordinary events are underestimated. So when people are trying to make decisions about what kind of prevention activities to engage in or whether or not to get tested or screened that this inability to accurately access the likelihood of things happening will bias people’s decision making. Another one is \_\_\_\_\_ [00:35:00] and adjustments. Ideally, when we make a probability estimate we want to keep continuously updating this probability, especially when information comes in one piece at a time and you always want to adjust your estimate appropriately based on this new information.

However, this process had two flaws. It starts off people often make an inaccurate initial estimate. Insufficient weight is often given to new information. It is either overweighted or underweighted and hence the final probability estimate depends too much on the initial estimate which in itself might be wrong. You can see this both in physician decision making and in patient decision making. A physician one is, estimate a patient’s prognosis often changes very little across space at least in this study in 1990. In the ICU despite continuous new information and similarly if physicians give estimates on different days. For example, the first day and then they keep adjusting over the third day versus bringing in a new physician the estimates are very different because one is adjusting and one is not.

So where this comes into account with patients is people often have a preconceived risk estimate. It is often likely higher than it actually is and then when they receive the results of this model for example, for example the Gail Model they fail to adjust their risk estimates which can cause them to over screen or over treat for example \_\_\_\_\_ [00:36:39], et cetera. The last one I am going to talk about is framing. So imaging there was a surgical treatment for lung cancer that had a 90 percent survival rate. Would you want that treatment? Most people say yes. However, if you ask them imagine that there was a surgical treatment for lung cancer that had a 10 percent mortality rate would you want the treatment? A lot more people say no to that and a lot of \_\_\_\_\_ [00:37:05] people say that they would want that.

So the way you frame it in terms of survival versus morality has a pretty significant effect on what people say what treatment decision that people make. This is primarily found in as you might imagine lower numeracy individuals. Are there solutions for framing? Yes. You can present it both ways and we have gotten really good feedback from patients when we give them both the risk of something happening to them and something not happening to them. Unfortunately, there is not a good solutions for availability or \_\_\_\_\_ [00:37:39].

Finally, I want to talk about disease knowledge. Probably stating the obvious, when people get a new diagnosis they often do not have a lot of knowledge about the diagnosis and their treatment options and it can be hard to learn. There is often a lack of available creditable easy to understand materials. There is a lot of emotions that are harming people’s ability to process complex information. There is often a time pressure that people perceive or actual in the amount of time they have to look over this information and make a very important medical decision.

So in terms of different types of intervention solutions for this, there is a number of decisions to support interventions. So why do we even need these? Well, one is explaining complex medical decisions to patients can be very challenging for physicians. They often do not have enough time to accomplish this task and patient often may be so overwhelmed by all the intake of information it is hard for them to understand it or remember it. What decision support interventions do is they explain what the problem is in language that patients can understand, they provide detailed information about the options, the risks and the benefits and there is a written record of this complex medical information So when the patient goes home and is talking to their family member, they can use it to discuss what is going on. They can refer back to it during the decision making process and they do not have to rely on their often faulty measures.

One way of doing this is using what is called a decision aid. These are tools that describe options. They are designed to help people understand their treatment options, help them consider the personal important of possible benefits and harms and to help them participate in decision making with their physician. Again, they are often used where is clinical equipoise as we talked about earlier. There are numerous different types of decision aids including brochures or pamphlets, websites, DVDs and the can be used either pre-visit so the patients can prepare for the visit by looking at a decision aid. A patient and physician can look at one together while they are discussing the treatment options or the physician can hand one to the patient and have them look at it following the visit.

Here are some key components of decision aids. To be considered, to be classified as a decision aid at least through the current standards that we have you obviously have to describe the medical condition, the risks and benefits of treatment and most have a \_\_\_\_\_ [00:40:07] clarification exercise which is to help people understand their values and then include some of these other resources such as glossary, citations, et cetera. Some decision aids also include personalized risk information, testimonials, decision coaching. For example, giving people an idea of how to make the decision or how to better communicate with their physicians and more \_\_\_\_\_ [00:40:30] value clarification exercises. In a recent \_\_\_\_\_ [00:40:36] review, people who receive decisions are more satisfied and more knowledgeable, patients have more realistic expectations of what their care can accomplish. Sometimes not always not even often they can change preferences and they can often lead to more conservative decisions.

Another decision support intervention that could be used is decision coaching which Jeff Pecora and Karen Sepucha and Laura Esterman have used a lot at UCSF. The idea behind this is to help the patient prepare to see their physicians. They start by thinking through what does a patient really want to accomplish in their next appointment? They come up with a list of questions and concerns that the patient have. Then also helps the patient think about their values and goals of treatment and have all of this information recorded so that the patient and the physician can review this together.

This has been shown to have many benefits both on the patient’s side and the physician’s side. It increases patient’s knowledge, satisfaction, belief that they can make a good decision. It also increase their decision quality. It decreases their decisional conflict and anxiety and it results in better quality question. Physician benefits include not increasing consultation time. It allows physicians to spend less time on their spiel and more time on tailored communication. Physicians often report that they have more confidence if their patient were to remember information correctly if there is a note taker present which is often a part of decision coaching.

Finally, we are going to talk about the understanding of values. We talked earlier a little bit about the lack of concordance between what people say is really important in the decision that they make and one of the reasons may be that patients often do not have an initial preference and their preference are being really lead by how the information is presented. So one potential solution which there is not really good evidence for is value clarification methods. These are methods that are explicitly designed to help people explore, identify, organize and/or articulate one or more feelings relevant to a health decision. There is a series of steps where an individual indicates what is important to the individual in the context of a health decision and the process…it typically does but does not always give an answer to the patient about which of these \_\_\_\_\_ [00:43:08] of their values are on their treatment recommendation.

So you ask patients a lot of questions. You can in many different ways which I am not going to have time to talk about today but at the end of it they send their answers. You can say well, based on your answers this was the test that this treatment reflects the values that you say are most important to you. This allows for the integration of people’s personal feelings about their decision into the decision making process. This is strongly recommended but there is little consensus on how to best design values clarification exercises. There is a huge variability across studies in what people have used in their success rate. There is not good evidence of which methods are best. In fact, there is a lack of good evidence that those clarification test improve decision making but this is an area that needs much research and we did a little review for the international patient decision aids standards collaboration on this topic if you are interested in getting a review of what methods are out there and how they are used.

So shared decision making is both beneficial and difficult. There is a lot of components to it, it takes a lot of energy, a lot of work and a lot of \_\_\_\_\_ [00:44:23] on the patient’s side and the physician’s side. There are numerous resources that can be used. Graphical representations of risks, plain language, decision aids, decision coaching and then just taking time. Time for the patient to ask question, taking time to ask patients questions about their goals and their values and just listening to patients. I would like to thank my colleagues who have helped me with these slides. Some of these slides have been designed by my colleagues Mary Politi who Assistant Professor at Washington University. Karen Sepucha who is at Harvard and Dominik Frosch who is at the Gordon and Betty Moore Foundation. Thank you very much and at this time I think we can open it for questions.

Heidi: Wonderful. Thank you so much Dr. Fagerlin. For the audience if you do have questions please use the question screen and go to webinar \_\_\_\_\_ [00:45:21]. I will just go through what we have in right now but please take this opportunity to send in any question that you do have. The first question that we have here. You mentioned the overlap between shared decision making and behavioral economics, could you elaborate on the overlap and differences?

Angie: Yeah, I would not…I am sorry I was unclear there. I would not say overlap. I think a lot of the things…the concepts when we talk about having biases in decision making when we talk about the framing effect or availability or \_\_\_\_\_ [00:45:56]. Those are often talked about in terms of behavior economics. I was making the point that those are very basic social psychological principles in that we need to be aware of whether you want to call them social psychology or behavior economics when we think about shared decision making because these factors influence people’s ability to understand information. So sorry about being unclear on that.

Heidi: Great. Thank you. That is actually the only question we receive in at this point. I think we can wait for a minute or two to see if we have any others that people are typing that hopefully will be coming in very shortly. While we are waiting I just want to let the audience know when I close the meeting out you will be prompted with a feedback form. If you could take a few moments and fill that out we would very much appreciate it. We really do read through all of your feedback and make some changes based on the feedback that we do receive. It looks like we have not received any other question here so we may \_\_\_\_\_ [00:46:59] up at this point. Dr. Fagerlin I do not know if you had any other closing marks you wanted to state before we shut things down today.

Angie: I am good. Thank you.

Heidi: Wonderful. I want to thank you so much for taking the time to prepare and present of today’s session. I apologize for the technical issues at the beginning. This happens sometimes when I present…when I am moderating from somewhere other than the office so thank you everyone for your patience while we were going through that. Once again, we did record today’s session. We will get that sent out to everyone as soon as we have that ready. Thank you everyone for joining us for today’s HSR&D Cyberseminar and we hope to see you at a future session. Thank you.