

## Final Transcript

### Washington State Shared Decision Making Workshop

January 11, 2024

#### **JUDY ZERZAN-THUL: Welcome and Brief Background of SDM in Washington**

(Presentation Slides 2-8)

Good morning everybody, I know we are all chitchatting. I was chitchatting. It is so great to see you all here today and people I know from kind of all over. So, thanks! This should be a really fun day and has been a long time and coming. Thanks COVID.

I would like to first thank our team that has worked very hard on this. So, you can stand up or waive or something. Mostly they are over there. So, Heather Schultz is our new medical director for those of you who do not know her.

Laura is working on the camera! (Laughs) But I think you all know her. Sarah, she has been the organizational brains behind this. We really appreciate that. And Heleena, I did not see... oh!

She is the one behind the camera, excellent! So those are the folks if you have any questions during the day, other things you want to know, those are who you want to go to. So there is a little housekeeping to go over, if you can come to the next slide, please.

Do we have a clicker? I don't have a clicker. And you know what, I realize I did not say good morning. I am Judy Zerzan-Thul, I am the senior healthcare official at the Health Care Authority. I will do that too, now I will click.

Today, this is also in your folders, we will talk a little bit about shared decision-making in Washington state. What is it? Why is it important? And then we will have, we have a slew of experts here today, which I am super excited about.

They are going to talk about implementing shared decision-making at Massachusetts General Hospital, how Patient Decision Aids support good shared decision-making, and we will have a panel discussion about that.

And then how might you put shared decision-making into the practice. So, there will be breaks in there, there will be lunch. I hope we have a good conversation today and learn some things. So, next slide. Oh! No, this is still me, sorry. My coffee is over there! (Laughs)

So, we are providing live captioning services today. This service allows our Deaf and hard of hearing attendees to access the content a few seconds after it is spoken. Please make sure to introduce yourself before you speak and ask questions to assist with that.

When speaking, please speak clearly and at a slow pace. If you are interested in accessing captioning in real time, please let Laura or me know. So, we have been working on decision-making for a few years. It started before I came here five years ago.

We have been certifying Patient Decision Aids, which is very exciting work. And so, I think most of you know that justice that the groundwork, shared decision-making is a process by which clinicians and patients work together to make decisions, decide on care plan, decide treatment options based on the balance of risk and expected outcomes.

And the individual preferences of the person and their values. So, early in the 2000's, way back when! Jack Wennberg actually came to our state and spoke to leaders about clinical variation across regions of the state.

That was sort of the early days when it was being discovered, clinical practice varies quite a lot and people have quite the difference in whether they get something or not. So the response to that here was to pass legislation to support shared decision-making with the aim of both reducing variation but also facilitating the choice of the person.

And the goal was to get to appropriate utilization and I am sure many of you know, evidence shows that shared decision-making decreases overutilization. It also helps correct underutilization. It helps get to that sweet spot.

There are several pieces of legislation we have had since then that support this work. The pre-collaborative was focused on unwarranted variation in evidence-based improvement strategies.

We will hear from the executive director of the foundation that hosts that. And it also established authority for HCA to certify Patient Decision Aids and provide some legal protections for clinicians that use them. In 2019, pre-collaborative developed recommendations for how to encourage shared decision-making.

So our goal at the Health Care Authority is to certify Patient Decision Aids. We started this a while ago and we are still at it. We try as best we can through the various levers we have to promote shared decision-making and patient decision aids.

We cover a little over 2 million Medicaid and 400,000 public school retirees. That is a nice chunk of the Washington population. We provide training and support to providers; we have online tools to help folks do that.

We collaborate on the development and dissemination of the Bree recommendations. And we do things like today, where we convene statewide discussions about spread and sustainability.

We have a total of 44 decision aids that have been certified so far. Our first set was on maternity care and you can see we have done total joint replacement, spine care, end-of-life care, cardiac care, screening for cancer, and behavioral health. Then we have had some recertification of some of those aides that are older.

So it is a process. So, with that, I would like to introduce Ginny Weir. She is the Chief Executive Officer of the Foundation for Healthcare Quality. That is a nonprofit organization dedicated to improving healthcare quality, equity and safety through convening medical data and driving best practice.

So, Ginny, it is over to you. Thank you, have a great day, this is going to be fun.

### **GINNY WEIR, MPH Shared Decision Making: Why, How, Who, Me?**

(Presentation Slides 9-53)

Welcome everyone, thank you Judy. I am Ginny Weir; I work for the Healthcare Foundation for Healthcare Quality. We are a foundation in Seattle. Dedicated to bringing together those who typically don't talk to one another.

I was thinking about your decision-making this morning, I was thinking about New Year's resolutions. For me, one of my resolutions was to not eat dairy products, at least for a month.

This is really hard for me; I am lactose intolerant but I have two young kids and their diet is cheese and milk. It is in our house, it is everywhere. We have a culture of a huge amount of dairy consumption.

Doing my own little thing is really difficult. I thought about that in the context of shared decision-making. We cannot expect individual providers to behave differently when their entire environment is really focused on doing the opposite. Not necessarily integrating Patient Decision Aids.

So I wanted to keep that in mind with these cultural changes, systemwide changes as we approach shared decision-making. I will talk a little bit about what our foundation is. Sort of what we are wanting to do with shared decision-making. We are home to a wide variety of communities that are all focused on improving population health status, and we do these in a variety of ways. One of the biggest is through our care assessment programs. These are communities led by clinicians set on improving surgical and spine obstetrical care processes.

We focus on these procedures and we also recently branched into having a separate yet equal community birth registry that is focused on improving the quality of transfers from community births into a hospital setting. Either during that labor and delivery process, or

immediately postpartum. It brings together those that are dedicated to improving safety. Our program focuses on harm in the process after a harm has occurred.

I'm here to talk about our Bree Collaborative. I always thought of it as an opportunity to ask, what makes us healthy? Who gets to be healthy? And how can we help improve the quality and the length of life for people within Washington State, and really beyond as well?

Our framework for action is set out through the bill that created our collaborative and that's House Bill 1311 that was passed in 2011, building on some earlier work. Judy alluded to some of the early quality improvement work and I think that helped bring the Bree Collaborative about as well.

We are named after Doctor Robert Bree and focus on appropriate use of imaging. That overuse of space that we have done a lot of work in. And so the bill sets forth our framework for action.

We have members who are appointed by the governor representing these different sectors, so public and private purchasers, delivery systems, quality improvement organizations, health plans and individual physicians. They will identify three or four health care services, high utilization, where they have a safety or equity issue that the community wants to do something about it really doesn't have a mechanism for action.

We look at a lot of information and data. Here are just a couple parts on life expectancy. I think it's important to question why that happened and why it is showing up in our state. A lot of those opioid overdose, suicide, alcohol use that we have seen show up in our population is low. And our discrepancies by race. Here you can see life expectancy differences by race, and of course vast differences there, and a real opportunity for us to help build a better Healthcare ecosystem.

And of course our life expectancy compared to our fellow countries that have similar GDPs - it's a lot lower and a lot more expensive. This is a space where we really hope to have an impact. And I also really like bringing in our social determinants of health into our conversations, that are length and quality of life are really more driven by our social and economic factors - those spaces in which we work, live, and play, and really exist outside of these clinical encounters. That clinical care really only results in about 20% of her length and quality of life.

As we moved through this space, we had a variety of clinical encounters and then we have this whole space in which we exist that drives our length and quality of life. We are all individual people and we accumulate these experiences, these exposures throughout that time. And probably a big part of that, a big contributor to these outcomes is our race and ethnicity.

It's not necessarily that it's anything biologically different, that it shows up in racism in our encounters with each other. I just want to read this definition of race and I think it's really important grounding as we think about the potential for Shared Decision Making to help increase the equity of Healthcare.

So race is a social construct that is used to group people based on physical characteristics, behavioral patterns, and geographical locations. They vary by country and they change over time. People who are assigned to the same racial category don't necessarily share the same genetic ancestry, and they have no underlying genetic or biological factors that unite them within the same category (Reads).

Using race as a biological marker and diagnosis really can give us the wrong answer about the true health status of a person, and that can lead to racial health disparities. And our big underlying theme at the foundation and across the work that we do at the Bree Collaborative, is to work towards a state of health equity. Really the state in which everyone has a fair and just opportunity to obtain their highest level of health. The Shared Decision Making space is a nice vehicle to help work towards that opportunity for the highest level of health.

A little bit back to the Bree Collaborative and our process. After a Healthcare service is selected by members, we convene a clinical committee or workgroup that is made up of experts and people with lived experience is. We go through a robust public comment process and then develop clinical guidelines that are focused on improving Healthcare quality, affordability, and equity.

Once they are complete, we send those off to Judy at the Health Care Authority and the intention is that the Health Care Authority incorporates those guidelines into their contracts. And we also really want to create change in our broader Healthcare community, but we kind of like the mechanism to do that, other than asking very nicely.

We have employers around the table that are dedicated to improving quality further members. We have health plan representatives that are dedicated but the mechanisms for getting change in the Commercial market outside of those three communities is a little bit more variable and difficult.

The process of creating guidelines and implementation is messy and it's important to keep that in mind as we think about these multisector spaces for improvement. We have created a lot of guidelines and you can see them listed here: they really group around chronic and acute pain. We've done a lot of work around behavioral health and working to increase access. We've created bundled payment modules, and of course highlighted in purple our Shared Decision Making work in 2019.

Shared Decision Making has always been a key component of our guidelines. We've worked to include in a variety of workloads and some of the obstetrical interactions, but we decided to create our own focus guideline around Shared Decision Making in 2019 to help increase utilization.

This year, I wanted to call out our new topics for this year and invite anyone who's interested to reach out to our Bree Collaborative staff to join. We are doing re-review's for integrating behavioral health and opioid use behavioral treatment. Let us know if you're interested.

Our new topic that I'm really interested in is on health related needs from climate change. There we will focus on heat, potentially wildfire smoke, and how we can create just a higher capacity within our Healthcare system to deal with what we know is coming.

So I have some of the same slides as Judy and I will just remind everyone of our Shared Decision Making definition. This process were clinicians and patients work together to make decisions, and select test treatments or plans based on evidence, that's balance with risks and patient outcomes.

I wanted to have a more realistic example focused on colon cancer screening. We know that Black Americans are more likely to get colon cancer. It is of course overall the second leading cause of cancer death in our country but it gets less attention than breast, cervical and prostate cancers. We develop guidelines in 2020 focused on colon cancer screening interventions.

So we look at these kinds of failures in this pathway and what leads to these disparities when we want to create a more equitable Healthcare ecosystem? Everywhere from the screening to the follow-up after, where polyps are seen and treated, there are opportunities for us to help improve our Healthcare ecosystem.

And our Shared Decision Making work is focused on that first part. That person centered care. And I've called out one of our key sources for Shared Decision Making tools and I think this will probably be called up later on.

This is from the Ottawa Shared Decision Making Group and the specific one is from Healthwise. Really it walks people through what their clinician, what type of test will work best for them. Having an at-home test or screenings. It's great at looking at the risks, the benefits, and where this person's values lie.

Why do we choose a in 2019? Highly variable. It is a patient safety issue. It has cost implications. It is a proven strategy for creating change. There is a lot of data in huge potential for impact. And it's also a Unique space for us to convene and bring together

opportunities for health plans, delivery systems, individual clinicians to really make a difference there.

There is also a lot of evidence. Here is calling out a couple of those articles and of course I'm happy to follow up with our huge literature review for folks who are more interested in diving into that. The evidence shows a better patient experience and better health outcomes. More appropriate utilization and more appropriate spending. It really works well in a value-based care space and it can help inform population health strategy is.

Reduces health disparities and helps to really counteract our assumptions about a person when they walk into a clinical encounter. So most of the studies used a patient decision aid. And I think most of the evidence really points to the use of a decision aid as appropriate in those encounters, instead of having conversations without that.

There is a huge impact on equity and this is just one study of Black patients with advanced osteoarthritis. They are less likely than white patients to undergo surgery as a population. After this intervention, which was a 40 minute video describing the benefits and risks, there was an increase in the type of Black Americans who underwent the surgery. So there was an impact in equity. Sometimes it can be an over utilization or an underutilization of space. Going back to our definition of Shared Decision Making.

Oftentimes a patient decision aid is used to help a person to participate and provides information on the options, oftentimes with one of those lovely pictures of 100 little figures and how likely, whatever the Healthcare service is, to impact that person. It really helps him to weigh the pros and cons.

This is just a link in the slide to the Ottawa Hospital that has a great list of patient decision aids. And this is the source I tend to go to look for them.

When should these conversations happen? When there is more than one treatment option. This info graphic is also shared in your folder, talking through one and what should happen during a patient conversation.

Something like advance care planning. Something like a PSA test. That's really the place where a Shared Decision Making conversation, informed by a patient decision aid would be appropriate. When somebody should be encouraged to have the intervention or the test, or the process of treatment.

Something like a vaccine or setting a broken bone - those are places where it's not a Shared Decision Making conversation and that's more of a motivational interview type of space. Or, when their strong evidence against something. So antibiotics for the common

cold is a great example of one example where Shared Decision Making is not as appropriate.

And of course, don't providers already do this? I think that's a really the common ethos here. Are we not already having quality conversations? I stole this from Emily and thank you for allowing me to do this. Subtext. Sometimes these happen but not all of the time. And when that variation occurs, this is really the sweet spot for the Bree Collaborative.

Most people think they already do this but it is specific. This requires sharing all options, talking about values for that person, helping them think through the choices, implications of doing or not doing, whatever the treatment or that procedure is.

Sharing neutral with that person. Versus the sign here, you should do this, I would do this kind of language that can be more common. Especially when the clinical encounter is very rushed.

Again, it is talking with the risks and benefits, especially for that person, for their goals, what are they wanting to do in the next year? What are they wanting to do in the next week? What are their values?

Would they be OK with more invasive surgical procedures? Is that something that is really anxiety provoking for them and may not actually be a good fit? But the impact of the options. Really sharing that decision, obviously, between the person and the clinician. Addressing questions and really documenting. When we create guidelines, we really want a shared definition, which we share with the Health Care Authority here.

Shared understanding and what the benefit of decision-making is, prioritizing clinical areas as a starting point for the community. Making sure we have a framework for implementation so we are not just making New Year's resolutions on our own, but we are already building capacity for the systems to support that type of clinical engagement.

And the documentation will help to get reimbursed in a really consistent way. We have a statewide movement using this shared decision framework, the framework that people are mostly familiar with when talking about individual change. So contemplation, preparation, action, and maintenance. We applied this to an organizational level and at the statewide level.

It is interesting that it can be applied in that space. We broke down the internal mechanisms, the drive of shared decision-making. We want this to come from multiple departments, multiple organizations, multiple people.

Thus, of course, it starts in educational space and can start in medical school or training through practice, maybe continuing through education. We also acknowledge that the



Patient Decision Aids needs to be useful and constantly updated. This is a lot of effort. We need to have constant review of Patient Decision Aids that are being added as medical information and medical changes.

Patients and family members need to understand how and why to use Patient Decision Aids, why they are being engaged in this way and how this can help make their care better. I wanted to call out the training on the Health Care Authority website that can help really just build the shared understanding and action items for individuals.

Lastly, we can call out the systems-based change, so it is really a culture. A culture to support these decision-making processes. The need to have clarity and consistency in how to use decision means and how they are expected to engage with people.

Tracking and reporting needs to be clear, it needs to be used appropriately and not feel like a burden, not feel like they are adding to the type of interaction a person is meant to have. It can be supported by reimbursement.

Judy talked a little bit about that, I will not talk in more detail but the legislation that helps support it. The work that is going on and we are really lucky to live in Washington State, that has created this capacity for reimbursement and really a cultural framework that helps to move decision-making forward.

So, the collaborative work group prioritizes 10 healthcare services, they are listed here, starting with surgical or procedural services go ahead. Judy talked with us and moved on to intense care planning including cancer screening and behavioral health.

So we really work to incorporate this kind of framework in our healthcare service guidelines when we created those. When we think about an implementation from here, we want to use a highly reliable implementation framework. We customize to an organization and here we call it too. specifically.

The national partners playbook, decision-making in healthcare. Really comprehensive, really usable. Organizes the process in these fundamentals. Basic, intermediate, and advanced steps. This really starts with leadership buy-in, building this culture for shared decision-making, patient education, engagement. Team knowledge, training, action, implementation. Tracking and reporting accountability down the line.

We also call out the AHRQ framework, to seek help, access and evaluate a shared approach - we love acronyms and had to throw another one in there. This one is cute and makes sense in this context. Also leadership buy-in, really in developing a team to tailor to your practice, provide training, provide ongoing support to all staff, and starting small and taking it to scale.

Creating a physical setting for this, the library of evidence-based resources and decision aids, so streamlining that process. That evaluation. The implementation of shared decision-making. Here you can see this maintenance in action.

These are all in the guidelines themselves. I encourage folks to click on the link and find more on that later. It goes into the mission, mission values - is this a good fit for us? Identify champions, select an area to pilot, implement in a small-scale and then seeing what works and what didn't work. Evaluation and changes needed. We also include action items for stakeholders as well as patients and communities.

What can people do to really be engaged and empowered? What can you do to ask and expect in a shared decision-making process? How to bring up what can be an uncomfortable conversation with the people in that encounter.

We talked about documentation, coding, and reimbursement. There are currently codes that can support your decision making. Our goal is for this to be documented like any other clinical encounter. We do recommend the development and use of coding that does not currently exist.

We talk about that in guidelines and talk about recommendations to make plans, purchasers, and really those who help support the framework that is kind of silently around chemical encounters and decision-making.

So this can look like incorporating decision-making as a value-based care model, center of excellence model, incorporating metrics around shared decision-making into standard reporting to a plan or to a purchaser. And metrics in guidelines. Really, it requires shared decision-making, potentially, as an optimization requirement as well.

There are mechanisms to help incentivize this as well as talking about it within the context of that workflow. So, I wanted to kind of end with an example that has worked really well.

So our total hip replacement bundle, developed by the collaborative, walks through kind of four stages for a high-quality surgical procedure that starts with documenting disability. That person had the opportunity for explicit nonsurgical care. This is where shared decision-making comes in.

It is really a good fit for the person, for the surgery, and that the surgery is a good fit for them. You can expect high quality outcomes to come out of that. This is another Patient Decision Aid that really talks through, should I have knee replacement surgery? Is this a good fit for me? Does it make sense? It walks through the facts, as well as making sure you truly understand what the risks and benefits are.

This is something you want to have. The implementation language in the original statute really does sort of lay out the best practice. So, the Health Care Authority is meant to consider the guidelines and incorporate them into contract standards. Once the healthcare system has built the capacity to offer those types of services and other commercial plans, it can also adopt that. That kind of requirement.

This has worked really well with hip and knee replacement. So the state, as an example here, works with the Center of excellence members. For total knee and total hip replacement, working to incentivize people to choose the center of excellence by waiving coinsurance, having travel reimbursement. People seem to really like it.

So, that is a great plus. I think it incorporates a lot of elements that we will talk about later today that you will hear from other speakers that are really based in shared decision-making. That the model has spread. This is a very exciting space for us and we celebrate successes because they cannot be very transparent when they happen or do not happen at all.

So Providence is also contracted, the name of the facilities and center of excellence for total hip and knee replacement. Following guidelines and HCA also spread this model for lumbar fusion, using the lumbar fusion bundle. So an exciting space, and other healthcare services they can use shared decision-making as well.

I will end with how to access these reports, this is a screenshot of our website. I encourage folks to look at our guidelines as they are stated here. I am happy to answer questions either now or later on. And this is just a plug for implementation support. I will call out Emily, our transformation partnerships coordinator.

Really working in the space as guidelines are being created. Thank you.

SPEAKER:

I welcome questions and am also happy to turn it back to the HCA Team.

DR HEATHER SCHULTZ:

Thank you, Ginny. For that excellent overview. I would like to introduce our next speaker, Doctor Leigh Simmons, a physician at Massachusetts General Hospital and assistant professor of medicine at Harvard Medical School.

She is the medical director of the Massachusetts General health decision science center where she studies the use of decision aids to help patients in the shared decision-making process. Please welcome Doctor Simmons.

**LEIGH SIMMONS, MD: Shared Decision Making Integrating into practice** (Presentation Slides 54-109)

Thank you and thank you to the Health Care Authority for having me. A day spent thinking, talking with others about shared decision-making is a dream day for me. I'm very excited to be here in Washington state where you have been at the center of so much innovation and support for shared decision-making.

I'm here to represent our shared decision-making science center. I am with Karen Sepucha, our Director. I may turn to Karen for the tough questions if they come up during Q&A! I'm going to talk about the decision aid model we have in our Health Decision Sciences Center. I've been doing it now for almost 20 years. I find the shared decision-making is a core part of my work.

OK, so, when I am going to do today is share with you all a bit about the background of shared decision-making. Just expanding on some of the definitions that have already been presented in making sure we are working with the same background info.

I will also give you the history of the shared decision-making at the Massachusetts General Hospital in the greater Boston area. I will talk about the culture of decision-making at Mass General and how we launched our Health Decision Sciences Center.

Then I will walk you through the four areas of implementation we focused on. This includes decision distribution in orthopedics, talked about earlier with Ginny Weir's presentation.

And in primary care, which is actually where we got started. I will talk a bit about how we were with our clinicians on the ground, seeing patients. To help them develop their own decision aids when things come to mind for them that are problems that may be solved by improved decision-making and decision aids.

I will talk about clinician training in the prime study where we work to train primary care physicians and strategies to enhance shared decision-making for colorectal cancer screening. I will talk about equity and inclusion through shared decision-making efforts.

All of these definitions are very familiar to all and consistent with what has been presented earlier. (Reads) The patient is engaged in the process of decision-making and are presented with information about the outcomes and treatment and the treatment plan is tailored to the patient's concerns.

Another definition that I like when doing trainings for medical students and residents, is that we are bringing your expertise in medical practice and the patient's expertise in themselves and their life experiences, and what they will be going through and will be willing to do to accomplish their decision and reach health goals.

Another important piece about Shared Decision Making is that we are really expanding the definition of what is appropriate care. We are used to figuring out if this is the right operation to offer to this patient? Is this the right provider? Is this the right place or enough excellence? Do we have the right patient? Is this what they want? Do they understand what they are getting into? Have they been presented with the options appropriately in making an informed decision?

High quality discussion with patients were informed and they received their preferred treatment - how do you get there? You have the clinical evidence that supports the options you will offer. You tailor that evidence to the patient in front of you. You identify the patient's values, their process of eliciting those, and you come together with an integrated and shared decision.

But it's not easy to get there. It sounds easy. Yesterday I was teaching our medical students in a session on Shared Decision Making and primary care practice and I thought that these students did great. They are First Year students and they are high-quality communicators at the level that we need them to be.

I kept thinking, "if I could just audiotape them, I could use them for training." What happens after that first year of medical school from where it becomes beaten out of you? To engage in a collaborative way? I didn't teach the students how to do shared decision making. They were already saying great stuff and I worry what happens if we don't continue to support them in being high-quality communicators.

We need a couple of things of having to promote this in hospitals and clinics. We need a shift in understanding about what the physician and the clinician's role is. We need the tools and the training to support this work.

We often think in our work in the Health Decision Sciences Center about finding the balance, we are directly quoting here, we work with an orthopedic surgeon, he's great, but he says, "my patients know when they need their knee replaced. They call me when they are ready." The patients are a little bit confused and they don't know what that means.

I had a patient say to me once, "I don't need to make a decision about my knee I will go to Doctor so and so (orthopedist) and he will tell me if it needs to be replaced or not." I wanted to encourage him that it was about how his symptoms were, as he was actually quite a sick man – with a heart transplant, and the decision to do a replacement was not straightforward decision. But he was certain that if the orthopedist examined his knee, he would know.

We are finding the balance between patients calling us when they are ready, the doctor always knows best, or in the middle. In our culture of Shared Decision Making, we want to

promote that our care teams are treating patients with, not the golden rule, but the **platinum rule**: treat others as **they** want to be treated. You have to ask how **they** want to be treated. "How bothered are you by the pain or the symptoms? How important is it for you to alleviate the symptoms? How much do you think surgery will help your symptoms? How worried about complications of surgery?"

You want to find out from your patient how bothered are you by the symptom? How concerned are you about the impact on your daily life? If you are talking to someone who is quite bothered by their problem, but not at all or worried, after they heard about the pros and cons of an operation to help them, go ahead and just do it. That should be an easy process.

But someone who has a high degree of bother and concern about potential side effects will need a lot more support as they make their medical decision. We also need to work with our teams to increase the comfort in discussing the trade-offs - that's not necessarily something that we train our physicians and doing and are nurses and doing as they learn about medical practices.

Talking about how there's no free lunch. We will have to talk about potential downsides of the procedure, what you might have to do to get to the outcome that you want.

Now I'd like to tell you about Shared Decision Making at our hospital and how we have worked to build their culture, incorporating the elements introduced in the beginning.

We work at a hospital, Massachusetts General, that was an early adopter in Shared Decision Making. It was developed by many familiar faces to you all in 1998 – Michael Barry and Al Mulley. Use all forms of technology to share video and audible communication. We use LaserDiscs and VHS. We've used DVD and online paper. We find paper are the most effective decision aid, as I will go into.

With collaboration from our primary care practices in 2009 and 2010, we launched the Health Decision Sciences Center at our hospital. We've been fortunate to have great support from our leadership and having Shared Decision Making right at the center for the strategy for Mass General Hospital. We've had lots of institutional support as we launched new initiatives, which has been wonderful.

Our doctors are no different from. They have been “doing Shared Decision Making forever.” Our job is to point out when they are correct – “yes, You’ve done a great job in Shared Decision Making in this area. But here's how we can make it even better.” This is our challenge, to do it in a nice and consistent way, always showing them many things that they can do to make the practice more interesting and fun with great tools that are easy to prescribe to their patients.

So our work at the Health Decision Sciences Center has been to advance understanding and improve the quality of our decisions, by getting interventions out by training and decision aids. Measurement of those interventions, measurement of the decision quality, and continued work on implementation strategies that support the work.

One of the stories we often tell - it sounds like a cautionary tale but it's a good story in the end. And it's the story of Mr. M. He was one of our very first patients to get a decision aid at Massachusetts General Hospital. He is 71 and he had progressive right hip pain.

He went to see his primary care physician who did an X-ray and referred him to an orthopedic surgeon because he did in fact have moderate hip arthritis. The surgeon wrote a lengthy note (for a surgeon), about 1 paragraph. This was the pre-Epic era.

We discussed the options and he very much wanted to proceed with hip replacement. OK. So at Massachusetts General, as is now, it still takes a few months to get that operation scheduled. During that wait, Mr. M started talking to friends and family. He continued to exercise and he actually started to have improvement in his hip pain and didn't have many symptoms.

He was at his required primary care visit to have a preoperative consultation to make sure he was fit for surgery. His physician said "they started this new program here to send out these decision aids. Why don't you take a look at it? I'm thinking maybe your hip doesn't seem to be bothering you that much anymore. Use this and see what you think if it's helpful."

OK. Take a look at this. This letter arrived in the mailbox of the primary care physician. Read it. Put yourself in the shoes of that primary care doctor that's trying out a new program at the hospital. Tell me what your reaction might be to that.

"Dear Doctor. I'm writing to tell you that at this time I'm not going to proceed with my right hip replacement. Please cancel my appointments for testing and surgery. Six months ago I added daily biking to my routine and I found that my nighttime pain was gone.

When I saw you in May for my consultation, I wasn't sure if this would hold but it has so far.

The patient didn't really mention to the surgeon that the hip pain didn't really bother him anymore. "Based on a conference with my primary care physician and reviewing the helpful information on a DVD that he prescribed, sent to me by the Blum Patient and Family Learning Center, I decided that waiting for surgery was the best decision."

They sent this to the director of the program in a panic. "Uh-oh. Our orthopedic surgeons are going to be really mad that this has happened." But the Shared Decision Making program and its very early days took a different look at this and said, "wait a second. This

patient actually didn't have bothersome hip pain and he accepted an operative option anyway? Thank goodness he had this option. He understands the pros and cons and said he will wait." What happened for Mr. M? Two years later his hip pain came back. He went back to a surgeon just like he said he would and he had his hip replaced. His primary care doctor said, "gosh. Should we have waited? Are you regretful?"

"Not at all and no regrets."

The story has been inspirational to us to keep going in our work, what seemed frightening at first, and we were worried we were going to get pushback. What is this new program that they are doing with Shared Decision Making? It has turned out to be one of many stories with happy outcomes, facilitated by the use of the shared decision aids.

You will hear more about these from the expert, Dawn Stacey, but I will just share a screenshot of a decision aid. It's an example of an online interactive tool. These cover key facts about surgery and nonsurgical options in this case, with emotion of patient needs to clarify their goals and concerns, and creates a summary print out that they can use in their visit with their doctor.

Here's another example that might be familiar to all. This is the Mayo Clinic decision aid. This shares data in an icon array format. This person has a certain heart disease risk profile and what the benefit would be to them to taking this medication.

Decision aids have been shown in numerous trials to do a lot to enhance Shared Decision Making. Patients who use them know a lot more about the decision at hand. They have an improvement in risk perception and they have an improvement in the match between their values and the choices they need to make for their health decision.

As we have heard earlier, the use of decision aids improves both the overuse of certain tests and treatments, and the underuse. "This sounds like it might be right for me after all. I would like to have that procedure or test."

There may be even greater benefit to people who have been historically underserved by the medical community. Patients who have lower literacy levels and lower socioeconomic status may benefit even more greatly than those who come to a consultation with higher literacy and socioeconomic status.

I think I'm proudest perhaps of this number, which no doubt has picked up in the last few weeks. I'm proud of the number of decision aids that we have delivered that is now over 87,000. When our clinicians order a decision aid through the electronic medical record, we do that so we can track who is sending them, who were they sending them to, and what kind of topics are they setting them on.



I'm proudest of the number of 2500+ clinicians. It's not just three or four really engaged doctors, it's 2500 people who have chosen to use these in our care processes since 2005.

We have found the most popular programs vary with what we are doing in a healthcare system. Some decision aids are tied to referrals, for example to see an orthopedic surgeon about hip or knee replacement.

You have the opportunity as the referring doctor to link a decision aid to that referral. Other decision aids are prescribed at the time of ordering, for example, a CT scan for lung surgery. That is requirement, you need to conduct shared decision-making.

An easy way to do that is to prescribe decision aids to patients. We have also led work in distributing decision aids for orthopedic surgeons across the country in a learning collaborative sponsored by the Patient Centered Outcomes Research Institute or PCORI.

We have already delivered aids to 40% of eligible patients at 12 different sites. I will talk next about how we have gone to frontline clinicians to get ideas from them on areas where we can promote decision aids in clinical practice.

So, several years ago, we decided to start hosting workshops where clinicians could come to us with ideas for things that they saw as problematic within the hospital, within clinical units. Where they thought, "I think a decision aid can help me here."

We developed workshops for clinicians to make helpful, short, paper-based decision needs to improve their client work. I am really proud to tell you that over the years we have hosted these workshops with clinicians, we have now had every clinical unit in the hospital represented. From psychiatry to podiatry, speech language pathology.

A physician assistant in interventional radiology, she shared a case that inspired her development of a decision aid. She... this is informational radiology PA, works placing vascular access. So a very typical day for her is doing many procedures placing Ports in the patient's chest.

She told us the story. "As soon as I saw Miss R, she looked terrified, and I could see the fear in her eyes. She was shaking, visibly anxious, and I said don't worry, I will put you to sleep and you won't know what happened."

She by the way has had cancer before and is getting chemotherapy again. She has been through medical treatments before. She said "oh, no, no. It is not my cancer that scares me, it is not the chemotherapy coming up."

It is actually getting put to sleep. I don't like how I feel, I feel really nauseated and the rest of my day will be shot, is going to be terrible.” And the physician assistant said a lightbulb went off for her.

She said “wait a second, I do these day in, day out. I am really good at it; we can just give you some local anesthetic. I will do your port and you will be fine. You do not have to be put to sleep. The patient said, "That will be great."

It went really smoothly and the patient, after having her dressing put on, was able to go home. So Melissa came to our workshop and said, "I have an idea. I think we can do something really cool in our department with vascular access workflows. I would like to develop a decision aid. I heard about your workshop that I would like to work with you all."

She developed a really cool decision aid called "Choosing a medicine for your port placement.” As you can see here, “It says welcome to informational radiology, you're having a procedure today called a port placement that will go under your skin.

We want to know what kind of medicine would be helpful to you during your procedure, your input is helpful to us. This decision aid gives people a chance to say, "hey, it is important to me that I do not feel groggy, I want to be awake as long as I don't feel pain, I don't want a long recovery time, I don't want to be drowsy, I want to be able to drive back home or to work today."

The decision aid covers the options: You have no sedation at all, just medicine to numb you, you can have mild sedation with an oral lorazepam or something similar. Or you could have moderate sedation, lorazepam treatment, and intravenous opioid.

So, when this was implemented, with just about 200 patients over the course of the year in radiology, they had a real change in their care process. Before, it was the standard to give everyone the oral lorazepam and the intravenous sedative.

It turns out only 37% of patients want that when given an option. The rest, about 35%, wanted lorazepam to feel a little calm, not anxious, but not more deeply sedated. 25% just wanted the local anesthetic.

They were always told, "if you feel uncomfortable during the procedure, we can give IV treatment, it is fine."

But no one changed their mind. They stuck with their original choice. This new process reduced recovery time. If you did not have sedation, you can get up and leave right away. Patients with moderate sedation had to stay for on average 37 minutes.

It improved for the patient, they had fewer minutes of recovery time, it was really nice. Something Melissa did not know, nobody could have, we had a shortage of IV fentanyl the following year. And radiology was the one division that was all set, they had already reduced their heavy dependence on that sedative.

Next, I would like to tell you a little bit about clinician training work that we have done in primary care.

This is a study on promoting informed decisions about colorectal cancer screening for older adults. So, as referenced earlier, colorectal cancer screening is really important. We want to make sure everybody who should get it has access to it.

Older patients are a group where decision-making is less about following one guideline for everyone and instead about promoting a high-quality conversation. Finding out from your older patients, how does this fit into overall health priorities? If you are dealing with end-stage COPD, you may not be that focused on finding out if you have this early colon cancer or not at age 82.

“How difficult is it for you to do the prep for colonoscopy? How concerned are you about complications? Do you know about testing options? How would you feel if your doctor said you could stop doing screening? Would that be upsetting? You're giving up on me? Or would that be freeing? Are you kidding? I don't need to do another colonoscopy?”

Another thing we found in our study was physicians needed help navigating this. For patients who had low potential, who had low potential benefit from a test, a colorectal cancer screening test, and also low concern for developing colorectal cancer – they may be a good candidate for a stool test or stopping.

If they have a family history of colorectal cancer and have had polyps before, but they also have a lot of concern about the prep for a procedure or complications, that is someone who may need extra support around the decision-making and some help.

So we realized that these are some of the themes that our doctors can use to help as they navigate this space with their patients. We also knew that when doctors embark on this, when you see a patient 76-85, it is a rare visit where I only need to talk to my patient about colorectal cancer screening.

I have probably also discussed three or four med refills, updating healthcare proxy, high blood pressure medicines, most recent A1c for diabetes care, among others. You all in primary care know this. There is a lot else on their plate.

We needed to develop ways to bring it to the doctor's attention. Let's not let this visit pass without discussion of this important issue. We designed a study that would look at the

reminder alone versus the reminder to do this was training to help you navigate the complex conversation.

So when we developed our training, we interviewed physicians about what makes this hard. We looked at what we had already done with the health decision sciences center in our training work. And we put together training that would highlight scripting and examples that would help you get through these complex conversations.

We brought in trusted clinicians and some patient actors who worked with us for a long time to help design videos for training. In these videos, we have learned over the years, it is best if the examples are not too extreme. We asked our colleague Michael Barry, whom you know as a wonderful clinician and shared decision-making expert. In this video he does a wonderful job of being a great guy, nice doctor, and does a terrible job at shared decision-making. We had physician participants in the training watch this and give him a grade. What did they see in this first video?

They only saw him invite the patient to participate but he did not involve her beyond that. He also did an example of high quality shared decision making in another video.

We also have scripts for our doctors to practice. What phrases might you avoid?

Guess what, it does not go over great when you say, "hey, you will probably not live long enough to benefit from testing." It has been studied; it does not work. I love the chance to tell my patients, you know what? I think we are done with colorectal cancer testing. In your case, your colonoscopy when you were 78 was totally clear.

So, what I want to focus on as we focus on the next 10 years here is bone strengthening, that kind of thing.

And we also introduce risk calculators. Now, in our work for this study, we have work from the strong feeling of patient and physician advisors that I am not sure I want to put up a prognosis calculator right there in the room with the patient.

But it would surely be nice to know how to use some risk calculators and the eprognosis [website](#). There is a link at the bottom, to say hey, in the context of the patient's overall health, they have had to admissions for heart failure in the past year.

How important, really, is it to think about colorectal cancer screening? When you are really concerned that your patient does not have much longer? That is helpful information to go into the conversation with.

Not necessarily to use during the visit but to build use these tools if you want to prepare in advance of the conversation. So, what we did in our study was the randomized control was actually the primary care physicians, we worked with physicians in this study.

We did not include APPs, not because we did not have nurse practitioners and PAs working in primary care but because we needed panels of patients assigned to a single clinician, and in the model at our hospitals, we did not have patients empaneled to APPs.

We also only worked with attending physicians, not residents, just for the purposes of the study because we would be following them over time and could not deal with the changeover of residents.

We needed consistency for the course of the study. And we were working with five hospital networks at Mass General hospitals and Maine medical. Our primary outcome here was the shared decision-making happening in the visits.

Was there discussion of colorectal cancer screening?

Did patients demonstrate knowledge about the situation at hand? What was their satisfaction with the visit process? We collected data immediately after the visits. We had a very high response rate from our physicians and patients. I like to think it is because there are not a lot of studies of our work as physicians to let us know what happened in the visits. What happened? They rapidly completed them, which was awesome.

We had a sample of patients with a mean age of 80 and largely similar in almost every area. All of these patients were familiar with colorectal screening and two thirds had colonoscopies before.

We found that when you compared the reminder only - this was an Epic that your patient was due for a screening, versus the primary care physicians who got the reminder was that training they were more likely to involve the patients in the decision for colorectal cancer screening. They are most likely to discuss it with their patients and bring that up to the top of the conversation during the visit.

The patients in these groups had similar preferences for the testing, slightly higher preference for stool based testing in the training group. The physicians in the training group were more likely to make a recommendation, largely attributed to more discussion around stool based testing, which traditionally have been a colonoscopy first initiative. And this training expanded the range of options that her physicians were comfortable talking about with their patients.

Are patients of the doctors in the training group had stronger intentions to continue with the screening. We didn't see that it made much of an impact of the knowledge of the

situation at hand. These were their primary care doctors for a long time and they had high satisfaction with the visits and conversations.

We did find a few things that were interesting. It seems like the Shared Decision Making scores for the oldest patients for a little bit higher in this cohort, slightly higher Shared Decision Making scores for male patients compared to female patients. And for patients who were at a higher risk of colorectal cancer, their Shared Decision Making scores, their involvement was a little bit higher.

This was an experienced group of doctors and we broke them down to under 25 years of practice or over. We found that the scores the patients reported were higher for the doctors who had fewer years of experience.

So what we learned from this in interviewing our physicians who participated in the PRIMED study, who had learned about ways to talk to their older patients about colorectal cancer screening, had participated and got these reminders, we were pleasantly surprised in our interviews with them that they found that this training was quite acceptable.

A few quotes that I will always remember: some doctors said, "you know when a patient is 76 and a reminder drops off of Epic, I don't talk about colorectal cancer screening anymore. Your training reminded me that some people would still benefit from the screening and might want to hear more about it. Thank you."

Other doctors said, "I feel like I can't stop doing the screening. I've had patients die of colorectal cancer in their 80s and 90s. It's a terrible thing but this training help me remember that some people would rather de-escalate and move to a stool test or stop doing the testing altogether."

Our electronic health records for the most part don't continue to remind you that somebody needs cancer screening after 75.

We are really glad to hear that the physicians thought the training was accessible and they felt that the reminders were helpful. Our next step is a broader dissemination study looking at a shorter training and automated reminders for all patients in the 76 to 85 range - not that they are necessarily due for screening but that they are due for **conversation** about it.

So this is one more way in which we are working to bring the idea that conversations about important health decisions are due - not necessarily the test is overdue, but you do need to have the conversation with patients.

And the last section, I wanted to talk a bit about Shared Decision Making efforts that can be used to advance health equity efforts in your hospital. I will talk a bit about our work at the Health Decision Sciences Center in March 2020.

We were just about to launch the PRIMED study. We could have never predicted that this pandemic was coming. And, while I remember saying to Karen, "we should design a decision aid of whether you want your visit to be virtual or are you willing to take a risk of an in person visit?" Such naive thoughts! In March 2020 there was no Shared Decision Making. Top-down decisions were being made and there was very little opportunity for patients and their clinicians to discuss anything when colonoscopy suites for example had closed.

There was this pause where a lot of people had planned screening tests and health interventions that just had to be canceled. One of our challenges came up with how do we recover from this and how do we get people back? How do we do that in a way that is comfortable for them and that we don't miss people?

We took on a project with our GI department to look at our patients, not the oldest patients by the way, this was a younger group of patients who had been referred for either screening colonoscopy or surveillance of polyps. People from 45 to 75 years of age. This did not include people referred for diagnostic colonoscopy to evaluate problems such as bleeding or follow up of colon cancer.

We looked at 800 patients who had their colonoscopies canceled during that first wave of COVID. We developed an intervention - it was a short and simple intervention. We used a paper decision aid, where we included a few quotes from patients saying things like, "when my doctor called me and said let's not do the colonoscopy, I was so relieved that the only good thing about COVID is my colonoscopy got canceled."

Up to, "I'm really scared. I have a family history of colon cancer. Having to wait is really upsetting me." We discussed the stool-based test that might be appropriate and we gave them options. The options were trying to schedule a colonoscopy as soon as possible. Postpone it for a year when things might be better in terms of scheduling things. Or do a stool test and some explanation about what that was.

The 400 patients who got this intervention worksheet also ended up getting a call attempt from one of our coordinators. "Can I help walk you through this?" The other 400, that the usual care was just the GI department trying to reach them to reschedule their colonoscopy.

So a little bit about what happened. Our decision coaches called the patients, but they also had a chance to find out what else is going on for the patients. Were these patients having any symptoms that had developed? In a few cases, because there was a conversation, the decision coach would come to me and say, "this patient actually says she has rectal bleeding," And we got that patient booked for a colonoscopy right away.

Other patients were given the opportunity to talk to some of their worries. "Would people be wearing masks when I come to the hospital?" "What's it look like at the hospital these days?" It was July 2020 and people still were not coming back for routine care. It was nice to talk through some of those concerns.

Here's what we found when we studied the outcomes for those two arms, the 400 patients who got the decision worksheet and the follow-up call attempt, versus those who just got the usual outreach from the GI department. We found that we had 14% higher screening at six months in the group that got that worksheet and call attempt.

The intervention had the biggest impact on nonwhite patients and those with highest degree of COVID worry, many of whom who didn't realize they had the option of doing the stool test chose that option instead, facilitated by the decision coach.

Patients reported more Shared Decision Making happening in their process and less decisional conflict. They were happy with the outcome and pleased with what they chose to do, whether that was a stool test, reschedule their colonoscopy right away, or postpone the process for a year.

What comes next in the effort? These are some of our undergraduates who are some of our Patient Support Corps. Undergraduate pre-med students who have learned a process of doing patient support, including calling patients in advance of visits and help with questions they want to be answered in advance.

Helping by creating a visit summary that highlights action items for the students to create afterwards. These patient support corps volunteers have been very helpful for us in some of our decision aids delivery efforts with follow-up calls to the patients to say, "how did that go? What was it like to review that decision aid? Can I help you make a question list in advance of your appointment?"

We were also working on clinical decision support for clinicians, reminders have those conversations if your patient is due for conversation about cancer screening. That's the work we are doing across our hospital. And then development of micro-decision aids as part of the intake questionnaires for patients coming in for their annual visits and screenings. "Do you know you have options? It looks like you are appropriate for stool test, home test, or scheduling a colonoscopy."

Trying to do some of the prep work in advance so it's not all on the doctor during the visit. Something that patients have already thought through before they come see the physician.



Just to recap: I hope I have shared how we have imbued the culture of care delivery at our hospital with Shared Decision Making, with both the training, but also the tools such decision aids that our clinicians can use.

It takes a while and we've been doing this quite a while at our hospital. What it takes to get this done consistently is time, training and constant communication with our practice leaders and clinicians and staff. We also know it's important to get feedback on how it's working, looking for ways we can align with other initiatives and population health to say that we have this training in Shared Decision Making and we have these great decision aids.

Or, one of your physician assistants developed a fantastic aid for Radiology and let's work together to get this new process going.

I will stop here and I would love to take questions and get ideas that we can take back to our institution as well. Thank you.

Yes?

SPEAKER:

Hold on.

LEIGH SIMMONS:

The question is about a formal process for onboarding new providers in training and Shared Decision Making. That is a really good idea. We don't have one as of yet formally but now I'm thinking about one area.

We have a year-long training program for new primary care physicians. They have focused training in different clinical areas and I'm thinking that might be something we should get on that agenda. As of yet, no, but I think it's a hugely important point to introduce people to the culture. Agreed. We do have regular practice meetings and as needed some of our specialists. We do catch up with them over the course of a couple of years.

SPEAKER:

I'm over here in the corner with the mic. Thank you for the presentation and that was wonderful. I'm curious how the physicians get the decision aids assigned? I'm assuming it's in advance of the visit and then is there a prompt during the visit to go through it? How do they remember?

LEIGH SIMMONS:

So a lot of these came to the primary care physicians who knew about the program, when the pilot practices knew about it and had a good prescribing experience, this was definitely an indicator that they would be more likely to continue.

We then found that another good way to remind people was actually to have them be familiar with the decision aids themselves. So when we use video-based one, we would show the entire decision aid of their choosing (we gave them 3 options) at a practice meeting.

So that was fine for our purposes when we first started out but that was heavily reliant on did this doctor know about the aids and remember to prescribe them? So we then looked at ways where patients could indicate in advance of a visit if they were interested in a certain program. We developed processes for they could look at the menu and prescribe.

In earlier iterations, we did have a patient problem list about available decision aids. That was less successful than you may think, probably because of two things. Alert fatigue, that is a lot to look at. Also, there may be a decision aid for the problem on the patient's list but maybe not an action or decision point right now. A good example for that, uterine fibroids may stay on the problem list forever, but the patient has already had a hysterectomy. That kind of thing. There is certainly not an action point, or it may not be a problem for them. So efforts like that did not succeed.

What has worked the best and what we use in current practice now is tying the decision aids to referrals or ordering a test. Referrals to arthroplasty which includes questions like, is this patient someone who is having a redo arthroplasty or an infection?

In which case, are decision needs appropriate? Not for those more specialized circumstances. If that is not the case, could we send a decision aid? So, referrals are great. And then tying them to the ordering of certain care pathways like lung cancer screening scans, sending a decision made about the decision aid and there is a decision aid from Healthwise that we linked to that.

I would say it is more when you are trying to get an action step. And of course, I briefly mentioned one about colorectal cancer screening.

QUESTION FROM FLOOR:

SPEAKER Emily Transue:

I will go, I'm curious. This is so great, just for starters. I know it was not as easy as you are making it look, very beautiful and smooth and easy. I am curious. I am sure it has not been. I am curious, can you describe one or two points where there was a real challenge and how you got through that?

LEIGH SIMMONS:

Well, I hinted at it but there have been times where people would say, "well, we have this great idea to get more decision aids out and we will link them to the problem list." Then that would be a terrible idea and patients were so upset to get things like, "is a PSA test right for you?" "No, because my prostate is already gone." Things like that.

Initiatives where we have not had enough curation of the process automated, it is good for some things and not for others. For sensitive topics, you really want the patient and the clinician involved a little bit more.

Other pitfalls, overreliance on only the doctor prescribing tends to be a problem as well. We did a small study, one of my favorites because it was in my practice, my little pod in primary care. We did a comparison of what the doctors did, what did the doctors prescribe?

PSA testing, for the most part. And colorectal cancer screening options. What did the patient look for? What did they want when they looked at the same menu? Anxiety, depression, back pain - so the right answer is not "always go with what the patients want." but if we are reliant on just what the doctors want, we are missing chronic pain and symptoms. In many cases, doctors did not know the patient was concerned about anxiety or depression treatment.

Putting decision aids out there as a tool to find interest in something, that turned out to be a really good idea and we had been missing that for a long time. I am going to think of some others but since Karen is here, I would love to see if she has perspective on some things that were particularly challenging as we have moved through.

KAREN SEPUCHA:

I think you have hit the big ones. In terms of infrastructure, we had two big challenges. One was changing decision aid vendors. People got comfortable and had their favorites, and then we changed and basically had to start from zero. That was a challenge. We also changed electronic medical records.

So then again, you start over from scratch because people knew what to do and then they had no idea where to go or how to get things. There are also big infrastructure things where you wipe out the institutional memory.

So those were big, disruptive challenges that we faced.

LEIGH SIMMONS:

You are absolutely right, there was a lot of grief, actually. We had extremely high quality, beautifully produced decision aids that our own doctors had participated in as content experts. To not have that anymore, we needed to do a lot of work to make sure people understood that the core of the program was still here.

It was very important. We wanted people to understand that shared decision-making, the program, and the process would not be based on just one product, no matter how beautiful the decision aids were. Yeah.

SPEAKER:

Hi, my name is Janice and I am a patient partner identified, and I have tried to come to this conference six times. I appreciate you being here. One of the things you mentioned in your slides and you mentioned is tailoring to decision-making. I do not say that very often.

I am involved in health quality research and I think that is super important and everyone should take note. I am curious how often patients are involved in this effort. I want to mention that I was asked recently, many, many patients were asked to participate in Oxford Cambridge Press.

They are coming out with, you may know about it, a new book on shared decision-making. Every chapter will have patient commentary in it. I guess to share on preventative screening, right? You really brought up some good points today. My idea was similar, I brought up subjects that are not normally thought of.

Anyway, I am curious because I think it may be a catalyst to having more patients involved in Patient Decision Aids. I do not think it happens very often. And similar, you know, situation of change. So...

LEIGH SIMMONS:

Janice, thank you for that question. That has been an ongoing part of our work to have patients involved in increasingly larger parts. In many ways, this has been advanced by our PCORI funding, because of having patients involved as research partners. We have an advisory committee of patients who have been involved in our work for specific projects.

Fortunately, they are generalist enough that they can get advice on smaller efforts that go beyond the initial study they were hired for. I am pleased to share with you that this is a big part of the work involved with patient partners, that is huge.

SPEAKER:

Hi, I am right here. So, I was just wondering if you could elaborate a bit more on the Health Equity piece of the design of future decision-making tools. You were saying you send DVDs out or patients need to go online, I think one study showed that 50% of participants had a college degree. I am making assumptions; those are people who have high English skills. And I am also curious about going off of Janice's question about tailoring.

Culturally appropriate and how you are kind of navigating that through your shared decision-making tools?

LEIGH SIMMONS:

Excellent point, thank you. We are glad to share that most of our decision aids, Healthwise decision aids have distribution through EHR. The majority of them, we have always had a significant percent of decision aids available in Spanish. With growing interest in having more languages available.

They do require, in their current form, that you are either accessing these through advanced use of the portal or you are working with a doctor who knows about the decision aid and will be printed out for you in your language. That you are able to read that well or have a family member read that well. I am highlighting some of the challenges.

I do think, though, I am proud to say that much of our work has now moved to words using shorter decision aids with more coaching throughout the process. Highlighting and use of patient support. Those students are able to reach people and help them get ready for a visit that may have challenges, like patients who do not speak English primarily.

People who may benefit greatly from extra support in advance of their visit. So I would say as we have moved away from just being focused on the decision aid and processes, I think that has improved. We are working with the hospital system that has put out effort making sure we are not seeing this digital divide among patients. That some are using my chart and some are not using it effectively.

We are not doing that alone, there's a lot of research. People are signing up and staff is ready to access interpreter support to have pages translated into Spanish or Portuguese or whatever is needed

There is increasing institutional effort to make sure those are not barriers to delivering high quality conversations.

KAREN SEPUCHA:

The two things, I don't know if we have time that you had a great story of how you might actually use the decision aids with patient with prediabetes, and then another, and is that it is pretty clear when you look at the order rates.

You can see how many people access our online decision aids, there are huge disparities. Maybe 20% of English will access the tool and 4% of Spanish. So we know this is actually a problem. Something we are working to do. I think we are mentioning and we realize we need different ways to find and engage whether that is coaching and connecting in other ways.

SPEAKER:

The story that Karen is referencing is the use of one of our video decision is available in Spanish, and diabetes decision aid. I saw patient I have cared for a long time who speaks English and Spanish but prefers to communicate about health information in Spanish.

I have been screening him for diabetes and his A1c came back across the diabetes threshold. I said, "I will send you a video I would like you to look at before we see each other again, I want to see you pretty soon and I want your thoughts."

No emergency, I wanted him to think it over. He came to his next video and watched a video and the booklet. He does not ask me a lot of questions generally. He started the visit and said should I start metformin Will I get a prescription from you for metformin today? And I said yes if you want that then we will start that."

Letting people absorb that on their own, he talked about it with his daughter who is a nursing student and they watched it together. Using those aids to help people take what happens in the visit home and discuss it with others, that can be a very helpful tool. Questions? Yes?

SPEAKER:

My name is Tonya, and I am a nurse in Washington. My question is about training. How prevalent is it for medical students or residents to receive training on shared decision-making? Can you comment?

SPEAKER:

Sure. I am pleased to say it is something that is part of our, I will speak locally for right now, our affiliated medicals school which is Harvard medical school. As a component of what we teach them in their first year course. It is something that I see and I look forward to - how are they trained as they move on after those foundational communications courses? That is something that we try to encourage when they are on their clinical work.

I think things fizzle out after that, as we know as lots of things do in medical practice. We had a part in shared decision-making and use of decision aids. Our feeling on that has always been that the first year residents are really good at it. And then as professional identity formation is in that fragile state, of you've taken care of a lot of patients and trying to figure out how you are going to make recommendations as a doctor - it's a lot harder to teach more senior physicians.

Once they are back in primary practice, they are all about it. We are there to ride with them and these waves of decision-making. I would say it's not as deeply embedded as we would like.

DAWN STACEY:

It's Dawn Stacey from Ottawa. I'm really interested in the measurement of Shared Decision Making because often we think decision aids... Can you talk about what you used to measure it?

LEIGH SIMMONS:

Also not as widespread as it perhaps could be or as we would like in the course of studies, we are doing patient surveys on the decision quality, what happened in the visits. As you saw in our PRIMED study, what happened in that conversation? What was your knowledge about it? What was your level of involvement in the decision?

Let me just see if Karen wants to add any other thoughts about what we have done at Mass General in terms of decision quality measurement.

KAREN SEPUCHA:

I think the one area where it's developers in orthopedics. We have portions for sure decision-making process questions and then six decision quality questions that are integrated into the patient report and outcomes registry. All patients getting spine surgery for lumbar, spine, and up answering those questions.

We do have some routine data that we are still trying to figure out what to do with that. And it's being collected post operatively because the preoperative varies so widely because often they happen before visits. The timing is imperfect but we are getting a glimpse of what the variability is across Mass General and trying to use that to identify some of the bright spots in who is doing really well and how did they end up having this conversation with their patients?

KAREN SEPUCHA:

The four questions. First, did they talk about options? The surgical decisions, did they talk about nonsurgical options as something to consider? Did they talk about the reasons to have surgery? The reasons not to have surgery? And did they ask you what you wanted to do to treat your hip pain or knee pain?

We don't have our website up here but all of the surveys are available on our website, so we can give you that website for folks who might be interested in looking at the survey questions. And they used to be endorsed, now they are PQM endorsed for performance measurement.

DAWN STACEY:

Can I complement you on having something really brief. Did you use Shared Decision Making? Patients always say yes, even when it doesn't happen. It also shows differences in your groups and measurements. I think that's all good.

SPEAKER:

One more?

SPEAKER:

I spent the majority of my career at Kaiser Permanente. I was just reflecting on experiences where certain cultures vacations will come anyone you do your Shared Decision Making - it's just those cultural sensitivities, or patients who come in with alternative or complementary medicine that they are already on.

Certain cultures, how does your program pull and competency training related to Shared Decision Making?

LEIGH SIMMONS:

This question comes up a lot and I am really glad you asked it. It comes up a lot in training. What if patients want me to make a recommendation? Does this take away my ability to make a recommendation? We emphasize, no it doesn't. You just make a recommendation once you have everything you need to know from the patient.

We train using an example like that. You can say, "I can definitely tell you what I say is best. Can you tell me a little bit more about how you are thinking about this option and how you feel about that?"

Complementary and alternative therapies, it's discussing way where if there is evidence to support that, if that is discussed - if there's no evidence to support it, then that's fine. that absence of evidence can still be discussed. What are the downsides? Is it costly? Is it



having side effects? Do they wish to continue in combination with something else that your practice can offer? Or do they want to substitute or integrate it into one of the many options, or combination of options. Is that a way to go?

Thank you.

DR HEATHER SCHULTZ:

Thank you, Dr. Simmons. We are going to take a short break. Our next speaker will start at 10:30.

(Break)

SPEAKER: (Presentation slide 111)

Welcome back everyone. My name is Laura Pennington. You probably received a lot of emails from me in the last week.

Before our next speaker, I wanted to share a personal story about the importance of using Shared Decision Making and the power of patient decision aids.

My mother-in-law, Sue, she was a 65-year-old female - this was several years ago in 2010. Four years before I knew what Shared Decision Making was. Sue was very sick and she was in heart failure. She had a pacemaker and the doctor at the hospital was not her regular cardiologist, so he didn't really know her but he gave her the option of the left ventricle assist device to keep her heart pumping.

This was still in the early days, so we didn't know much about it. We knew that Dick Cheney had one and that was about it. So my husband was over there and I was not. He was trying to ask the doctor questions.

"What does this mean? What is she going to be able to do? What are the risks versus the benefits?" The doctor really didn't answer his questions. I called to check in and he was really frustrated.

He stated, "I don't know what to do." So I asked him, "can your mom understand?" He said, "yes but I need to get my questions answered first." I asked what questions he was asking. "What are the risks versus the benefits?" All of the information that you would see in a high quality decision aids was the information he was trying to understand through his questions.

Unfortunately, the doctor who did not know my mother-in-law could not answer his questions to his satisfaction. This was before I knew anything about Shared Decision Making. So I said, "maybe you're asking the wrong question?" "What question should I

ask?" I said you need to ask if she will be able to go back to her normal life and to the things that she loves. "What does your mom love to do more than anything in the world?"

That is gardening. She was so proud of the garden at her house. I said that this was the question that you need to ask. He finally nailed the doctor down and said he had to get to the question now. We won't be able to agree or disagree to the procedure before we know if she will be able to maintain her same level of activity.

He said probably not. Will she be able to garden? Most likely not. There will be a lot of medications and doctor visits. He called me back and I said, "tell your mother that and ask her what she wants to do." So he did.

"Do you want to have this procedure?" She shook her head no. If she could not do what she loved to do, she did not want to. She was able to say a final goodbye to her family and then she left this world the same way, she came in, on her own terms.

I didn't know that was Shared Decision Making and that it is really about understanding what is important to the patient. I appreciate all of the patient advocates that are here today because at the end of the day, this is what it is all about. We are talking about how critical it is that we truly understand what is important to that patient. And the nurse told him afterwards that he was very lucky that she was able to make that decision for herself.

She shared that just the day before, she had witnessed two brothers fighting out in the hallway because one wanted to keep mom on life support and one didn't. You've heard some stories this morning and you continue to hear these stories throughout the day.

I have the honor of introducing our next presenter. Someone, who when I think about Shared Decision Making and patient decision aids, this person comes to my mind. It had the pleasure of working with Dawn Stacey since the beginning in 2015. And Dawn Stacey is the Vice-Dean of Research and the faculty of Health Sciences at the University of Ottawa. She's a Senior Scientist and co-scientific director of the Research Group at the Ottawa Hospital Research Institute.

In addition, she leads the Cochrane Review of patient decision aids and cochairs the Steering Committee for the International Patient Decision Aid Standards Collaboration. She is an expert on all things shared decision making and patient decision aids and we are so grateful we have to the opportunity to work with her. Dawn?

**DAWN STACEY RN, PhD, FRSC, FAAN, FCAN, FCAHS: How patient decision aids support good shared decision making** (Presentation slide 112-185)

Thank you, Laura for that introduction. But also, I am very excited and happy to be here today to be part of this really, I think of it more as a think tank. Allowing me to have the

headspace to sit and think about this shared decision-making, Patient Decision Aids, and in particular, the biggest challenges around implementation.

The title I was given was how Patient Decision Aids support good shared decision-making. I'm not sure I talked about good very well through my presentation, you can also prompt me on that.

In terms of disclosures, I share knowledge about patient translations and the only thing I have to disclose is being invited to presentations. Thank you to the Washington Health Care Authority for funding my travel to this visit. In terms of my outline, I will share my experience with patient decision aids and then talk about decision aid standards and evidence on patient standards.

What are the proposed changes coming to IPDAS and information standards? I only have two slides or something around implementation. I quickly looked to make sure we were not seeing different names, but it's a process by which decisions are made by the patient, maybe family as well. So the three steps I come back to talking about is first of all we need to be clear a decision is being made. Most of the time patients don't know there is a decision being made. We need to be clear about what are the decisions and the options. I like the word exchange because often we talk about what we tell patients are the options but we should also ask them what are your understanding of the options? What options are they putting on the table? We may not know some of them and then the other is around the preferences and values, roles, and concerns.

There's a lot of ways we talk about that piece of it. And this is really the crux of patient centered care.

Clinicians are poor judges of patient values and preferences and patients often receive poor quality decisions or achieve poor quality decisions. We know there are effective interventions like patient decision aids or decision coaching not routinely used in practice. In terms of myths of shared decision-making, this is a paper from (unknown name). One of the first on the list is shared decision-making is not compatible with clinical practice guidelines. One of my frustrations with guidelines as they say that you must do this. We see a shift in clinical practice guidelines, more of them recommending shared decision-making in the review on decision-making is now cited 110 times in clinical practice guidelines. We see these guidelines are talking more about shared decision-making. We are already doing it; we talk about it everywhere. It's already happening, shared decision-making takes too much time, I'll come back to that one. And sure decision-making is easy, just give them the decision aid. In some cases there is no aid available. So I also want to put on the table the

barriers identified from the patient perspective of why sharing decision-making is important.

Having knowledge of the disease conditions, options, outcomes, and knowledge of personal values and preferences. At the same time, patients feel a struggle with that power imbalance... In order for them to influence decision-making in the encounter, it really depends on them being given permission to participate, feeling confident in their knowledge, and having self... Feeling self-efficacious in using their shared decision-making skills.

They have also talked about the only way they see overcoming these barriers in the same paper is that they wanted nurses to explain the information, provide support by listening to patient preferences, and tell the doctors what the patient preferences are. I do not necessarily agree with this product -- approach, but this is what decision coaching often does, it takes on this type of role.

We have done a fair amount of work in Ottawa around decision coaching and we have the Ottawa personal decision guide that is often used as a generic decision aid for all decisions. Because there is not a decision aid on everything that is available in multiple languages. Our most common is a version for one person, but we also have a version for two. Especially when it is children and parents.

What is a patient decision aid? It provides information on the facts, the condition options, edifice, harms, some decision aids communicate probabilities, but it does not have to be defined as a decision aid. It helps patient clarify their values by asking them which matter most or sometimes describe things in enough detail to allow patients to think about what is most important.

Some decision aids talk about patient experiences, and again, that is optional. Also, support them in the process of thinking about the decision. This really fits with those three elements of shared decision-making, that really facilitates or supports shared decision-making because it makes clear what the decision is.

It provides information, it is an exchange, because it is not a one-way delivery. It also helps clarify the values preferences.

They come in print and other formats to be used in either part of the consultation, or within the consultation. There is not one way of doing decision aid, if it meets these -- decision aid, if it meets this definition, it follows through as a decision aid. The first systematic review conducted or led by Annette O'Connor, was published in the British Medical Journal (BMJ) in 1999. At that time, it was already showing improved knowledge, less decision

conflict, stimulated patients to be more active. Did not increase anxiety. And it had a variable effect on the decision.

So, in 2003, we were starting to worry about, you know, anyone could create a decision aid. And actually negatively influence decisions. Or control decisions.

So we, at that point, knew decision aids could affect uptake of options, reduce some options, increase others. And we could be providing biased information with decision aids and we really were pushing at that point to establish international standards and that is when it led to the international patient decision aids standards collaboration.

So, we establish this in 2003. To enhance the quality and effectiveness of patient decision aids by establishing a shared evidence informed framework for improving content, development, implementation, and evaluation. You can see here where there is many people in the Steering Committee that I co-lead with Bob Volk.

So, Michel Barry is also on the committee and Karen (Sepucha) is here. And we have representation from other companies as well. Since the International Patient Decision Aid Standards (IPDAS) Collaboration was originally established in 2003, we created the IPDAS checklist, which includes defines criteria for high quality decision aids. You can see the checklist had 74 items in 11 dimensions. And this was done by over 100 contributors in 14 countries. Because of the long list, and people were like what do we do with this list, in 2013 we put this into what you need to be defined as a decision aid, what you need to minimize risk bias decision, and what are the other criteria.

Now we are just going forward with a new vote to look at some revisions to the last set of 2013. We also concurrently have done evidence updates to inform the - in 2013, the most recent update of evidence was published in 2021.

So, what are the defining criteria? I mean, Washington state knows them very well. But it needs to describe the condition of the problem, it needs to state the decision, it needs to identify the target audience. Which isn't actually in the defining criteria, but part of the proposed coming.

I know Washington state listened when we were here to help them establish a certification program for patient decision aids and incorporated a subset of the IPDAS certification criteria. They made sure that this was at the top of the list. The target audience was always there, but it was only under these probabilities. The reality is that it is important to be there as part of qualifying criteria.

It describes the options, talks about the positive features, the negative features, and helps clarify values. Either by describing what it is like to experience them, the consequences, or explicitly asking people to talk about what is most important for value clarification exercise.

Those are criteria that in 2013 were called certifying criteria. To minimize the risk of a biased decision was equal detail on positive, negative features. Providing citations to the evidence to know where the information came from. Having a production date or a publication date, so, and we did a study in Ottawa of over 500 patient admin materials at the Ottawa Hospital and I think 60 to 70% had no date on them.

Like, this was done in 2005. Maybe we have changed a bit over the time, but it is really easy to forget the date. Even though it looks like that is an obvious thing, it can be missed. Having some kind of update policy so that there is some responsibility for not just putting it out there and saying this is it for good, but saying, OK, we will check the evidence every so often.

Whatever the often is based on the content, which may change frequently, or may not change very much. So, frequent change right now is on the -- COVID-19 vaccine, the evidence is emerging continuous. When were we have not seen a lot of fast-changing evidence is in birth control options. Sarah is here in the audience (Laughs). Who knows it better than me. There has been a fair amount of stability in the options over many years.

... Probabilities are used. These are just estimates. And then findings used for the development. As our conflict of interest or a negative influence around who funded the decision aid. We also have some civic for screening aids such as screens attest that is designed to measure, it has the Next Steps after a positive test, or a negative test.

And then the consequences of detection -- testing a benign condition. There is a few extra criteria specific to screening decision aids. The rest of the criteria recalled quality, which makes it confusing, because all of it is about quality. But we have them grouped in different categories. There is a whole set of criteria around presenting balanced information. So, an example here showing positive negative features with equal detail.

There is a whole bunch of criteria around guidance and decision coaching. So, one example of guidance is that it provides a step-by-step way to make a decision. Another set of criteria is around the scientific evidence. So, in that one, it talks about the signed -- quality of the scientific evidence. How good is the evidence? Are you using it on Wednesday that was done in a small hospital here in Washington state, or did you look at a systematic review that combines evidence or clinical practice guidelines often if they are done well. Is another source of a nice piece of evidence.

Talks about conflict of interest. So, because of the authors, credentials or qualifications are all included, there are several criteria around conflict of interest. Health literacy, it is written at a level that can be understood by at least half of the heart -- target patients. Councils on Developmental Disabilities. Present probabilities using event rates in a defined group or a specific time period. So, I think there is 11 or 12 criteria under probabilities.

And then the development. The development asks patients what they needed to prepare them to discuss a specific decision. And then Karen is in the audience who has been leading the effectiveness one. Which is, there is evidence that helps patients know about the available options. That the decision helps patients know about the options. As one of the examples of the effectiveness criteria. So, Washington state, congratulations. Since 2016, it has been the only formal certification process in the world.

For patient decision aids. They have based the process, yes, based on IPDAS criteria. Norway does use the criteria before they go on the national platform.

The Netherlands talks about using them as well. In different ways. But the only one that is formally discussed and available is here in Washington state.

This is there criteria, and if you read them, they read as the same -- the same as the ones I just that. They identify the eligible or target audience of the decision aid. It is right are the top of that list.

We also use them in the A to Z inventory of patient aids, where if you click here on this list, you can actually see at the bottom where we rate the decision aids against the IPDAS criteria and those three groupings. We talk about the define as a decision aid, and if it does not meet those seven, they do not even come into the inventory. The risk of a biased decision and then the rest after that.

So, I was asked also to talk about IPDAS, and also to update on what has happened with the (indiscernible) review and patient decision aids... Including Maureen Smith... She is there this morning. We had another advisor meeting on this project.

The Cochrane review is a focus on adults making decisions about screening or treatment options for themselves, child, or incapacitated other. It needs to be patient decision aid about screening or treatment.

It needs to compare it to other care or an alternative intervention, but not another decision aid. This is general information, clinical practice guidelines, consumer summary, for example. Or a placebo or no intervention.

And then we have a broad range of outcomes that are eligible. Which you will see later. And then it has to be evaluated in a randomized controlled trial, or a cluster randomized controlled trial. So, there's lots of other studies out there, but these are the studies.

And then the language has to be able to be translated to be included. So, you can see here, in March 2022, we just updated the search. We now have added another 104 randomized controlled trials. We doubled the number that were published in 2017. So, there is 209 randomized controlled trials included.

What is interesting is that there is 102 that are identify it is ongoing randomized controlled trials. There is tons of research going on and being published around patient decision aids.

In terms of countries included, there is 19 countries. The United States has 106 of the 209 randomized trials. So, half of the trials. And then this update included nine in new countries.

Which are indicated with an Asterix. So, the topics in these trials are around medications, so, there is a 22 that are around cardiovascular, like atrial PHEP. I do not know if (indiscernible) should be under medical, maybe it should be under surgical actually now that I look at my list. There is a screening for colorectal, 15 in prostate, 12 in breast.

Lots in cancer screening. In surgery, breast cancer surgeries, prostate cancer surgery or treatments, joiner placement, you can see nine trials can move we have had a lot of discussion around this morning... After cesarean trials. Vaccines. And then you can see a few other examples.

So, in a patient decision aid is actually considered a complex intervention because it is not like a pill where you take 81 mg of aspirin. And you know every trial a test of 81 mg of aspirin is testing the same intervention. A decision aid is considered a complex intervention because they are all sort of a little bit different. So, 100% have options, outcomes, and it was her Expo said values or clarification because really, they do not have that, and they are not a decision made, we would not include them. That is why that is at 100%. 92% provide more details about the clinical condition.

88% present probabilities, which I actually was surprised how high it was. But you can see, we also looked at the first 105 trials. Now, the second set of trials, you can see there is actually a shift to having fewer with probabilities.

This could be because the topic does not lend itself to presenting probabilities. So in COVID, decision aid around location of care for frail elderly, we do not have probabilities to include in that decision aid. It is optional. In terms of guidance and steps you can see now we see an increase in guidance. For explicit values clarification you see an increase in more



trials, decision aids and trials using explicit values clarification. Patient stories, we see a huge decrease and probably because the evidence is actually very strong and is quite controversial around the use of stories. Patients want them in decision aids but there is a lot of complexity and I won't talk about it today, around if you are going to do it you have to be careful to do it well and right. But IPDAS does have criteria if you want to use them there is guidance there. What do the results show? On the slide I will show the results and compare it to the last update. The last line tell the 75% better informed values-based choice match. That means the decisions being made hit with an informed patient and the best match between what is important to them in the chosen option.

The other thing I will talk about is, how good is the evidence? This time we have moderate confidence in the evidence using the GRADE rating, it gets us three stars out of four. Last time we only had one star on confidence. We know there is a much more significant improvement and this is the gold standard for what is a quality decision, this is what we are aiming for. 12% higher knowledge. You see we have high confidence already in 2017 that we can reach this outcome with a decision aid. 94% more accurate risk perceptions. You can see here... Again, high confidence in the outcome.

10% feel less uninformed. We have high confidence that this will happen. 8% feel less unclear about their values or 8% feel clearer about their values if you frame it positively. And 28% less clinician control decision-making. This is measured on three points, clinician controlled, patient controlled, shared. What we know is patient aid shifts from clinician controlled but it may be considered shared or patient control. There are problems with how it is measured. The patient sometimes think they are doing it by themselves even when it may have been shared or it may have been... They may say it is shared but really it was more patient controlled. But it probably is not too bad of a measure saying we are shifting to patients having a more active role in decision-making and again this time we have high confidence in these results that the last time we only had moderate confidence.

But we are seeing much stronger confidence with increased patient involvement in decision-making. They are more likely to discuss the topic with clinicians. This was measured in 11 studies and you see there was an improvement, we do not measure confidence in this outcome because these are some of the secondary outcomes we are tracking. But it was variable based on what measurement tool used and that's what my question was earlier, what were you using Karen? To measure this. So we know with option 12, which is an observer instrument for your video or audio record, you listen if it happened or not. We see a shift to more shared decision-making. If you use option five which is only five reduced option to only five elements it was not... Significant.

Collaborate is another instrument out there that only has a few items. It is not showing it is positive. This is from the European groups and again it did not show a difference. But your measure has not been used or reported, that we are able to include it here. And then this is a big one, time. Everybody's like it takes too much time and we will not do it. What we found is eight used the decision during the consult and it did increase the time. But when the decision aid was used in preparation for the consultation there was no difference, it did not increase the time. The amount of time it increased as one and a half minutes. Not... It was not huge. So every time I taught good implementation there like we cannot use decision aids because it takes too much time and so I think we have some good data here that is different if used in preparation or in the consult but really if they consult even is 10 minutes and you had a minute but I know it's 10% of the time but it is using the time differently as well. No difference on regret, one of the decisions we talked about with the patients who said no for surgery on hip replacement. He did not regret it at that time.

We consistently see no difference in regret across studies, 22 studies. And cost, I put this in here for Logan because he did the cost analysis on my trial which is second on the list. Three of the eight trials show cost savings but generally there is no difference in cost. There was cost of some of the early decision aids from the foundation for informed medical decision-making which chose to use complex computer programs. It was the cost of developing decision aids that was the costly part but anyways.

You can see a trials of 209, almost nobody measures cost. So I'm writing a chapter for the new book on shared decision-making on decision aids and I put this in to show what happened in 2017, 2024. All we are doing is showing much stronger results, more confidence in results for all the primary outcomes.

If we were a drug we would have this prescribed by everybody but I think some of the challenges are more with the implementation. Because we had 109 trials I was very excited because I do research and then we then look at a network of meta-analyses. The reason this is important is I told you decision aids are complex and have a lot of different characteristics so maybe it is about the characteristics that make it work or not work. So in the work we have done up until now we say, is the decision aid versus user care, versus what is better? And I told you the answers.

In the network meta-analysis we still have A and B there but we look at the different elements in look at indirect comparisons because we do not have a decision aid versus decision aid here. We have only decision aid versus usual care. So we looked at 209 studies and we were able to access 113 or 76% of patient decision aids because we needed to know exactly what was in the aid, not just what they reported in the paper. Then we also want to know, did this element in the decision aid have an effect on our primary outcomes?

You will see a few extra things here. One question was, was user involvement in development of decision aids an unimportant element? We looked at no users involved, patient involved only, healthcare team involved or patient and healthcare team and we looked at if it had an effect on outcomes.

The results on the right-hand side, compared to usual care with or without users was better, but compared to healthcare professionals only on the team it was higher for patients' knowledge if patients were involved. Patients or healthcare professionals involved.

Or no users. So no difference for other outcomes. And the next question is... What about involvement in testing of the decision aid done prior to the randomized trial? In the same sort of outcome. What we found was there is no different generally for the other outcomes.

It is about the development of the decision aid and not necessarily some preliminary testing that is done. Values clarification. Explicit or implicit. If you do explicit this is the long list of ways it can be done and so in the decision HS says, was it there or not? Any values clarification. What we found is explicit or implicit was better for all outcomes.

Implicit values clarification had a significant reduction of passive decision-making compared to explicit.

Part of, we only got these results over the Christmas holidays so I think part of why it is affecting passive decision-making is because I think trials that you sit in the consult are the ones that measured involvement in decision-making more than those that use it pre. So I think the bottom line on values clarification is implicit or explicit, both are good and do not worry about saying you have to have explicit values clarification.

Theoretical frameworks. So we have IPDAS, we think if you use that it should be good, right? But there are other frameworks like the Ottawa decision framework, the foundation for medical decision making framework Molly published. There is the edutainment theory from Texas and then the option grids. So what we found is compared to usual care a decision aid with four without a framework was better for all outcomes, decision aids are better. But compared to IPDAS alone, you would get more if other frameworks were used. I think it is because now a lot of people are reporting they use IPDAS but we don't know if they do or how much it guides development.

We also tested cognitive demand. I have all the results on the slide. Does side-by-side help? No difference. Step-by-step? No difference. The worksheet help? It reduced passive decision-making when there was not a worksheet compared to when there was. So sometimes maybe the worksheet is... Bennett does not get scuffed in the consult so we need to look at what that means. Ways to present probabilities.

Presenting probabilities is good to improve realistic expectations and improve knowledge. But our numbers better than pictures? Pictures better than numbers? I was looking at yours here... It was smiley faces versus dots, circles is better than a stick figure. And stick figures or smiley faces are better than just a dot or circle for some outcomes. I was looking at which once the Mayo Clinic had and they were in between a circle and a smiley face.

All of this is to say we need to do more investigation around what this means. If you are using probability you should pay attention to what works and what does not. Health literacy, the health literacy group one is a whole new pile of criteria around health literacy and from a theoretical perspective it makes sense but when we were testing having a literacy expert on the team, does it make a difference? We did not find one, but I think almost nobody uses them.

So if we look closer at the data we probably do not have enough on this. Readability level. Again, we looked at if it was reported or not because that's all we save with IPDAS and there was no difference. Use of media, picture, audio, these are mixed. So it's not bad to use more mixed media but you may not want to overdo it. And enhance communication. So a list of questions, encouraging discussion with the decision aid. Personal summaries had mixed results. A lot of times I did research and personal summaries we had the patients and their summary to the surgeon and we think the surgeon never used it which is part of the problem with implementing a decision aid. If you do not stimulate the surgeon side, we may not change what happens in the consultation, we probably do not.

Even though my trial tested it with that, it probably did not affect... Picking a difference in outcomes, I do not know. Timing of the decision aid. In preparation for the consult, so before or during the consult. When it is used before the consult it was better for increasing knowledge, reducing feeling uninformed and no difference on other outcomes.

There is a lot of chat, there are some people who only develop them in the consult and I am more pre-consult but I do both a little bit. The bottom line is I think you need to look at the decision and situation and what is better for that decision, not say but oh Dawn said it was better before the consult. It depends on what it is. For example, joint replacement, there is a lot of information and it's hard to process that in a consultation so I think you need to look at it in a decision.

Paramedics are proposed changes, we are looking at changing the titles of the three broad categories, so one is qualifying. Does it qualify to be a decision aid?

The second is instead of calling them certifying we are calling them essential criteria to minimize risk of biased decisions. And then we are calling all the rest of the criteria

enhancing criteria. They are likely to enhance the decision aid but do not fit into the other two categories and are all part of our quality framework because they always were.

So in terms of changes we are looking at voting that is hopefully coming in February. 31 new or changed items that need to be voted upon. One new for qualifying. One change to a qualifying criteria and then the others. So this is an example of qualifying criteria, we will have no change in the first one, the changes the decision aid lists... We have two items. Decision aid with healthcare items and under enhancing criteria was lists the option of doing nothing. The vote will say the decision aid list the options including watch and wait if relevant. And we are merging those into one. But we do not know if that will change, like the accepted as part of voting. And then newly proposed is that it identifies the target audience. So we moved out from enhancing to being part of being qualifying criteria which I mentioned and you already here in Washington.

When the item is proposed as a change, it will propose a vote, and there is a rationale if you want to understand why the item is being changed. In terms of voting, the voting document has been reviewed by the domain leads. On Monday, we are sending it to the Steering Committee. And the vote will happen in February. We will be rounding up people that know what patient decision aids are across the world to vote on these changes.

So, the last couple of slides I have, that pertain to implementation. When we did the 2017 review of patient decision aids and we had 105 trials in that review, we went back and talked to the decision aid developers to find out what happened after the trial. Did they ever do something with their decision aid? We know that almost all trials are positive and good. But what happened to the decision aid? We had a 92.5% response rate from the trial authors.

And only 27% of the patient decision aids were ever implemented after the trial. When we wanted to know was, like, what happened? We did a very simple email communication.

So, the barriers were that there was a lack of a posttrial plan. Most researchers say, "this is my decision aid to be evaluated." And they do not take about what they would do after. By the time the trial was done, the decision aid was outdated, so we have no money for an update. That was it, that is -- trial is done, the decision aid is done. Some reported that the clinicians disagreed with using it and there is more description around us.

And then the infrastructure support or funding did not support the use of the decision aid. Like, we had a research coordinator in the clinic that gave out the decision aid committed the randomization, removed that person, no one was there to give out the decision aid anymore. So, this is why hearing from Lee this morning, it was aborted so how the decision aids were being operationalized without having a physical research assistant there to give it

out. What they said for facilitators for web-based delivery because they are easier to update.

Endorsed by government organizations, so all of the ones certified here, that is a good example of a way to increase use of decision aids.

And then they need to be designed for the care process. We also talked a lot about that. Where do they fit in the care process? Who is responsible? What is the best timing? They had to re-change the timing in the joint replacement to say, "OK, this is when it fits. We are getting too late in the process."

So, IPDAS and the evidence update part of 2021, one the papers in the special collection published in medical decision-making was... I'm trying to think of the type of analysis. It was a rapid realist review. Realist review looks more around how do things work as opposed to does it work.

In their recommendations, they said, "we need to coproduce decision and processes or locally adapt, like, take a decision aid from somewhere else and adapt it. But work with the team when we are doing it. Coproduction, work with the patient, and with the Healthcare Professionals and figure out how to make it happen."

They said, "we need to train the entire team, including the admin people asked the front, if they are going to be involved in it. We should not just train the physicians; we should train the nurses. Wrote -- we are part of that team. We need to prepare and prompt patients to engage. Not just expect that -- sent them the decision aid, one of the nurses in -- and one of my patients that I got this big bag of resources from the nurse. And he dumped it out on the table. And in that big bag was a decision aid. But he did not know, he did not know it was there, he did not know how to use that, he found this big bag of information overwhelming, he did nothing with it."

That is a good example of, we need to prepare and prompt them and say, "this is a good resource to review." We need senior level buy-in, and that came up in Ginny's and Leigh's presentations and we need to have the support of leaders in organizations. In way to measure to improve. Which comes back to where I was asking how did you measure did it happen.

So, I am coming back to our website where you can get the cochlear (?) review. We did not pay the \$7000 to have open access when it comes out in the next week or so of this update.

But I do have permission to put a copy on our website. I did ask Cochran if they could make it open access without me paying. But we will see what happens. The other thing about our

website is, I actually have, I think, \$15,000 to spend by the end of March trying to improve the website to make it more patient friendly.

And more Healthcare Professionals friendly. I think when you come to our home page, we will have a patient portal healthcare professional portal, researcher portal, and the researcher portal, the researchers that do not change anything because we like what you have. Do not touch it. But we will have a patient Porter unhelpfully, have a way to think -- make things more user-friendly for patients. It was never set up for patients in the beginning, it has always been a research portal.

But we have the international aid as inventory... You can see it up on the top of the list.

The Ottawa personal decision guide is there as well. I think that is my last slide. I will stop for questions.

SPEAKER:

Questions, anyone?

SPEAKER:

Thanks, Dawn. I am always a little starstruck when you're around. For those of us who work in the space, you are a really important person. Just a quick question.

One challenge I have had selling these in grants and things is there classify activities. Do we need an individual RCT for each new decision aid. I am curious how you answer that when that comes up. It is clear you talk about it as a class effect with the Cochrane review. But I am sure you get this criticism sometimes. So, I am curious how you navigate that.

DAWN STACEY:

classified with drugs means... We will just prescribe the drug. In 2017, I went through this, the king I will never do this update again (Laughs). This is a lot of work. -- Thinking. Now I am thinking about you need to be writing a paper on this.

So, that is like a different, like your question of whether you want to make it public. If we do that, vendors will not find any more RCTs of decision aids if they say we do not need to do anymore trials, right?

But when I work with clinical teams, developing decision aids, on our templates, because we know the Ottawa templates, we have done an analysis, 25 trials shows the Ottawa approach has the same outcomes as the Cochrane review.

So, if you use the Ottawa approach and we have an online training to do this, then I say, we do not need another trial of this decision aid. You do need to still do some evaluation to find

out, get patient feedback, does it help, doesn't work. And to do some minimal evaluation, but it might just be a proposed test, not another trial. -- Reposed. If you are moving into some of these more other areas, it might really call for a trial.

Because some situations are so complex that you cannot just say, "oh, it works for everything." If I was to move into an area where I think it is just so novel and new and it does not necessarily fit with the old model, then I might look at doing a trial.

SPEAKER:

Hi Dawn. Thanks again for sharing all of this fantastic data. I have a question about the tailoring or need to do that local adaptation. I think it is a wonderful idea. But thinking to lean I, we have hundred and 10 different decision aids, if every practice wanted to adapt... (Laughs) Is there evidence that you actually need... Practically, I think that provides actually more problems.

DAWN STACEY:

... You cannot change the intervention to change how well it works. I talk about tailoring, it is like, do we need to put our local on it. Can we put our local on it or stamp on his connect to any to look at the resources at the end to find more information to add the local resources.

But you should not be changing sort of the core content of the decision aid that has already been tested, already, like, unless you thought that there was data missing. I would go back to the people that produced the decision aid and say, "why didn't you include this trail? It is a newer trial. Is your decision aid out of date?"

I go back to authors of I think or content of the decision aid should change.

SPEAKER:

I have a question. So, I noticed that you mentioned under treatment options, the option to do nothing. So, when we first started our certification program, we felt very strongly about adding that option to do nothing was imported. But we were invited back to the National quality forum for a discussion when they were talking about setting up your own certification product -- program.

The differences in opinion in that room are very stark. So, I would be really curious to know how the IPDAS community feels about including that as a criteria.

DAWN STACEY:



yes. So, in the 2013 criteria... The do-nothing was an optional, like, in the down and the quality criteria. In the new voting, we are removing the do-nothing into be part of the quality criteria that says including do-nothing if relevant.

Because there is actually a higher push that we need to talk the option to do nothing. The other thing about do-nothing is that there is a lot of pushback on saying to patients we will do nothing. Tammy Hoffman just published a paper in 2023 where they talked about how to use this term -- 2023. You will see in the IPDAS voting, we are changing to wait and see as opposed to do nothing.

In the wording of, like, when we did the original IPDAS, we said do nothing not thinking people would say do nothing in their decision aids.

But anyways, wait and see is a better terminology. I have also heard of supportive care as another alternative to doing nothing. But we are - that paper is available. And that is the only softening, we are softening the nothing part.

SPEAKER:

Thank you, I appreciate that.

SPEAKER:

Hi Dawn. (unknown name), great presentation. I'm wondering about the impact of decision aids on surgical procedures. It seemed like a prior review, I hope I did not miss it in your presentation, but it seems like in a prior review, people were less likely to choose for elective surgery, they were less likely to choose basic options after presented with the decision aid.

Any information about that at this point?

SPEAKER:

I did not present the data; it is a secondary outcome. The goal is not to reduce outcomes in the... It decreases if rates are high. With the actual data I know off the top of my head, in the UK, when people have an enlarged prostate, the surgery rates were super, super low.

For the use of decision rate -- decision aids it actually reduce decision... It increased it. And then in breast cancer, we actually see decreasing of invasive surgeries in light of more conservative surgeries, or maybe not reconstructive surgery, there is some differences when patients sort of start to understand what the options mean. And what does the outcome look like. Because they all think a new breast might look perfect.

And then they realize what it really looks like. There is data. The Cochrane review, we have all that data, but as a secondary outcome. And I decided not to present it because I think too many people focus on that, and I wanted to focus on what is sort of the key outcomes of decision aids.

QUESTION FROM FLOOR:

Hello. My name is Mandy Lee, I work at the Tacoma County health Department addressing racial equity and health disparities. This is the first time I have in at an event like this so I'm just checking in so much information. You may not be the right person to ask this question, but one of the things I have been wondering about all morning is how do PDAs help address the internal biases patients have when they come into these decision-making spaces with their doctors? For example, historical consequences of relationships between black communities and healthcare providers has created a distancing for even looking for support from healthcare providers.

Do PDAs help address internal biases patients may have?

DAWN STACEY:

So the patient decision aid just provides the facts and help them think about the decision and their situation. What you're talking about is what happens when the discussion happens in the consultation where other things can influence how things are exchanged. We presented a study that looked at joint replacement in Black people or Black males. Where they actually increased surgery rates in Black people... Maybe it was in colons. But their decision can readjust, they see options that are different.

In the usual care group they did not offer joint replacement surgery to women as much as they offered it to men, and when it was used and the new that they had the option of joint replacement we actually changed those rates between men and women. The same thing happens with Black... People, for joint replacement. In a few of them. Marianne did a synthesis around 2014 around the topic on equity and we referenced the (unknown name) paper from 2021 with IPDAS where they talk about how decision aids can help with the disadvantaged populations. But it does not change the consult because it only influences the consult by preparing patients with understanding their options.

SPEAKER:

Thank you, that helps a lot.

DAWN STACEY:

and Lee has a comment or question?

QUESTION FROM FLOOR:

So I been thinking about an unstudied aspect of this is there is a therapeutic intervention of having a conversation, a clinician showing I'm interested in you as a patient and will spend time talking with you can have a great therapeutic benefit on its own.

I think that is an interesting thing to think about as we think about our training. The other challenge, the best decision aid can be destroyed by a clinician who says, that option does not really apply to you, maybe it does or does not but that is a big part of training. To make sure we are not destroying the content with an uninformed recommendation on the part of the clinician. And that is been published on by Dominic and others about rectal screening.

The patient says, "I would like to do the stool test" and the doctor says, "I don't do that, I only do colonoscopies." The patient may not do anything at all and now it's really unfortunate. So, you're asking great questions about the proper deployment.

COMMENT FROM FLOOR:

I just wanted to make a comment, in the Cochrane reviews we do not include advanced care planning because that can... So when I asked (unknown name), we did not do things for behavioral lifestyle, we had to limit it. So, we continued with the focus on screening treatment decisions but values change over time with advanced care planning so it is a decision which needs to be revisited. So anyways, I wanted to give that description and why your papers are not in this review. (Laughs).

COMMENT FROM FLOOR:

I just wanted to make a comment. When we launch the voting in February, it is my goal to ask people who know anything about patient decision aids and want to participate or from around the world, we are looking for policymakers, patients, researchers, clinicians. We will have you contact Meg Carly who is a research coordinator and will give you a link to the survey, but we are open to everyone doing it. We are sending out wide announcements when the time comes. And we will let you know, Laura. To have participation from here!

SPEAKER:

I would love to forward it to this group here, thank you. Right, Heather?

SPEAKER:

We have lunch now that I believe is offered outside of these doors and we plan to meet back at 12:30 PM for our afternoon session.

Laura Pennington: (Presentation slide 187)

Alright, welcome back everyone. Hope you were able to make some good connections at lunch. Before we get started, you have to hear one of my stories. This is a personal story again, in the patient decision aid in decision-making. This one is about my grandmother back in 2007. My grandmother was 98 years old. She was ready to go. Her quality of life had diminished. But other than that, she was really healthy.

She was diagnosed with dementia a couple of months before. And then she had a stroke. In true stroke fashion, they took her to the nearest hospital, which happened to be a teaching hospital, in Denver.

On so, my aunt who was down there with her at the time, she was there, she called me about every 30 minutes and said," they want to put a feeding tube in her. What should I do?"

I said," she has a DNR. You know what her wishes are." She said," I feel guilty. People are coming into making her comfortable."

My grandmother knew what was going on, but she could not talk. After three days of this, people coming in and out, she did not know what to do. She asked a couple of the doctors, younger doctors what they would do. They were taught to heal, so they would definitely offer the feeding tube.

Then she asked an older doctor, and he said, "As a doctor, we want to do what is best, but as a doctor I want to heal. As a son, I would do what she would want you to do."

It took the pressure off my aunt, she went to hospice and passed away peacefully, two days later. That is another example of understanding what the patient's wishes are and honoring those, even when we have DNR's and we know what their wishes are, it is still hard for family members. That is my story.

And so, you do not have to listen to my stories anymore. I think it just helps me when I do this work that I am so passionate about, understand why we are doing it. We always talk to doctors. We always talk to patient decision aid developers. It is really the patient voices why we are doing this.

Again, I am excited to introduce the afternoon session. We have a panel of a very mixed panel of folks with different focus areas. They are going to come up, one at a time, tell you more about themselves, and give you a brief overview of the work that they are doing. And then Dawn will walk them through some questions. Once we get through that, we have plenty of time in the afternoon for questions from the audience.

I will turn it over to Dawn. And the order we will go in is, Dan, Dan Matlock from the University of Colorado, Randy Moseley from Confluence Health, recently retired, Sara Monroe, University Washington, Maureen Oscadal - sorry if I messed up your name,

Harborview Medical Center, and Karen Sepucha, rounding us out from Massachusetts General Hospital.

**How Patient Decision Aids Can support Shared Decision Making Panel Discussion, facilitated by Dawn Stacey, RN, PhD, FRSC, FAAN, FCAHC, FCAN, University of Ottawa**

First Panel Member

**Dan D. Matlock, MD, MPH: Implementation of Shared Decision Making in Cardiac Disease (Presentation slides 190-208)**

**DR DAN MATLOCK:**

Hi, thank you all. I am Dan Matlock, as she said I am a geriatrician at the University of Colorado and I lead the patient centered decision-making. I will talk about a couple implementation experiences in the cardiac space, defibrillators and Left Ventricle Assist Devices (LVADs). We have developed and done work on it for several years.

You heard Laura, it was great that you shared a LVAD example earlier. The stories like that are things that we are interested in as well.

Excuse me. I will start with just a little description. This is Cliff and Don, two guys in the (indiscernible) video. They signed releases that we could use their video. On paper, they are identical. Mid-sixties, white male, ischemic heart failure, and not a lot of other things going on, goat, little things. Otherwise, they look identical.

Cliff chose to get an LVAD. Done very well, been in commercials with the 14 quarterbacks we have had since Peyton Manning left. Don wrote a letter to the clinic asking to be told he did not need the LVAD. Had to tell the clinic to stop the rating him to get the LVAD. They shared their stories in the video.

If you do not know what it is, it is a heart pump. It is an open heart surgery, it pumps into the left ventricle, sucks the blood out and blows it down the aorta so you get more output. It is pretty amazing; it helps a weak heart get more blood flow. It comes with a whole host of risks. One in 10 people will get a stroke in the first year, two in 10 will get a chronic infection, and five in 10 will be hospitalized.

If it goes well, it goes really well, both quality and quantity of life improve. It is a huge dice roll. If it goes poorly, it goes really poorly, and people suffer. There is a huge trade-off to consider here. It is becoming more and more common, more common than transplants.

I am not sure if that is still true with the COVID pandemic, where transponders are starting to go up. That is another story.

We studied it with a PCORI around the country. Significant improvement in knowledge and significant improvement in (indiscernible).

Secondarily, reduction in (Unknown name) between the control group and the patient's absolute reduction of 25%. An important part of the story, as we transition into implementation. I will not spend a lot of time in the research because this is an implementation talk. I want to get to that.

We went to PCORI and said we have a trial, an effective intervention. PCORI is finding things to try and get the results out. We said let's implement this nationally. 175 (Unknown name) programs. So we did. We looked at adoption. This is her adoption, over time between 2018 and 2022. Adoption is a low bar...

When we had a few people that we were friends with at the beginning, that is the green bar at the top there on the far left. We did surveys and got contacts from that. After the surveys we did a lot of social marketing, trying to find people. We found all contacts at 175 sites. Only six sites that you want to try.

Some of the concerns we heard were that... We only heard that from a couple of people that that was their concern. Implementation, we surveyed the people over the four years of the trial. We surveyed them over four months and asked them how many they handed out, what proportion of your patients is that? We only asked six or seven questions. We got a good response rate from the surveys.

By the end we found out that lots of the sites are using it. Always using a standard of care, 23 said they are using it frequently. This is really in our impression, really successful in fermentation much better numbers than we ever expected.

I will talk about why I think that is, at the end. I think it has a lot to do with the context of the decision, and not us. Shifting gears, I have been working on ICDs since my research fellowship, in 2008. I think ICDs are the little device that is under your chest, delivers a shock, if you have arrhythmia.

This is what got me into the shared decision-making, and into research. They are beneficial. Main Medicare trial that shows the benefits of ICDs and convinces Medicare they should pay for it. Over five years, 7/100 will have their life saved by an ICD. That is what this trial showed. This is the same data as an icon array, which we have seen presented in a couple of other slides.

ICDs come with a host of harms. There are procedural risks, some data that people who get ICDs have more heart failure (indiscernible). You took somebody who would've died of

sudden death. They started to get admitted to the hospital. Some data on anxiety and depression and inappropriate shop and device malfunction.

Some really tough papers about suffering at the end of life if the ICD is not turned off. People are on hospice, dying of cancer, they forgot the ICD was there, and they are dying and they start to get shocked, while the family is standing around.

There are trade-offs and things for patients to go with the decision.

In 2018, Medicare came in and said they would mandate shared decision-making for ICDs, which was great. They actually referenced our decision aid in their coverage decision. We have had a ton of implementation for the ICD decision aid, as sites have come to our site, accessing the decision aid. Which has been great. It completely ruined my trial.

I was ahead of that and I was studying it. All of the sites were in the control group, because it was a design where they rolled over into the intervention group, over time. All of my control groups had to use a decision aid. Setting against usual care as Dawn said we should do, in her talk. It was not something I could do anymore. The pandemic hit in the middle and the last three sites, we have lamented where impacted as the cardiologists were getting pulled into ICU shifts, while the doctors were getting pulled into COVID shifts. We did not implement it very well either. It was hard, but we get a lot of barriers with the trial. I do not want that should the results. Still writing the paper. Dr (Unknown name) was on my team, very frustrating trial. All outcomes are negative. But they move in the right direction and some of the secondary outcomes are positive. Trying to write this paper to say, please do not believe that this does not work. It really was the context of this trial. It is frustrating.

Why are these different? This is what I really wanted to talk about. How am I doing on time? OK good.

I think implementation is what is really hard. And who will deliver the decision aid. In the (Unknown name) space, we did not have to have a research assistance. It was plug and play. The coordinators did not like the... They were happy to use our tool instead of their tool. They already have this education process where they are going to the ICU with the patient whose family is trying to learn it was so easy to implement, and contrast to ICD, Visio patient dock. Do not have a lot of time. Trying to get them to figure out if they should do it before, during, send it home afterward, was a mess.

Even though there is a mandate from Medicare that they have to with ICDs, it is still so much easier with the LVAD.

Some of the big differences is with the LV AD, the clinician saw a need for it. The heart failure clinicians see the benefits and they see the risks. They see patients before and after, and patients with LV AD who do well. One of the highest values of surgeons in the country told us that he wanted to do a lot of LVAD, but not do one on someone who does not know what they were getting into. We did not have to overcome the barrier of I do not need to do this.

It was a perfect context for shared decision-making. ICDs are back to what Dawn was saying about the guidelines. People with these criteria should have an ICD, class I guideline. The trial I showed from (indiscernible). We are fighting the barrier, why are we doing shared decision-making for this?

I think that continues to be a barrier. I talked about the inpatient outpatient.

These are some of the questions that we keep getting. Should all shared decisions be decision...? Why are we doing shared decision-making for the ICD? Why did Medicare do this to us? Is the goal to change decisions with the LVAD? They are using it less. It is scary for some. They do not want to change. Should Medicare be mandating this? It does create the perception that they are just trying to control costs. Which then creates the suspicion. We can debate the merits and pros and cons of that, but that is something I hear from a lot of folks.

That's just one example of implementation. I love the desert Southwest and we talk about what is the value of a decision aid? It's culture change in dripping water over time. You drip water overtime and in the Southwest, you get the Grand Canyon. And I think a lot of the work we do is more valuable in this way then it is for any individual decision. With that I will move on to the next speaker.

### **DR RANDY MOSELEY: CONFLUENCE HEALTH: Shared Decision Making Journey**

(Presentation slides 209-221)

There we are. Until come full of months ago but now I mostly retired. This is the confluence of the Wenatchee River. That is what Confluence Health is an important.

Confluence was formed in 2013 as a union between Wenatchee Medical Center and Central Washington Hospital. We have about a dozen clinics, over about 12,000 mi.<sup>2</sup> and we are pretty dispersed. The headquarters is in Wenatchee. We have 150 mid-level providers.

We are resource limited because 70% of our patients are Medicare and Medicaid and we live in a challenging environment. We are not an academic institution.



Soon after we conflued, we started trying to figure out what we should do as an organization and how do we practice? In my quality position I had a number of primary care doctors complaining that our female patients were getting really mixed messages about what they should be doing for breast cancer screening.

They were getting one message from the mammographers and another from primary care. I was quite naïve at the time and I actually thought about what I should say but this experience left me with quite a bit of PTSD.

I naïvely thought that we could come up with a couple recommendations. I convened this multidisciplinary group. Several people from primary care. Some folks from quality. It was actually a really good working group of people that were really active in our organization in terms of clinical betterment.

And we got together and we started talking. This was the environment 2014, and frankly it's only a little bit better now. But in 2014, recommendations were all over the map. One extreme at that point the entire country of Switzerland was discussing discontinuing screening mammography. They were saying you should have a yearly mammogram. Those are pretty extreme things and there was lots of stuff in between.

It varies a lot from country to country, and from organization to organization. This is kind of a mess. We thought maybe we could do something with this. Oops (Laughs).

So we started talking in this group in a very rapidly became apparent that there was a giant chasm between most of the group in the mammographer. I had no idea how dedicated - it's almost a religious fervor that they had for really helping women to avoid death from breast cancer.

Beyond data-driven sort of things. What they do every day and it's what they say every day, and I don't think I really appreciated that position but it was clear that we were not going to get to any kind of agreement. So we thought maybe we stumbled upon Shared Decision Making, and we really hadn't done it up until that point in the organization. We thought maybe this was a way through.

One of the mammographers quit because she said there was no medically reasonable options. There is only one option to get it every year starting at age 40. That's a pretty hard thing to work with. The other one stayed on the committee and we march forward.

We thought this was clearly a very complicated decision and we needed a decision aid to help people do this and help providers. We started looking around and we could not find one.

I actually called Dartmouth because they have held themselves out for years as paragons and innovators in Shared Decision Making. I talked to somebody there who told me that they were never going to get a decision aid for mammography because it was open warfare between them in primary care - that's just an off the record thing but that was a real phone call.

I thought, "Oh my God what have I stepped into?" (Laughs). There were some bits and pieces at that point and we stumbled upon a lot of resources and crazily decided to do this ourselves. What we found is that it was really hard to find information about screening mammography.

Most of the things we did find really emphasize benefits over harms. In frequently, there was no transparent discussion about what these harms were. At least 50% of women need to come back for additional imaging and at least 20% undergo biopsy.

The other concept is hard to swallow but overdiagnosis is an interesting phenomena and it clearly exists in a number of cancers. Kidney cancer and prostate cancer... And thyroid is the really big one. You are finding cancers that don't really mean anything clinically and there's pretty reasonable information that this happens in breast cancer as well. That you find tiny tumors that would have never manifested in a woman's lifetime, but now we are finding these with mammography. In as much as 20% that are over diagnosed or undiagnosed.

The benefits are really inflated. There was one article in the 'New England Journal', in 2014, that said, they interviewed women aged 50 and asked him what the risk of dying of breast cancer with and without mammography in the next 10 years and what would be. A hundred and 50 would die of breast cancer in the next 10 years but the real number was five.

We've done a really good job; I think almost of terrorizing women about getting a mammography. And with mammography by the way, the number is four. It's really not a large effect.

We decided naïvely to make a decision aid since we could not find one and try to capture these things. And we talked about that there are really three decision points at the time: at age 40, should you do this not? At age 50, in most organizations, the consensus is you should be doing something. It's really, how often. When you get to be about age 75, it should you continue?

We made three different aids for those three different decision points. It was a lot of work and we did a whole bunch a literature search and research. We talked to Mara Schaumburg. We talked to several authors of papers in the topic. We looked at (Name) and

we worked with marketing to try to make things engaging. We finally rolled out our first product in 2015.

We preprinted a couple hundred of these and get some feedback before we went gung ho. We had very few people who said they didn't want anything to do with us.

The first pass in 2015 had a lot of compromises with mammographers. We encourage a baseline mammogram, which probably was not the smartest thing to do. We wanted cancer screenings to be certified, so we decided to see if we can get certification.

We worked on that brought together the same group and we had some of the same issues. But ultimately, we got our decisions made and was certified in 2021. One minute left. OK.

So the challenges. We found this was a huge project and it's really hard to do this yourself while. It's really hard to treat providers. People have talked about that they do this already and I don't think we need to rehash these issues.

How to get this embedded in workflows and make it easily available? There's a lot of epic work to do. How to get the aid to the patient at the right time, and the right person? And that takes a lot of epic resources to do these things.

The final products, I've got links to the Health Care Authority at the bottom of each of these slides, if you want to see the full brochure and how we try to make them engaging in all sorts of ways. I think they are visually appealing and we have lots of nice graphics and we try to follow criteria for how to make these.

Our biggest mistake that I didn't put on here was starting with 1/3 rail project (Laughs). We should not have started our decision-making journey with something so hotly controversial and so challenging to roll out. It would have been easier if we start with total joints.

I thought I probably should've put that on here but I think the rest of it, this was complicated and I don't think we understood how hard it was going to be when we went into it. I think not pursuing formal training with our providers was a mistake. We underestimated the workflow challenges and we really didn't have the capacity to measure results.

The best I could do was find out how many was being printed each month but it was a pretty good update. Anyway, that's kind of it. We did continue even though it was discouraging. We have since rolled out projects for lung cancer screening, colorectal cancer... That's where we are. So, thank you. Did I make it? OK.

**DR SARAH MUNRO: My Next Birth** (Presentation slides 222-233)

I'm Sarah Munro. This is a really nice warm welcome to Seattle to come and join you all today. Before that I was at the University of British Columbia and I will walk us through some lessons learned from a project that I conducted there, to develop a patient decision aid called my next birth.

It's an online tool that supports families making a decision between vaginally birth and an elective for PDS's cesarean. It's an organization that supports the provinces, Healthcare professionals and patients with things like clinical practice guidelines and point-of-care tools, and surveillance data.

10 years ago when I was in graduate school I started to look at their surveillance data for C-sections. They have six quality indicators that they felt really closely and one of them is attempt at natural birth.

This is from the PSBC website and it looks at this quality indicator for feedback. We were interested to first understand why we were seeing this variation in C-section rates. The chart that I'm showing is for hospitals and have selected the larger peer groups. They all provide care to similar patient populations of similar acuity.

In this here is a close-up where we see the ideal target rate for attempted feedback that is being met by hospital in northern BC. It's 36.6% - that was their attempt at feedback right. The lowest rate was in urban Vancouver.

No studies in BC have some really consistently that these variations are not due to clinical indications or differences in patient population. They are due to differences in decision-making patterns. So we decided to address this unwarranted variation. We had some high-quality tools and here on the right is the birth choices booklet.

This was developed in Australia by Doctor Alice (Name) and it demonstrated the effectiveness of a RCT. It was later adapted in the mid to thousands by a team called Power to Push. They took the booklet and they added some content that was relevant for the BC context. Although they had demonstrated effectiveness in improving decision quality, what we really wanted to do was implement and embed it into routine care. Our goal was to figure out what works to embed patient decision aid like this, in routine care. And then, we wanted to draw from some emerging best practices.

I am an implantation scientist; I am interested in understanding how to get good knowledge to stick. We already had best practices available for implementation of decision aids. These are some of the strategies for success that we use, an expert project. This is work that has been synthesized recently and with evidence from 2021. Scan the QR code and you can see the larger implementation of shared decision-making update.

How could we adapt to meet local needs? I like qualitative research. We learn from patients, and from healthcare professionals what they are currently doing. We learned as well that the earlier folks are initiating Shared Decision Making, the more likely it would be that key team members that would be involved. Those that had information about the primary cesarean section, those who understood what the patient's preferences were for that first birth, and how those values might change, over time.

It also helps families in making a values conquer and choice that is more consistence with good evidence. As you can imagine, after having a first birth, everyone is giving you advice. You are finding it from social media and from peers, what you want to do for your next birth is this or that. This is what happened to me in my birth, so you should do it that way.

The earlier we engage in Shared Decision Making the better chance there is that they will get consistent unbiased evidence.

Second, we thought to get shared purpose and engage teams across the province. We brought together champions from hospitals to be In Fermentation leads. There was one region that was...

What does safety mean to them? We included an open-ended question in the patient decision aid that users could fill out and discuss with the healthcare team.

Third, we knew that it is typically 18 months or more between a first cesarean, there is that interval to make sure the pregnant person is recovered and is ready to become pregnant again. This gives us lots of different points in time to implement Shared Decision Making. And then, to prompt patients in their next pregnancy to have the encounter with a healthcare professional.

We also wanted to collaborate with senior-level decision-makers, and in the final step we wanted to learn from those decision-makers what evidence did they need for measurement in order to demonstrate that this is a tool that we want to embed in routine care and is having a positive effect.

Early in the research process, what we did was use surveys, and interviews to understand when Shared Decision Making was happening and when we could intervene.

First in the immediate postpartum period is a really great time to introduce that there is a decision to be made. In between births is when we can exchange unbiased high-quality information. And then, later on is a time to engage in shared decision-making for it is longitudinal. Not just one point in time. Preparing for in fermentation helped us to understand when the different key points might be.

We also prepared for implementation by developing and adapting the tool in a systematic way. I led collaborative design with key advisory groups. Developed strategies that could help with the decision-making over 18 months. Then I conducted focus groups with nurses, midwives, and physicians at a couple of hospitals. They helped us to refine the tools and make sure that they would be accessible for use at point of care, which is really important. Sharing with physicians, this is what we want you to use, but having healthcare professionals tell us that this will work in the routine care.

Then we went back to future users. We interviewed them at the very beginning, and once we had the prototypes ready, we asked them if they were usable and acceptable?

After engaging in the collaborative process, we were ready to implement the decision aid and the different implementation strategies. First there is a decision-support algorithm. This is something that perinatal services BC already creates, for a variety of different services. It helps care providers to see what are the different tasks that you can complete, a different point on the patient journey?

For us it is a Shared Decision Making pathway.

Then there is a post birth conversation guide. I thought it was lovely hearing some of the questions that (Unknown name) raised in talking about questions that you can prompt for patients to help them understand what matters most to them.

This is really helpful, after primary cesarean section to exchange information and make sure that families know what was the actual clinical indication for your primary C-section? What do you want, in terms of planning and spacing pregnancies, if you want to have more children?

Finally, we have the patient decision aid. A family can look at this, in between births, and then it produces a preference summary that can be printed out and emailed and used in a Shared Decision Making encounter.

We implemented My Next Birth in 2021, so this was mid pandemic. It took us a little bit of time before we were able to get it out there, for public use. It is hosted on the Perinatal Services BC website. The website for the main Maternity Hospital in BC. We also have a text message based prenatal education program, in BC called smart mom. Anyone enrolled in that program that says they have had a prior C-section will get a text message with the link to the decision aid.

Here on the right is one of our tweets from a social media campaign. This parent here, Liz, was one of the patient partners on the project. Over the course of the study, she became

pregnant with her first, had a C-section, and went through the process to make her choice after the cesarean.

We also have patient decision aid posted on the BC Government's main health website. This is Babies Best Chance, kind of what to expect when you are expecting, it's handed out to every family in the province.

The decision aid we developed has replaced our health wise decision aid, for mode of birth. I think that it is really impressive to see how many people it has reached, so far. There are roughly about 5000 families in DC who face this decision, each year.

We have had since implementing the tool, 5600 visits to the tool. About 900 individuals have engaged, 560 have completed it, and produced a preference summary to share with their healthcare team.

You can learn more about it by sending me an email, or going and visiting the website, and seeing the different implementation strategies that we have developed.

For next steps, my team is working with perinatal services to embed more digital health tools for different sexual reproductive health decisions.

And I am just really excited we will talk about this when we do the Q&A, the level of buy and that we have had from policymakers has been really wonderful, especially for something like a hot button topic, like a repeat cesarean section. Thank you.

**MAUREEN OSCADAL: Shared Decision-Making for Medication for Opioid Use Disorder**  
(Presentation slides 234-242)

Hi everybody, my name is Maureen Oscadal. I'm a registered nurse, I work at Harborview Medical Center with the office-based opioid treatment team in the adult medicine clinic. I work in primary care about 70% of the time, and the rest of my time is spent as a nurse care manager trainer with the University of Washington alcohol drug and addiction Institute, state opioid response, opioid treatment network training team. A lot of acronyms, I will try to spell them out.

I am wearing two hats. I work in clinical care a lot of the time. I have been involved with the updates in this patient decision tool.

I will be talking about the patient decision aid, but also during the panel discussion can share a little bit about the work that we do in clinic, when we are doing Shared Decision Making.

To start, why Shared Decision Making for medications for opioid use disorder, or MOUD. To set the stage, opioid use disorder is a chronic, treatable, medical condition. Medications are the standard of care. There are three FDA approved medications for the treatment of opioid use disorder, and those are methadone, a full opioid agonist, Suboxone, a partial agonist. Vivitrol, extended release. Three treatment options that we are talking about in the patient decision aid.

One thing I want to bring forward, in addition to all of the other benefits of Shared Decision Making, with an addiction treatment, it is often siloed and separate from medical care, and mental health care, even though substance use disorders affect... It is not part of the conversation because addiction treatment is often siloed. The person could be doing shared support in program like (Unknown name).

We wanted to bring it to the forefront because patients really need to know and be educated about the medication options.

The other piece is that people with addictions often are not given choices around treatment. Traditionally addiction is addressed in the criminal justice system, and that is the one that dictates what happens for a patient. The option of medications and the whole spectrum of medications is often not included.

But Shared Decision Making allows us to really recognize that patients are experts in their own lives. This is true for people with opioid use disorder. And they get to decide which of these treatments is going to be best for them, given their context.

Not only considers the medication and the pharmacology behind it, but also the treatment settings, context, things that go into treatment. Because, in our country, here in the US, methadone is only offered in certain settings. Those settings are not available to everybody. (Unknown name) is more widely available, but not all prescribers available. (Unknown name) has issues with getting started on it. I will not get into all of the details. Those are the things that we want patients to be aware of.

What we know though, when patients are given the options, they are more likely to engage in treatment, and adhere to whatever medication they choose. These medications are lifesaving. I will not get into the data around this either, but (Unknown name) and methadone are reductions in... As well as opioid...

The patient decision aid I am talking about is the medications for opioid use disorder brochure that the Addiction to Drugs and Alcohol Institute published initially in 2019. Discussions between Caleb Banta at ADAI, and a social worker at a low barrier brief clinic in Seattle. Caleb was talking about how she has the conversations with clients. How did



she talk to patients about the medications that are available, and how do patients make decisions?

Out of that came the idea to create a guide. This was several years ago now. The guide was many pages long. But it was a script for providers to share with patients and do some shared decision-making.

That was initially tested in two studies. Initially, they did an implementation study with the Washington Department of Corrections, and that was looking at the feasibility and acceptability of the treatment... Decision guide. It was found to be both acceptable and feasible to implement.

Follow-up observational study looked at using the treatment decision guide with people who are being released from four different jails, in Washington.

The impact from that was that a majority of the people who were engaged, and who participated in the treatment decision-making side of things, with Shared Decision Making, were more likely to initiate treatment, one month after release.

So that led to the development of this brochure. A little bit easier to... For patient to navigate, better than the multiple pages of the script. Since 2019, multiple versions have come out. It has been updated several times to incorporate new things about medications. We now have an injectable version of (Unknown name) available. 10,000 copies have been distributed.

In addition to the brochure, we also have some resources online for providers to use.

Our goal here is to increase access to treatment. So we are not only empowering patients with this information, but we also really want providers to be learning more about these options so that they start prescribing more.

So this is what the brochure looks like. You can see the front side and this is a fourfold out. The back is actually the part that says what next, but it allows patients to learn what opioid use disorder is and what medications are.

A big aspect of opioid use disorder treatment for us is that there is a lot of stigma amongst people with opioid use disorder around the role of medications. So one of the goals of this guide is to provide patients with objective information about what the goals of these medications are, and to try to destigmatize use of medications.

So then we have a breakdown of the three medications, sort of comparing not only what kind of medication it is, but then also where the treatment settings typically are, what kind of counseling requirements may be required because methadone might be a great option

for somebody, but maybe it's not feasible for them to get someplace every single day. So we want to be having full conversations with patients around what they are getting into.

And then like I said, we have a complementary version of this brochure, a treatment guide and decision-making guide for providers and clinicians online at [learn about treatment.org](http://learn.abouttreatment.org).

There is a hard copy that people can print out and go over with people in the field if you do not have access to the internet. Then there are also modules that people can go through and it includes scripting, because again what we really want to do is encourage more people to be making this medication available.

And these are all the resources that I was talking about. So [learn about treatment.org](http://learn.abouttreatment.org) is the ADAI website that has a lot of information on it. All of this information is available on the website. And that's all I have.

**DR KAREN SEPUCHA: Orthopedic Shared Decision Making Learning Collaborative**  
(Presentation slides 243-255)

Excited to be here to wrap up the panel session. My name is Karen Sepucha and I am at Massachusetts General Hospital. I will be falling long from my colleague Leigh. My background is a PhD in Engineering and decisional science. I've always been interested in how people think about decisions and risk. And how do we do that in situations where you cannot be doing that alone, where you actually have to work with someone else to make this decision?

Medicine has so many examples of this. I was thinking there were so many right answers and signs would just tell it what to do. You just peel back the layers and just realized that there's so much we don't know and so many opportunities for decision-making.

I will talk about a project we're just wrapping up focusing on orthopedics and continuing that theme we heard this morning on how to get this into a surgical scenario?

So just for some background: we had a committee that we started back in 2018 and they were helping us with an implementation project to try to figure out how we might integrate decision aids at our hospital into our orthopedic practices.

Leigh and I had given the grand rounds with the Mr. M case and back then only primary care physicians had access to the tools. The Chief of Orthopedic Surgery had asked for those. Scarcity is sometimes a good motivator for implementation. We ended up working with him in the orthopedic group.

We had video decision aids at that point. About a 50 minute video with a 50 page booklet and it didn't take too long for advisors to feel confident in what we were doing. "Is there anything shorter, because it's really long?" They also challenged us. We need to make sure this surgeons are listening to us in understanding what is important to us.

We ended up conducting a randomized trial and made a little bit of a detour based on the questions that our patient partners are raising. We compared this longer conference tool with a shorter tool, and actually found that contrary to our hypotheses, that the shorter tool was better. Patients were more likely to use these and got some more benefit. Both were good and better than usual care.

We tried to shift our focus to figuring out how to get these into people's hands. This is a work that's been funded by the patient centered outcomes Institute. After that we went into randomized trial hosting and implementation project through a learning collaborative. You bring different groups together that are all trying to implement the same evidence-based practice, and here it was in permitting a decision aid for hip or spine. We have of bunch of the sites, who at the time was switching their vendor. It was a really nice inflection point for their implementation but we did have good representation across the country, mostly academic centers but also a couple of community practices and safety net hospitals.

Our goal was to reach 20,000 patients as part of this project. Just a quick summary of what we did: across the 13 sites we had 87 surgeons and specialists that were involved in using the decision aids. We did almost reach our goal; 19,658 decision aids were given out to adults. We had four different decision aid vendors. They had to have their own decision aids or we could use help why decision aids.

We got some examples and had to work on workflows for different types of tools. The two main workflows, the previsit workflow, so that they can get the decision aids out to patients through the portal. And a day of visit workflow for many of the sites that did not have that integration. In our implementation strategy, we had a monthly check in with the site just to make sure we were keeping things going and that they were moving forward.

One of the things that the sites had to do is give us insight on how many decision aids they were using. Give feedback on how they were doing for the delivery and break that down into graphs to show what was happening across the providers and their practices. This also helped us in those one-on-one calls to figure out how we are doing and if something was changing?

If you've tripled it or going to zero, what was happening? That was one way we were working with the sites to work through the workflows and get these out. One of the biggest things we did as we were starting this learning collaborative was focusing on motivation.

We did a baseline needs assessment with each of the sites, where we surveyed their surgeons and front desk staff - basically anyone who would touch the patient during that decision aid process. That really gives a lot of information about the potential resources that these sites had and also potential barriers.

We definitely had some concerns about leadership buy-in and buy-in from nonclinical staff. How are you going to engage your colleagues and firmness for folks? Each site had a surgeon and administrative champion but thinking about how they will spread this out. What are the taglines and how will we do this?

The other thing we did with the sites and the benefit of a learning collaborative is you get a bunch of different practices working together on the same problems. At the beginning of each session, we had each site talk about a rose, something they were really proud of that happened since we last met. A thorn or challenge they were facing. And then a bug, something they were looking to tackle next quarter.

Some examples of some roses. And the most important things of having buy-in from staff - this could not have happened without the staff implementing it. Really thinking about what was working well.

I have a lot of thorns related to IT and trying to figure out, wanting to have this automated and integrated and have it be really frustrating. We launched us in October 2020 and it was really challenging to do any type of practice redesign, so we had real challenges with IT.

Also we had one site where the buy-in from staff is important but we also had lots of staff turnover. Some sites where there is no medical assistance and nobody else in the clinics. Real challenges when thinking about getting these processes up.

So we distilled the insights into an implementation toolkit. I think we will have resources available for you guys on our website right here, but hopefully we can get that to you guys in a way you can access it. Really think about what kind of research support on how you might sell this to leadership, workflow designs or templates, how do we think about all the different steps that are important for getting this out, what can you do with EMR light, and EMR enhanced? What are the kind of tools that we can build?

Leigh mentioned the idea of having a best practice alert on the referral. We have some examples of things that don't take a ton of IT resources and then things that, if you have those resources, how you might use those.

The scale up strategy. How do we think about the training and getting the buy-in from everybody else? And how do you think about spreading the efforts across the system in your practices? The decision is a delivery. We had 13 different sites. We have a distillation

of what was the workflow and issues for each of those sites. These are 13 different examples of how they have integrated these different tools, what their barriers were, and what their strategies were to overcome them.

And then monitoring and improving how they can sustain effort. We have examples of the dashboards and how do we think about collecting the measures. We've heard a little bit about the challenges of where to find the resources to measure whether this is actually happening. I think it's important to build that in.

It's been wonderful to make sure we have our patient partners available throughout. They work with third learning collaborative sites and were really active participants in thinking, how do we really go about this and get this into practice?

Just to summarize. I gave you the 19,000 sites but often we are interested in the denominators. How did we reach eligible patients? That was about 40% and that ranged really widely. Some of our sites had prior experience and some of them had none. Some of the sites did really well, even better than those without prior experience. Some of them did better than others.

But I think the other thing is contracting with the decision aid vendor and integration takes a lot of time. I think that was something, how to start the early, and that staff turnover was a constant issue for the sites in the practices. Thank you.

DAWN STACEY:

Thank you very much all the panel members. I think it's a great example of how Shared Decision Making and patient decision aids can be used in many different settings and topics. Each presentation had different little pieces but there's also similarities.

We will enter now into the panel discussion and I will ask a question to the panelists and give them time to answer the questions. I have a series of questions and then we will open it up to discussions of the whole room. We still have another hour and 1/2.

The first question to the panel is how do you engage providers in the Shared Decision Making process? Including use of decision aids, training, and determining readiness? Maybe you can think about one or two sort of key things that you think are essential to engage the providers. Does someone want to go first? Dan?

DR DAN MATLOCK:

There you go. Thinking of one or two, I do think it's not sufficient but it's essential to do some education. Some introduction to the topic and the tools. Some belief, showing them how the tool was developed and that it was developed rigorously. That's kind of the

perception they sometimes have. You have to have some sort of education of where the tool comes from and that it was a pretty rigorously done process.

DR KAREN SEPUCHA:

I follow-up. I think it's always going to be easy. There's going to be challenges and you don't have to worry about getting them but one of the things that we have mentioned, we would go out to the practice team meetings and show them their decision aid data.

But what we try to do is highlight someone in your practice that is using them and then have a discussion of why are they using them. What impact is it having on their practice? They are hearing from their local peers and I think that was a really important way to get some of the folks who are hesitant or thinking they we would go away if they just waited long enough. We would keep coming back and they just realized that we would not go away. I think those are the two things that we did.

SPEAKER:

Engaging providers around determining readiness is something that we keep having to revisit over time. I do not know what exactly has changed. Maybe it is a covert influence. When we first started doing this work, and were ready to implement in 2020, we had engagement from specific healthcare teams across different hospitals. Everybody was aware, everyone knew the tools and the strategies, and were ready to go.

A couple years later, I was on a panel with one of those physician leads, and she was giving a talk about the tool as an example of how they had to go through and do a QI process to use the QI resources to get buy-in from people that they did not know who needed to be brought on the team. The idea of readiness there will always be hidden in corners of the provider healthcare team who maybe are indifferent or have not bought in yet and need to be brought on later. It was an independent QI process that identified the gap and came up with a strategy to address it, I was impressed.

For something like this, I called it a hot button topic, there are always folks who are resistant to something like presenting an option for VBAC versus elective cesarean. Coming back to what is going on in the environment, and the site, is another thing that is important around readiness.

Do the clinicians feel that this is an option that they can provide? What is changing, in terms of access to the operating room, or anesthesia availability that may make it difficult for people to offer that is a sure decision? Yes, it is an evolving thing in determining readiness, I would say.

DR DAWN STACEY:

Maureen?

MAUREEN OSCADAL:

I will answer this from both my perspectives, from the work that we do at the state level with ADAI, I want to echo that training becomes really important from the way that we do things because we are outside of the healthcare systems, coming in and trying to encourage culture change. And so, a lot of what we do our webinars, technical assistance, and outreach, and Shared Decision Making and the conversation around Shared Decision Making is incorporated into almost every single training that we do. Whether it is talking about medications, opiate use disorder, how frequent you are seeing patients, use of drug screens. We are always incorporating that Shared Decision Making language, into our trainings.

And then with regard to my work at Harborview, on the office-based opioid treatment team, to what Sarah was saying, multidisciplinary teams really come in handy in these cases. We meet regularly to talk about difficult cases or things that come up in patient scenarios, and how we address it.

The provider might say they are on methadone, and they want to switch to (Unknown name). We talk about is a team to support them, to have the conversations with the patients, and make sure that we also are on the same page as a team around these conversations that might be happening with one patient, but that trickles out to other patient scenarios.

It really is helpful to have not only providers and nurses on the team engaged, whoever is involved in patient care contributing to those conversations, because, including the patient obviously, but having the Shared Decision Making conversations even within our teams, on a regular basis.

DR DAWN STACEY:

Randy?

DR RANDY MOSELEY:

This could evolve into a large discussion, about change management. I think the why is important. And that might be one thing, with our project, that was good, really, is that pretty much everybody in primary care understood the problem. And they wanted a solution.

That was goodbye in that way. There was a good why, at least with primary care standpoint. That is important. We need to understand the advantage to them and their patients.

DR DAWN STACEY:

Given the importance of training and education, there are different ways in which this is done, around the world. If you go to (Unknown name) hospital in Denmark that implemented... Change for everyone including cleaners, physicians, people who deliver the food, everyone got at least one day, clinicians more engaged in Shared Decision Making but two days. When I walked to the hall and asked anyone to tell Dawn what they knew about Shared Decision Making, they could. Hospital wide, 100% approach to training.

In Norway, (Unknown name) is busy on her PhD and she has developed a bunch of modules. There is a module for leaders in the organization, one hour training. There is a module for the interdisciplinary team, a module for train the trainer, and she has a whole series of modules that she is working on, and testing.

I want to come back to the whole issue of training. We talk about how important it is, but what does it look like? Who should we be training? How do you approach training?

SPEAKER:

I can start with how we do our training for the core work that we do at the state level, here in Washington, with ADAI. We have an interdisciplinary team, two nurses, a provider, a prescriber provider who is a psychiatrist, psychologist who works with the jails, almost exclusively, and then epidemiologist.

We take a sort of our specialties and offer trainings to the groups of people that we might gear our trainings to. For example, I train mostly nurses, but really anyone in a care management role can participate. Similar to the prescribers, any prescriber could participate in the trainings that are available.

The waiver for (Unknown name) went away. Opportunity to do a lot of training. We do target groups, but we have a team, and we work collaboratively to make sure that for example, in May, we will be talking about hepatitis treatment, and we will have each of our specialties address that from the angle of what that provider offers, in clinical care.

SPEAKER:

Great.

SPEAKER:

First with My Next Birth, what we found with the survey across the province, many of them had not done Shared Decision Making training. The midwives do engage in placements with professional teams. Spread of Shared Decision Making that happens in maternity training,



so we decided not to mandate that there were specific Shared Decision Making training for people to use this. But I would say what we used for training was an orientation.

We want people to be oriented to know that these things are available, and this is how you might use them with fidelity. I have done different rounds across the province to provide that orientation. And to show people how they can build on their existing shared decision-making skills to use the decision aid.

Another child it will give an example of, I was part of the information team for a PCORI trial looking at contraceptive Shared Decision Making interventions. We found that in doing no training, just orientation, sexual health clinics did really well at integrating these option grids into practice. They were able to bring up the printed versions, people interacted with them in a clinical encounter. Orientation alone worked, in part because they actually did training and Shared Decision Making with their staff.

In primary care, the decision aids were handed out like information. No actual conversation about the decision, benefits, harms, and different options.

I would say it really depends on the context, and whether people are prepared with their existing skills. And I would say that in that example, orientation alone may not even be enough to get people to understand the concepts of Shared Decision Making.

SPEAKER:

Trying to figure out what to add to that. I do think the idea of context really does matter. We would do different types of training depending on if we had a decision aid involved or not, how do you integrate the decision aid into their care or is there a situation where there is no decision aid, but we want to think about Shared Decision Making, and what it means?

We try to do it at different levels, what do we have for medical students, for internists, practicing clinicians, etc. across the hospital? It does vary. It just used to be Leigh and I going out and doing it. Which is not a sustainable or scalable model.

We worked with Harvard's online CME and created an online CME course. But then there are questions of can you mandate this? How do you think about doing this kind of training, and making sure people are really authentically doing Shared Decision Making. We have been doing fun things with stimulated patient interaction, also the kind of training where if you do not try it, and have the conversations, and try to do it, we can talk but that does not really help to develop the skills. Thinking about how do you do those skills is training, is important for this area.

SPEAKER:

yes, thinking about a couple of things to add. It is like peeling an onion. I think in the implementation of science, it is very different if you're trying to implement something they agree with versus something they do not. In primary care there is philosophical agreement and getting over the challenges. When I work at the cardiologist I am fighting a philosophy that we do not need this. There are guidelines. Trying to convince them that there are some trade-offs and some decisions to make.

Maybe they will not sit through a four hour training. The amount of money that they would lose for themselves in the hospital, doing that, is prohibited.

We are trying to think of how you could train electrophysiologist around defibrillator Shared Decision Making power with some entertaining vignettes. I like the Mike Berry being a really bad, really nice physician, that kind of stuff to be a little bit entertaining. But at least making those points to get over the philosophical barriers.

And the skills, I try to make the simple as well. If I could assess the goals and values. What is important to you, and does this fit? You have gone so far down from where we are now, maybe they are not talking about the risks and benefits perfectly, but tailoring what is important to that person. I try to peel the onion, and not go too deep to overwhelm people. At least get the buy in and get them talking about values. Then you can come along way. Then you can go into more and more skills. That has been my approach with cardiologist. I am not sure how successful it has been.

SPEAKER:

I said in my talk that one of the mistakes we made was not giving some foundational Shared Decision Making training, or at least starting out with that. I am not real convinced about that statement.

What we did with primary care, we are trying to help you solve a problem, in your practice, and here are tools to help you do it.

We went to every department, every primary care department pod to roll it out, with individual discussions and introduced our decision-making principles in that context.

In some ways, maybe that was not so bad. We had an opportunity to introduce Shared Decision Making principles in the context of something that we were already interested in, a clinical problem they were having trouble solving. That is just my further insight to this.

SPEAKER:

Yep?

SPEAKER:

I think Leigh said something this morning that works well too. I forget how you said it. You do a good job there, and you could do it better. The baseline that people are trying to do their best is much more effective than showing a bunch of data of what a terrible job they are doing. Rather saying they are doing a good job...

SPEAKER:

Talking about the interprofessional team and who is the team that needs to be part of that training? That you need something sustainable. If you only have a couple of people on the team doing it, then it's not necessarily sustainable. Or people just think it's your thing and it's not really up for the rest of us.

Also, thinking about what's the minimal amount of training. When I look at some of these programs that are days long, I think in Germany it's three days long or something, what's minimal? We need to get people to the table to attend.

And then the next question is the range of different ways of training. Online, in person, do we need assimilated patients? Also some do tape of interactions and analysis. There is still a fair amount of questions. But the bottom line is and it comes back to Sarah's point, where she got the midwives to attend but how do we get the right people to attend and what do we need?

None of you talked so much about the leadership team. I think it's also important and that's why am happy to be here with Washington State Health Care Authority, we need the leaders to understand what this means as well if we will actually work on implementation.

Karen, will you make a comment?

DR KAREN SEPUCHA:

I think with our learning collaborative, we track to give out decision aids and there was like 204 people. 64 of them are surgeons and that just tells you that it's not just about the surgeons - there's a whole team here. That challenge with workforce turnover really brought it to the forefront quickly.

Is this in their job description? Are there steps you are supposed to be identifying and who should get a decision aid and ordering what we're handing them to the patients? Thinking about how you build this into their job descriptions, so that it's just part of their SOP once onboarded. Thinking about the training and logistics that can be built in the things that are already there in the system so it's not something completely separate you were pulling out. It's just sort of part of the fabric of the process in the clinic.

I think that's one of the things we also tried to do in our experimenting. At micro training, can we train them just when they need it, as opposed to just training them once a year later they finally have a patient they can use it with and they cannot remember what to do. Are there many trainings that they can use with scripts?

SPEAKER:

There's also another study where they trained everybody at the hospital and anybody could come for training. A year later, they went back to see who was doing it. They found the people more likely to be successful only when the whole team came together. Those people go back, one offs and nothing happened in their clinics, other than maybe individually they might have done a little bit but it didn't really shift the clinic to do more training.

Lots to think about with training. I will go into the next question. What are the biggest challenges you faced with implementing Shared Decision Making or patient decision aids? And then how did you overcome them? Maybe if each of you can talk about one of your biggest challenges, or maybe two? Dan, I see you looking up.

DR DAN MATLOCK:

I just cannot handle uncomfortable silences.

I mentioned the philosophical barrier and I think that's the biggest challenge, but I won't talk about that again. I think some of the rules of decision aids - I've had to violate some of them just to get buy-in from the doctors and I know some of the decisions we have made are less effective than what the science would show.

The risks of defibrillators. We have the benefits as an icon array but when I had those, the doctors told me they would never let me show this to their patients because it was about 7/100 benefit and risk. I had to violate some of these rules.

I think just getting comfortable designing for the users and using the theory to support and make sure they are aware of it, but then making sure the design is for the users - I think that's one of the barriers that took me awhile to overcome.

DR RANDY MOSELEY:

This might be an odd thing to say but it really starts with how medical research is published. We love to talk about relative risk reduction in percentages, and that's the way doctors now think and patients do not understand that.

And I think it was a challenge to get doctors to start talking about numbers, cases per thousand and not - because breast-cancer mammography reduces the risk of death by 25% roughly, but in real numbers that's a really small number per thousand women.

I really think they should invade the medical research industry and create new standards for how research is published because percentages are just a terrible thing to use. And I think we are so embedded in reading that sort of stuff, that it's hard to make that shift.

SPEAKER:

Biggest challenges with implementing decision aids. I will say briefly, making sure that folks with power in the room step back so that patient voices can be heard. It was really difficult as a community-based researcher, who comes into a space and brings in patient researchers that feel like they are invisible.

We put a lot in the work behind the scenes to make sure we were facilitating in a way that the patients felt included and respected. It was really hard.

SPEAKER:

I will comment on really specific medications for opioid use disorder. There is an under prescribing in these medications and most people with this disorder do not get access to medications.

A bigger that we continue to face is just the fact that we don't have access to all of the medications. Not all patients have access to even some of the medication sometimes.

As much as it's really important to have these conversations with patients, if we hit barriers with access, it's very challenging obviously. So solutions to that are really changes at the systems level.

We can encourage, and as we are doing and trying to train more providers to prescribe depo morphine and naltrexone, increased access to methadone, but ultimately we need bigger systems change. My role as a Nurse Care Manager at Harborview does make it a lot easier for providers to do prescribing, but my role is funded by grants and not the hospital system.

So there are opportunities but it's a work in progress for our area.

DR KAREN SEPUCHA:

I agree with all of these challenges that folks have mentioned. I think I want to add one that I think we struggle with, which is a feeling that high tech is going to save us. It's going to save us time or make it easier to get the decision aids out, which it does but it doesn't

always make the most authentic connection with patients in getting these aids used, which is what we want and having those good conversations.

I think the challenge of trying to push this all into a tech solution, to automate the delivery, and losing that idea that this is the conversation. But we actually want to support good conversation and that requires some face time. I think that's one thing we are really struggling with.

DR DAWN STACEY:

I will move on to the third question: how have you used Health Policy or other levers to support patient decision aids or Shared Decision Making? I think this is a good question given we are located in Washington State, that also has some policy levers.

SPEAKER:

We would always try to work with leadership to figure out what is going on in the system priorities. Our first push was when the hospital was trying to transition everything, and Shared Decision Making was part of that policy initiative.

In the next one we did was the system that was doing behavioral health support, and so we cut decision aids for depression and insomnia. We always tried to tie it in to other change that is happening and what role decision-making can play in that.

SPEAKER:

I think the phrasing of how I have used it. I think we got lucky with the Medicare mandate for the defibrillators and when that happened, it does work. It certainly creates a lot of discussion and I talked about how hard it was to implement.

If I'm being really honest, we do get a ton of hits on our sites just going to that one tool because people are trying - I think most of them are just checking a box and I'm not sure if they are really having Shared Decision Making, but it has started some conversations.

I've gotten some really interesting emails from doctors in the community that have shown that it's at least doing something and getting people to think about Shared Decision Making. In that way I think we are leveraging policy but we didn't make it happen though. I'm not even sure why. I've even had to have some follow-up conversations with Medicare. When you do this, how do you choose what procedures?

It is creating maybe some unintended consequences with pushback and belief maybe they shouldn't do that. So, I guess that's at least related to the policy question.

SPEAKER:

When we decided to update our decision aid for breast cancer screening and get it HCA certified, one of the ways I got resources committed was the Washington State statute, giving you a little bit extra liability protection if use of certified decision aid in your discussion.

That was a lever that I think is unique to the state. But I used it.

SPEAKER:

Two things that were just really great opportunities. One, we had something called the BC patient centered care framework in 2014 published by the Government that laid out, involved patients in decisions as partners.

This is work that you want to accomplish and here's how we can help you achieve that goal. The other thing was being a younger researcher and training, coming in saying to folks, "Tell me what you are currently doing. Can I interview you?" I was able to pick their brain in terms of the research process and then they felt like that had some sort of knowledge attributive they bought into the process. They felt like they were already consulted about it.

It's pretty strategic to use it at the beginning of the process to make sure folks were informed and had that buy-in.

SPEAKER:

I think the one thing I would comment on through the state of Washington, medications for opioid use disorder are covered by Medicaid, which makes this sort of conversation at least something that can be had from a cost effective perspective. That we can talk to patients about these options if they are all available and cost is not an issue for Medicaid.

That includes pretty expensive medications like the long acting injecting version of depo morphine. That's been something we've been able to utilize in our conversations.

DR DAWN STACEY:

I want to merge this question around having engage providers in SDM. One of the answers there was around organizational factors that can support the implementation, so I want to bring it down from the health policy level to the organizational level, to ask a question around what are the levers at the organization level that you have tapped into that can really help with supporting SDM or decision aids?

Karen, I will put you on the spot. In fact, I have your toolkit up because I think it's a good summary of different things to think about with implementation. You really focused on Mass General, which is an organization where you have had lots of success.

DR KAREN SEPUCHA:

As Lee had shown we had the Shared Decision Making at the heart of the population health management strategy. Trying to figure out how do we connect this to the important initiatives going on, within the system.

DR DAWN STACEY:

That also ties into Sarah's comment around the province having that type of framework that can be tied in. But we also need to know what is the driver within the organization that Shared Decision Making fits in.

DR KAREN SEPUCHA:

Well, the things I mentioned, now there are external drivers, for example a lot of the providers has written in milestones relating to Shared Decision Making and decision-making use into the quality contract for MGH, or MGB. Obviously, when there is money tied to things, it gets people's attention being patient centered does not necessarily do. Sometimes external requirements.

SPEAKER:

I do not think I have an answer to that question, but I have a comment. We are, like many organizations have contracts with external accountabilities for various milestones, health organizations etc.

The measurements are usually what percentage of your patients who are eligible get colon cancer screening, mammography, those kinds of things? I think a little bit of that is in the way of when the focus becomes, get it done. I would actually rather see, I am heartened to hear what you just said, because I would rather see the demand be, what percentage of your patients received Shared Decision Making discussions for these things, rather than the end result. Yes.

SPEAKER:

I forgot that one of the organizational leavers was around medical legal concerns, and we have turned to Washington State's guidance on using certified decision aids as part of the process, informed consent to ensure that patients were really well-informed if they were choosing an option that went against their particular clinical circumstances.

That was a big issue. Fraser Health Authority where there have been high-profile cases of people not having access to a cesarean section quickly, and then having adverse events that affect their baby. And so, they really felt incorporating decision aids and decision-making would be an extra step for them and returned to the Canadian Malpractice



Protection Association as well, a really nice guidance around informed consent. They had some a Shared Decision Making language in there as well.

Thinking in a medical legal perspective, and what that was for the organization's priorities.

SPEAKER:

I do not know if I have commented on this much yet. But at Harborview, we also have an addiction consultation service. That is where the conversations, more often than in the outpatient clinic where I work, where patients were inpatient, for whatever reason who have opioid use disorder that can be offered medications and get started while they are in the hospital. These conversations about what medications would work best for you happen a lot in that setting. We have nurses and peer support specialists, and physicians who do that work.

In terms of where we have been most successful in getting buy-in, across the board in the hospital around having a conversations outside of the consult service, we know that when patients are getting the medications, that they need both for their withdrawal symptoms as well as pain management, they are more likely to stay in the hospital, and not leave against medical advice. They are more likely to continue the treatment that is recommended. Which is associated with much better health outcomes.

Those kinds of conversations with nurses on the floor around making sure that patients get the medication they are wanting, and making sure their pain is also being managed becomes really important. The decision aid is not just important for patients but also comes in handy with the providers who are not necessarily doing this work all of the time.

DR DAWN STACEY:

The question around the organization levers really leads into how do you measure this. Measurement is really important for showing that you are doing it, but also for feeding back into the system to say that this is where we are at. I want to open the comment around how do you measure this? Everybody is looking at Karen. Karen is the measurement person at the table, probably more measurement oriented than most of us in the room.

DR KAREN SEPUCHA:

A lot of times we have tried to get (indiscernible) to do the measurement, because it is not easy to do as part of fermentation. One of the models that we had is hospital and health system provides the funds for the in fermentation. They contract the decision a vendor. They have integrated it into (indiscernible). We use that as a lab to say we have funding to do some research on this. And surveying patients as well as tracking what is being used. We have good data on which aids were ordered when and by which providers, to the extent

that the patient is on our portal, if they have opened it, used it, and if they go through the whole thing, we get a report back from the decision aid about their how they did.

Using it is not as good as having a conversation about it and making a good decision. One area where we have done some measurement, done a lot of work as you saw in orthopedics, and worked with them to get approved, get some measures into the patient reported outcome (indiscernible). They are in the process, for items, MPQ M, endorsed measure for decision-making as well as decision quality which has the knowledge items and reference item. We have that data now routinely, I know (indiscernible) on all patients. Still trying to figure out as I mentioned earlier how we use the data.

As you can imagine, we are finding that some people do not, cannot answer the knowledge questions. Did not prefer surgery, but already went through the surgery. Mr. M, we have data on him as an anomaly, how often is this happening? Luckily, it is very small. But it is 5% of people who wanted nonsurgical options but had surgery. A little more if people were unsure. It is not never happening.

We have a project now going on with her medical malpractice insurer (Unknown name) to look at the informed consent process in orthopedics and Shared Decision Making and look at what was documented on informed consent, and the scores. How are those related to see what kind of elements we might find that would work well?

A lot of the detailed measurement is through research. We have some limited but good data on decision-making, otherwise.

SPEAKER:

I mean, personally, outside of research... Indirectly we have not done... A system that is really hard. Karen, a four measure is really great, but in fomenting his heart. I think some of the implementation measures, we measure use, but also if you look at diffusion of innovations and the theory, early adopters, and some of the innovators, if you can measure their experiences and share those with other people, some of the late adopters, late or early majority, you are likely to get by in. We have tried stuff like that with the clinics that we have three or four doctors who are (indiscernible).

We do measures of acceptability, sure that with the group, and maybe get a little bit more buy in on some other things. Not measuring Shared Decision Making, but something else we are trying to measure as part of implementation.

DR DAWN STACEY:

We are talking about quantitative measures, SDM process, only for items. Is it possible to integrate into the health system, also looking at qualitatively how can we get the stories or the experiences and communicate them forward, as well?

SPEAKER:

Work with researchers.

(Multiple speakers)

SPEAKER:

Researchers who are really really keen to do that work. Those are the kind of questions, not just what is happening but what is the process like? How do people feel about it? What continues to motivate them to engage in the work? Where are they finding the barriers? All great qualitative questions that can be used in mixed method studies or parallel studies, alongside the qualitative.

DR DAWN STACEY:

One of the other things I think about with measurement, we have measurement for research study and then for practice. When we do measurement for practice we want to have a few items with an easy response scale, yes or no it did not happen. We want to measure for research, we want all of the different questions and a bigger response full-scale to show two at a five or 3 to 5 as opposed to going from yes to no.

When it comes to measurement, if you are thinking about it is a research study or is this something as part of a process in measurement and practice that you want to integrate in and monitor?

SPEAKER:

I will make a comment, I do not know people I have talked to like (Unknown name) might be interesting to work that out and see if this happened in a visit, does that improve patient satisfaction? I want to ache a quick comment, unrelated. Your comment about the malpractice piece, a big part of my job the last 10 years was cleaning up the mess with bad outcomes or upset patients.

What I realized anecdotally, and I think this is backed up by data, patient expectations are really important and if you start out a lot of surgeons in particular say it will be great. And when it is not, it is doubly bad.

I think this tool is potentially really powerful to create appropriate patient expectations.

DR DAWN STACEY:

I will add the question of what not to measure. From your experience, what would you not repeat in terms of what to measure? Or warn people, in the practice setting?

SPEAKER:

As a researcher, I love all data (Laughs). I am trying to think. Dunn did Shared Decision Making occur? That is a wrong question.

SPEAKER:

(Indiscernible) You were talking about making it short. Short is important. Can I do something different if you give me that result? There are some measures. Do I want to do Shared Decision Making? Some measures are not, process of creating for item measures, did you talk about the options? Did you talk about the pros, cons, differences? You can figure out, orthopedic surgeons for hip and knee are not talking about nonsurgical options. They are not talking about the cons. They are middling on asking patients their preference.

Spine surgeons are doing a better job on all of those things. We tell them what they need to do. We tell them where the gap is and how they might change the conversation, so that we can see a difference in the score. Making sure is actionable is more important than the length necessarily.

SPEAKER:

That is a good comment. Understanding your question a little bit, it was a really hard question.

The challenge with Shared Decision Making is it happens in a black box. What you really want is to go in and listen and see if it happened. You cannot practically do that. There are a lot of measures that if they do not give you much. The (Unknown name) measure we use that a lot. It has mixed effects. Some patient satisfaction measures, everybody scores really high. They do not have value. It is hard to find things that are distinct. Karen's measure really is good because it is asking about specific behavior. It is not asking if you like your doctor. It is asking if they asked you a specific thing. Those are a little bit better for after visit measures.

SPEAKER:

Were you going to comment?

DR KAREN SEPUCHA:

Yes, I have been looking at the surveys and figuring out ways to integrate the items into CAPS. Not that the questions are problematic, the sampling procedure. In the last six

months, have you made a decision? So generic that people are not focusing on a major decision or a meaningful decision. So, I think you get very different results when you are saying when you talk to your doctor about treatment for your depression, then answer the questions, versus whatever the conversations you might've had over a long portion of time. That is the other challenge of sampling and how are the questions being asked, as well as the questions.

DR DAWN STACEY:

They don't even know they have been involved in a decision. They might not even realize that this happened but saying, did you talk about management of depression at your last visit? That's much clearer.

DR KAREN SEPUCHA:

But then you get to such a small end, you don't ever have enough data to help them really.

DR DAWN STACEY:

Ways to think about measurement. I will move now to a completely different topic. Question number four on your list: how can Shared Decision Making in patient decision aids advance health equity and inclusion?

We had some discussion this morning. Any comments? Health equity and inclusion.

SPEAKER:

I can talk a little bit about how it works for our work. I will start first by saying the decision aid, the brochure that we has helps by allowing for the conversation to happen between patients and clients and not just prescribing providers, where there sometimes is a power dynamic.

But also if someone like your support specialist, it's outside of their scope but they can certainly review somebody. A nurse can do education around stuff but having a visual aid is really helpful. It allows more people involved in the patient's care, the clients care if it's somebody who is not in a medical setting, to be having these conversations. And it levels the playing field a little bit.

The other piece is that, and I mentioned this earlier, or I think I touched on it. There is still a lot of stigma around medications for opioid use disorder and opioid use disorder treatment using medications.

So decision aids like this one came to really allow patients to see these as medications for chronic health conditions. Reducing the bias around using medications, which is really

critical because certain demographics are affected far more significantly by opioid use disorder in opioid overdose than others.

And medications themselves can be prescribed differently based on someone's race or socioeconomic status. We see many more white people getting access to Suboxone, which is available through primary care at pharmacies here in the United States. And more people who are Black, getting access to methadone.

The two medications are great but they should be equally available to all people. And so what we want to make sure is that people are getting information, not only about medications themselves, but all of the medications so that people can be making these informed choices on their own.

I think this decision really helps with that and it's a really a huge piece of that.

SPEAKER:

We have roughly 30% Hispanic population in our service area and many of those folks are Spanish speaking only. I think almost any provider in the room has had the experience where you are working through a translator and you ask a question and there's like a minute and 1/2 of conversation. And the answer is yes (Laughs).

What was that? I think it's hard to deliver the same quality of Healthcare in a language that is not your own. And I think translating decision aids, not just the language, but making sure that the message is culturally appropriate in that context as well, is really important so that at least you are starting out and the patient can look through this information. It levels the playing field. I think it makes it that much better and we've been careful to do that.

SPEAKER:

I think a distinction between Shared Decision Making and decision aids, as Leigh was answering this morning to the question, I forget exactly what was said, but about Shared Decision Making. I think good Shared Decision Making is an inclusive behavior in exploring someone's values and asking what is important. That is a path towards inclusion.

I think decision aids are a little bit interesting. We have a colleague who is Black and she's doing hospice Shared Decision Making for Black patients. She did some focus groups with some other Black people in Denver and asked if she should tailor this. Should the narrator be Black?

She got some pushback saying no and it would be so far out from what they normally see that they would almost not trust it and think you are trying to do something. That was almost as a surprise: can you make a tool that's inclusive or does it need to be tailored? I

think that's still a bit of an open question. Having a tool for each individual thing does create implementation challenges. It's hard enough to implement one version of a tool in implementing different tools for different groups it's hard.

I think the question of decision aids is still a little bit open and there's a lot of work we need to do on the as researchers. I think the behavior of Shared Decision Making will lead to better inclusion and better health equity.

SPEAKER:

I think I met this person. She said the outcome that comes up strongest in the Black is increased confidence in their involvement in decision-making. It even led to a different outcome that we don't necessarily see in White people, but again it's about being transparent about the evidence and communicating the facts.

SPEAKER:

Just one comment to add to one of the things we have been trying to work on is thinking about, as our implementation efforts are going, where's the flexibility and how do we make sure we are tailoring things to the different group's needs? Someone might just need a different type of decision support. Maybe presented to the patient portal with a call from our digital team who help people get on the portal, maybe they need a little bit more to get to the same place.

How do we make sure we are adjusting our resources and doing extra outreach to folks who might need more help, to get to these tools and to use them?

The other thing goes back to the development process. We are actually helping develop some new tools. If we know we are translating this into four different languages, we will design the tool differently, especially if there are video components. There are some things you can do to make it a lot easier to work better in multiple languages.

SPEAKER:

We have a couple of examples of what happen in Ottawa. We took the guide that I showed you and brought it to Indigenous women on how we could adapt it to the Indigenous population. We had to change all of the framing to be positive. Instead of saying you have a knowledge deficit, it says you want more information.

One of the other things that they said to us is the addition of Healthcare is funded through the Federal Government, whereas my Healthcare is funded at the individual level. When they saw it as a personal decision guide, they thought it was just another form to fill in. They wanted it to be another talking stick and not another form to fill in.

All of these decision aids should be talking sticks and not more homework for the patient to do. If you want Shared Decision Making, just give them a decision aid - that's not true. We need the decision aid to be that talking stick.

We also did a project in pediatrics with parents and children with types of insulin delivery. We were able to get children under five years of age to be part of this decision. One of the couples were divorced, with the child, and the father consented to the study and the mother did not. They went forward - it was facilitated by decision coaching because of the child. We wanted the child's voice to be part of this.

In the end the mother was like, "Oh my God, this is the first time we have been able to sit down and have a conversation about her child. It all focused on the decision coaching process, as opposed to all the conflict going on in the family."

I think there's a lot of other incidentals of how decision tools and Shared Decision Making and have other types of influences in situations where there's confliction or differences in terms of culture.

Sarah, you were going to make a comment.

DR SARAH MUNRO:

Just the idea that we need to reinvent what the format looks like in certain circumstances. Family planning tools right now, where Indigenous communities, clients have experienced a lot of coercion historically about forced sterilization.

The idea of engaging in shared decision-making for contraception choices - that's not the right approach to take. It needs to stem from talking to me about your family. What are your goals for having children? And just having the conversation is not talking about contraception first and foremost, but about family.

There's an interesting resource being developed in BC for the funding actually comes through the province and not federally. There is a First Nations Health Authority, in BC. They have developed a Shared Decision Making resource for Healthcare professionals in counseling for contraception choices to reduce the type of coercion that happens especially postpartum.

That's when there's been more cases of sterilization without any consent. This was developed in BC with (Name) to mitigate that practice that has been happening.



DR DAWN STACEY:

She does know what Shared Decision Making is. The one where we did the cultural adaptation and the talking stick. I will go to one more question and then open it up to the audience. What has been the most rewarding part of your work? I will go down the panel.

DR DAN MATLOCK:

It goes back to the slide with the Grand Canyon. It's really about that it's just a little bit counterculture, in a way that I think is important. That's what's rewarding to me and that's what gets me out of bed on the stuff. You are making the culture better, in my opinion.

DR RANDY MOSELEY:

I think I have similar feelings to that, that this is a bit changing the way medicine is practiced from less paternalistic, to collaborative. I think it's been exciting to be part of that.

DR SARAH MUNRO:

I started really young as a doula and not as a developer. Coming from those early practices, and seeing how the system has shifted, I think, like Dan said, it's really encouraging to see the changes that are happening in doing this work.

MAUREEN OSCADAL:

From a clinical perspective, I think working with people who have substance use disorder in people who use drugs, Shared Decision Making really supports that work and allows me to develop rapport with people that often have had pretty difficult interactions with systems generally, including the Healthcare system.

And being able to find out from people what they are looking for and harm reduction is a big part of my work and shared decision-making supports that. I appreciate being able to work in a setting where that is available to me.

DR KAREN SEPUCHA:

For me, I did mention I was an engineer. I really would like to change things and I'm not satisfied with this writing something and putting something in a journal. I really want to change in our backyard, and make sure that anything that we learn from the literature in the evidence gets put into practice.

I think the most rewarding thing is seeing how we are trying to integrate this into care at our hospital in our health system and making the difference for patients in helping to make sure we are amplifying their voice and giving them an authentic decision-making experience.

DR DAWN STACEY:

I will open it up to questions from the audience. We have a lot of time to hear your questions to the panel.

SPEAKER:

I'm Tonya and I'm a registered nurse at the Health Care Authority. Thanks everyone for the great information and it has been really exciting for me. One thing that stands out to me is that a lot of talk is about the providers and I think that a really big miss is with nurses and the other staff.

I have a daughter that just graduated from nursing school and she's never heard the term and she works in Acute Care now. I think it's obvious that nurses that are going to work in the areas that use it, like orthopedics and those kinds of things, will need to be educated and understand what it is but as everyone know nurses move around.

I think teaching about Shared Decision Making, what it is, how to use it, how to promote it, making it more of an open term in nursing school would be great. In addition, with patients and staff - I don't know if everyone remembers the big movement with washing your hands.

"Ask your caregiver if they wash their hands." Let's get some stuff about, "do you know what Shared Decision Making is? Ask your provider or nurse." With that the question is, has there been any movement in the nursing schools that you have seen or that you know of around educating the student or nursing students on Shared Decision Making?

SPEAKER:

I think I am the one on the panel that can answer this question. I am a registered nurse; I work in the school of nursing. When I started in 2005, I integrated into the curriculum, I integrated in four years and had modules and every across. And I published this. And then they changed the curriculum.

They decided it would only fit in with the theory course where we were able to talk about the augment framework, and the user online training module. And it could fit on the module -- in the module on breast-cancer period.

I had a birth control and first year. I had it integrated with decision coaching, skill development, and also, the University of Ottawa does not let us evaluate students very well from a research perspective.

It makes it extremely difficult. So, I kept teaching at the graduate level. I teach a graduate course in this to nurses. And my reward is, I have taught this course since 2005, or earlier in 2004. And Annette O'Connor set up the course and taught it before me. Every year,

students do an individual project, and it has never been harmful. It has always been eye-opening and positive. I think the thing that is most rewarding to me is when it works.

There has never been, even if it does not work very well, it is not harmful. Most of the time, you see that it is super helpful. So, I work with nurses around the world now. To try and really develop the nursing side and work with interprofessional teams and the training. And so, we have probably moved forward with decision coaching the most as the intervention where nurses feel comfortable in that role and decision aids.

So, happy to talk after. Anyone else on the panel can speak to nurses. I thought I would answer your direct question about nursing schools.

SPEAKER:

That work that I presented is almost exclusively influenced by (unknown name) or... and they are 80 to 90% nursing. Again, I talk about... We have not had the same success in primary care, even the outpatient cardiology, getting the nurseries engaged. -- Nurses engaged. Mostly because they are tasked with so much stuff, they are so busy.

SPEAKER:

Another opportunity in nursing that is in the literature is shift change. If it does -- is done at the bedside and engaging the patients and that and bedside rounding and patience even talk about. Like, there was a study in Australia, bedside rounding was happening and they were talking over the patient. And the patient visually just pulled the covers up over their head during that. Because they might as well have not been in the room.

So, it was a good example around it as an opportunity to involve the patient in terms of how decisions are being made and priorities. It is like they are at the bedside.

SPEAKER:

I would just add, from my experience and as a nurse, I think the first time I really started to hear about shared decision-making and work in that space was with my work with (unknown name) and I mean, I have been a nurse for about 10 years, so that was five years ago I was introduced to it.

To your point, it feels very natural in nursing to be doing it, but it is not something that is called out. It was not part of my education and I guess I graduated 10 years ago, so, yeah.

SPEAKER:

Thank you. I am (unknown name), I am from (unknown name) health.

SPEAKER:

Across medical director...

SPEAKER:

I was recently in some conversations around neuro- diversity and sort of how to be supportive of the neuro diverse community. And it occurred to me as we were talking today, what a great set of tools these are as well.

You know, maybe for people who cannot process something in the moment of a conversation. Not because of the language barrier, but because of cognitive deficits. And I am curious if there has been anything explicit around that. Has anyone's or thought about those populations specifically and how shared decision-making fits there?

SPEAKER:

I think we probably need a lot more work there. The only small study that we have been doing, just because we have so many needs are for older population, we have been looking at mild cognitive impairment, and does that make a difference in terms of their use of a decision aid. There are scores on shared decision-making. We actually found there was not any difference.

This was a study we had done. So, people came I think it was about hundred and 20 patients who were scheduled for a surgery and about 30% screened positive. They had not done a full assessment but screened positive for some cognitive insufficiencies. So, just trying to understand how we design these tools to be more accessible for folks who have different learning styles and communication issues.

SPEAKER:

I think that is where the power of the decision aid comes. You know, there were comments he made about what reading looks like. That was a challenge. We figured out we could not get him added ninth grade reading level and still be meaningful. So, there will be a segment of the population that will miss this.

I was saying that this being (indiscernible) to the open notes project. I am blinking on the lady at Harvard who has done all of this. Anyways, what one thing they found in their open notes study was that actually the people who benefited the most from open notes, meaning you can go and read your clinic notes, were people of lower literacy.

Because they did not get it when they were in the appointment for sub you have to know what you're talking about. They can go home, they can read it, they can talk to their more sophisticated friends and relatives and get it explained to them. So, to me, I think having decision aids that family and friends and whatnot can help with is just like that open notes.

I think that is a research-based statement (Laughs). Based on the open notes data.

SPEAKER:

I am not aware of any specific targeting. We did assess for this in our national needs assessment where we collected data on 2000 Canadians during COVID to look at what decisions were made. And we asked about demographics around neurodiversity as one of the areas.

We did not specifically, I cannot remember. It is published. I should go back and look at that group. I do not remember that group as standing out as having different needs than the others, but I should go and look at the paper.

SPEAKER:

My name is (unknown name), I am a patient advocate, so I am so glad to be here. And hearing your practice and sharing patient decision-making into the practice. So, I think that is great. So, my question to any of the panelists, what is your best practice to get a patient to be engaged in this shared decision-making?

They use at patient decision base (?). I know when we go to the doctor's office, it takes just a few minutes, 10 minutes, and it is very short.

And when you have this type of conversation, it is really not to say, "I have the greater tool you can use to make the decision." It is how patients engage to better understand the risk-benefit. Which is sometimes doing nothing alternative. We needed time to explore that conversation.

So, I am just curious, what is your practice? Your research that you found is a factor practice to engage patients to get involved. And your training to patients and in some way...

SPEAKER:

I might start with an answer. What we found is that patients need to be invited and explained. So, if you are using a decision aid, it is to say, "this resource is going to help you sort of think about the different options."

And then after you have had a chance to look at it, we will come back and talk about it. Patients have said they need to be invited in and then they want you to then talk about it after. Like, not just say, "this is your homework, go do it." And never hear back. After they want us to then say to them, "oh, let's talk about it. Do you have questions about it? What did you think about it?" It is the invitation at the beginning and end, I think, from my experience, is most important.

SPEAKER:

Is in the 2021 evidence of date for implementation. We described it as pairing and prompting the patient, exactly that. Just making sure that patient knows that there is a decision to be made... Decision coaching from another member of the team. Prompting again when there is an opportunity to have that decision encounter with a healthcare professional.

I think it also depends on the nature of that provider. Thinking of the differences between nursing versus a primary care visit that is 10 minutes long. Or a midwifery visit that is 60 minutes long.

Having the patient be involved may require different background support. Depending on how complex the traces are. So, just finding out what sort of tools are best for that specific choice for preparing and then prompting the patient. Because I do not think it is a one-size-fits-all answer.

SPEAKER:

In primary care, just generally, but also for opioid use disorder treatment, I think it has been really helpful for me and my team to ask patients what they already know and what they have already tried. Specifically, for opioid use disorder treatment, lots of patients have tried something.

It may not have been prescribed to them, but they may have tried (unknown name) or methadone or something that someone gave them. And they may have had a sense of what they did or did not like. In tandem with reviewing the patient decision aid, also gathering their expertise, and trying to gain rapport that way as well.

And building sort of a bridge for what we are trying to offer them is helpful. I think that could be applied to a lot of different primary care treatment options, whether it is hypertension treatment, or depression treatment, but specifically, opioid use disorder comes in handy because a lot of our patients have experience.

SPEAKER:

I think we have different wording, but similar messaging. So, we call it the warm handoff. You know, there has to be sort of this invitation and recognition of the decision and what they are shooting with this decision aid. If we are handing them something. And then close the loop. An opportunity to have a conversation after so they have a point to ask questions. And he won the team. It may not be the physician. Sometimes in primary care... It did not come up until -- as an issue until that visit. And then you can read this, talk it over with your family, and then we will follow up and figure out what that decision is.

As a phone call, is it a visit? Making sure there is that opportunity to close the loop.

SPEAKER:

I really like the work you are doing to connect the shared decision-making aid with patient reported outcome. That really tells how we are doing with this and how to impact the care meaningful to patients.

And I also like the question you asked about this equity issue; how do you use a shared decision-making aid? We know people with different languages, and also, people in general, are not literate about understanding medical terms.

Sometimes they do not understand that. So, you need time to explain to them to get them engaged. And that would be found out some way to really not just them, but even their family members, and they can help them to really understand what the tools and questions to prepare for the meaningful discussion.

So, thank you.

SPEAKER:

Hi, my name is Rex Johnson, I am with (unknown name) patient safety, I think that speaks for itself. I really thank you for what you are doing here. Most certainly, shared decision-making is extremely important. May I make a comment. I noticed we have providers, we have nurses, we have all kinds of researchers on this panel and in this group.

But you know, I see something missing. You know what I am talking about, right? I do not see a patient up here; we should really have a patient. And in your work, I would hope that you would do that.

I work with the University of (unknown name) we work with all kinds of medical institutions, and we are the patient. We are the voice that you are supposedly helping. If you leave that voice out, I think you have forgotten someone very important. Thank you.

SPEAKER:

I think you're absolutely right, Rex. It's easy to leave that voice out. When we started our shared decision-making journey – did not have a functional (unknown term) and if I were to do that again now it would really be helpful to have that from the get-go.

What we did is we tried our best to try and create something to impart useful information, but then we tested on patients. We actually gave it randomly to patients who were in the right demographic and asked them for feedback in a structured way. We got something like

100 responses or more. Some of them were like, there was an English teacher who just crossed everything out. (Laughs)

But most of them were really helpful and constructive things. Like the one for women aged 75 and older, the colors were such that there was not enough contrast in the print on the page. Really some practical things like that that we had not noticed.

So, we did try to get the patient voice and feedback before we finalized the product. But I think you are absolutely right, and I think 2014 we didn't really have a functional (unknown term) and if I were to do that now with confluence I would start with the (unknown term).

SPEAKER:

Sarah and then Dan.

SPEAKER:

A probably be misquoting this because I was looking this up yesterday and it was a systematic review by colleagues of ours, the anchor author was Hollywood remains in its lead by (Unknown Name). They looked at the user centered design of patient decision aids. One of the outcomes they looked for was outcomes of studies of patient was involvement in decision a design.

While patients were involved in testing tools, I think it was 8% of studies who put it that patients were actually involved as members of the team and involved in the development process and most studies didn't report on what that looked like, where they member of the team, advisory circle? I think there's a lot of work left to be done in that.

SPEAKER:

In the update reviewer presented this morning we put whole section and on whether or not patients were involved in the development, and it was terrible. It was around seven or 8%. I don't know the number but it is really super low. Surprising with Corey saying we should be doing this, but Maureen Smith and we have two other patients, Janet Gunderson and (Unknown Name) from Denmark, they are also the ones in all of our meeting saying we need to think about the patient all the time.

My graduate students have patience on their research studies as well so they get used to entraining learning how to work with patients as part of the project team.

SPEAKER:

I was going to jump on the (unknown term) comment. When you're talking about organizational buy-in I think the patients in our hospitals and family centered care counsel



has been helpful in pushing conversations up in in our research group we have a standing patient panel that we meet with every month or two to just advise us on various ongoing work. And then for each project we bring them in, but you're right. When it comes to doing the work of implementation, we haven't even really figured out what is the best way to utilize patients except for creating conversations like that. I think it's a good comment.

SPEAKER:

I'm Janice (Unknown Name) (unknown term) advisor and I work with these two. I have some suggestions , rather than questions.

One is for years I have been using informed shared decision-making, and people will say to me, whether implementers or researchers, "What does that mean?" In my opinion it means both the patient or care partner or whoever is where's the clinician are providing a really informing each other and it's implied and shared decision-making. I don't think it's necessarily called out.

I just wanted to mention something on DEI. In the last year the Black baby in utero came out and that made such a humongous, it was the first time mother saw a graphic of a Black baby and a Black mother and people were so excited about it. I think if nothing else the situations, mortality, and maturity situation, that's an area where it would be worth it to have if not a central but a secondary Spanish-speaking to have African American maternity.

The other thing is going to comment on was something Don mentioned earlier and I forgot to mention. It was around literacy, but it also has to do with shared decision-making around a diagnosis because more than once I have heard of individuals who had a positive test and they thought it was positive, not understanding that it means they have the cancer or the blood count is high or whatever. You can comment on none or any if you'd like to. Thank you.

SPEAKER:

It's really helpful having the reflections of the three of you actually around the conversations we've had today from the panel in thinking about the patient's voice in all of this. As your mentioning we need to be thinking about their interpretation and what this means visually, what this means it's very concrete how important this is in terms of having patients involved in development and decision aids, and the team evaluation and our team of systematic reviews it was super helpful. They've been involved since 1999 in the Cochrane review because Cochrane requires us to have patients on the team.

Then also in implementation because we need to be thinking about how we listen to their voice. This can be done through consultation with advisory panels. My preference is I like

having them on my team if they will volunteer to come to our meetings every two weeks and I have had success because some people actually get really excited about being able to be on these projects and really on the leadership team of the project.

Any other comments around the patient's voice on our work that we do?

SPEAKER:

I was just reflecting on my experience with implementation in an integrated delivery system and HMO. One of the things I was thinking about was cost. Cost usually comes up in some form. Whether RX or the treatment you are talking about.

And then in training even my learning is that some providers are not comfortable talking about cost, and in healthcare system a lot of our members don't understand the benefits and coverage. Just with your experience how can payers or health insurance companies be better partners and make sure your shared decision-making tool is successful?

SPEAKER:

We were involved with the project led by Emory taking one of our decisions, I don't know if it's a decision to about one of my colleagues made this patient directed tool route heart failure medicines in his study was to randomize people adding cost to it or not. The hardest pieces what is that patient's individual cost because it's different for everybody.

We worked with this company that's giving tailored costs and it was a ton of work so how could insurance companies help? They can help us be more transparent about the costs. It would be a lot easier to talk about because I think a lot of the fears the doctors have are that we just know that you don't know what the costs are. We know whatever you say could be wrong based on their insurance. I hypothesize, it's not as much of an aversion to the discussion as it is we don't know what to say and did not try we actually saw pretty big effect. It was recorded in the outcome and will be coming out soon but there is an increase in cost discussions when you add cost to this thing.

I don't think it's here those cost discussions, it's just we don't know what to say because we don't know the costs. I think insurance companies could really help with that.

SPEAKER:

I agree. We don't get training as physicians in medical school around that. I think talking about cost can really help the patient in front of you decide and make the best decision for them, and that something they might even bring up with you in the work that you are doing. Thank you for that.

SPEAKER:

I encourage you to look at Mary (Unknown Name)'s work because she's been publishing on reporting costs and decision aids. When he went to do it was in intersex babies and the cost of genetic testing. It was a nightmare to figure out. Nobody publishes the cost.

But what Mary has done, if I get it correct, and she actually uses the number of dollar signs, just like restaurants. When you go and check restaurants online you can see a number of dollar signs or is it a one \$ type restaurant or a five dollar signs restaurant on a scale of 1 to 5.

I think that might be a better way for us to think about how we talk about costs and the decision aid. But then there's problems with insurance coverage. Which is even a more complex cost, or an issue around cost.

So, costs have not been consistently integrated into patient decision aids. (indiscernible) has no criteria on costs because it's complex. It's complex for everybody.

It's Mary, right? She does the dollar signs, yeah? Oh yeah?

I think it gives us a good time to just wrap up the session thinking about implementation. I went back to Karen's slide to keep it up during the panel discussion because I think in this line, she talks about two things you need to be thinking about with implementation, many of which have come up during panel discussion.

We really need leadership support and thinking about how we do that. We need to think about workflow design and not think decision aid or shared decision-making is automatically going to fit.

Looking at the EMR and how can we capitalize on that in terms of the delivery process, and also on capturing data or measurement and can it be used. We need to think about monitoring improvement because really, it's that number thing and it can be used to bit as a competition when you're looking at different sites across the US or Canada or whatever when we are doing research, but also internally.

They want to look at how do we continue to improve. And then decision aid delivery. It's a fiscal thing that needs to happen and how is it going to be delivered?

And then the final one we didn't touch on very well, or not at all, is the scaling up piece. I look at Kiel University Hospital in Germany and they have exploded in a couple of years and implemented 86 decision aids in most of their departments. It showed cost-benefit of the whole thing and I'm like, oh is this sustainable? Are they going to be able? They scaled up immediately but sustainability is another issue we need to be thinking about.

And so, as I mentioned in studies if we have someone delivering a decision aid that's paid for the study trial and we need to about how do we have that happen within the system as opposed to an external cost or an extra cost.

And then the center is champions. We need to think about champions that are researchers, champions that are clinicians, champions that are patients. I have champions that are patients who are fantastic to work with because they really are getting the message out. We need to think about who it is we need to be thinking about when it comes to implementation, so hopefully we stimulated you with lots of thoughts to take back to your own settings and what you might think about with implementing shared decision-making.

SPEAKER:

Thank you Dawn and panel members. We appreciate it very much. Let's give them one more round of applause. We will be breaking for 15 minutes. We will come back here at 3:15 PM.

There are some snacks over here to get you through the rest of the day. So, thank you.

(BREAK)

**DR HEATHER SCHULTZ: Implementing Shared Decision Making into Practice: Next Steps** (Presentation slides 259-270)

I will go ahead and get started with the last segment of today. Which is taking everything that we have heard and talked about earlier to transform that into what are the next steps that you can take back with you. What are resources that you can use to implement shared decision-making into your practice or into the practices of organizations that you partner with.

So, included in your folder is a one page sheet that has an action template on it. It is two-sided. The first side has a few questions to think about as you are approaching thinking about implementation. Starting with the current -- is your organization do -- doing share making for some of the answer to that question is yes, think about where you are at in that process. Is it a nameless the implemented workflow -- seamlessly.

Are you early on? Are there barriers that you are coming up against? If the question is no, think about what would need to change in order to get you there. And regardless of whether the answer to that question is yes or no, whether you have started on that process or whether you are just thinking about it, really thinking about solutions for barriers that you may be facing.

And one of the resources that we have included is this national quality partners playbook that was included in everyone's folder. I will go into a little bit more detail about how to use that playbook on later slides. But the playbook has very specific actionable solutions for each barrier that you might encounter during different phases of the implementation process.

Another important question to think about is, who do you need to partner with? Who else needs to be at the table as you start to think about putting this into action?

And then what specifically might you need from those partners to make this a reality? At the bottom of the slide you will see that there are links to both the online version of this playbook, and then also, the brief collaboratives, report, and recommendation, which the template is pulled from and then references, the national partner of qualities playbook.

So, the national partner of quality framework has a six fundamentals that are included in the playbook. Starting with what we have talked about many times throughout the day. Leadership and culture is foundational for any sort of change initiative. So, you really want to make sure that leadership at all levels of the organization are engaged and aware, and then make it a part of the culture of your organization.

So that shared decision-making does not feel like a side project that is off to the side that only some people are working on, but that everyone throughout the organization can really talk about. It is important and how they are implementing it. As we have also heard and talked about today, patients are at the center of shared decision-making.

So, patient education and engagement is key. It is not always clear, as we have heard from some patient advocates today, that we include the patient voice at all of the steps through the process that we should. So, thinking about how you can include them when you are in that contemplation phase and thinking about getting input from them.

As well as educating patients so that it does not become a situation where you are just handing them a patient decision aid, expecting them to know what that is or how to use that. Providing a framework for what is expected from a patient when they are part of that shared decision-making.

It goes without saying that the third fundamental healthcare team knowledge and training is also very key. As we have heard from a number of people today, it is not something that is necessarily part of formal medical education. And it is something that providers often feel that they are doing in some way. Because we know about patient education, and we know about informed consent and most providers do experience dialoguing with patients and having a back and forth.

But really providing more explicit training and what is shared training is and not focusing solely on the clinician. Nurse practitioners, nurses -- physicians, nurses, but also office staff, and people who are providing ministry to support our key, too. Because they may be the touch point for handing out patient decision aids. Or the contact point when patients have questions about that.

You really want everyone to understand what that process is. Those support staff can also be helpful in figuring out where the kinks might be in the process as you are trying to implement something that is not going to disrupt the current workflow that the healthcare team has.

Obviously, after thinking about engagement with leadership and the healthcare team coming in and getting specific about what does that look like to put it into action at your organization. Are there ways that you can incorporate it into your electronic medical record?

Are there clear barriers to getting that work done? Or will there be additional staff that is needed? I think as we all know, there is no additional staff for most healthcare systems right now. So, try to be thoughtful about how do you incorporate this work into work that is already being done. So, I think from a planning perspective, you really want to have buy-in and ownership from the people that are involved.

Right from the get-go. So, they can walk you through what it is they are currently doing and how they can incorporate this shared decision-making work into what they are currently doing.

As we have also heard from several of the speakers today, once you get the process going, it is important to actually check back in and see what kind of progress you are making. So, as we talked about, there is a number of challenges in figuring out how exactly you measure that. Is utilization enough? Probably not. I think when you think about just initial steps, figuring out anything you can do to start tracking so that you can at least get a sense of where some pinpoints might be are where you need additional information.

And reporting that out regularly. The sixth fundamental that national quality partners describes is accountability. And that is -- relates to trying to feed all of the things that we talked about into consistent reporting and goals. So, at every level of the organization, either there is performance measures or expectations of how that work is being done, or how shared decision-making is being incorporated in all of the work that is being done at the organization.

So, the pre-collaborative's report on decision-making uses, for the template that was included in the folder, a stages of change approach. And then they overlay the national quality partners six fundamentals on each of these stages of change.

So, for the six fundamentals, they provide examples of basic, intermediate, and advanced, and the idea is not that you are necessarily on a set guide where you are moving through this very fixed steps, but the different categorization of basic or intermediate or advanced is more about how much resource you need to do it.

How much organizational effort and time intensity you need. So, you do not necessarily have to do basic first. Although, as this contemplation slideshows, probably when you're thinking about how to get this going on your organization, if you have not started at all, going through the different six fundamentals, and looking at the things that are less resource intensive is a great place to start.

And then focusing on changing culture and getting leadership buy-in at the start. And the slide as well is a link that we will give you shows the page that you would look to in the playbook to get more specific examples. At the end of each section with the fundamentals, in addition to showing basic, intermediate, and advanced, they also have a specific, real-life clinical vignette of an organization that put this into practice, and challenges they face and how they overcame those barriers.

Moving into the second change of stage preparation, that is when you really want to get your healthcare team on board. And make sure that you have appropriate training and that they are knowledgeable, as I mentioned, on the previous slide, you do not have to start with the basics.

If you actually have the organizational support and resources, you can do some of the more advanced examples. If you feel that you are ready to do that, or if your organization is already there and has started that, that can be the next steps as to move into the intermediate or advanced more resource intense evidence of knowledge and training.

Obviously, what you really want to get to is the action itself. As we talked about throughout the day, really thinking about the logistics of how you make it work.

What are the things that you would want to focus on in terms of is there a service line, or particular department, or a decision, clinical procedure, starting there. If you are a little bit further along and you have things working, is there a way you can take that work and move it to other places and organizations?

As we have talked about multiple times, I think, the importance is getting as much feedback as you can throughout the process. I think sometimes in healthcare we have a

tendency to get the experts in a room, figure out what the right plan is, and then try to roll it out, only to discover that there are many different things that we did not consider.

So, I think it is really important to, before you get to the action phase, think about all the players that you need at the table and talk with all those folks to figure out how you can best problem solve some of the obvious barriers. There will always be struggles and challenges that come up with any new implementation of quality work.

If you can get people who do the day-to-day work, as well as the patients, and get some input, I think that is a good foot to start off on. And then maintenance. This fits in with the fundamentals of tracking, measuring, and reporting.

And the thing I like about this slide and the little circle is that this process is iterative. It is not like you get to the end, you are in maintenance, and you are done. This is the type of work in which there is probably always going to be opportunities for improvement or utilizing it in different areas that you are not currently utilizing it.

So, thinking about ways that you can track what you are doing, get that information back to the people that are doing the work, get feedback from them, and importantly, get feedback from the patients to know if the work that you are doing is having the outcomes you are expecting.

This piece again is where you can hold people accountable by setting some goals of this is what we expect in terms of utilization, or these are the type of goals that we are expecting in terms of outcomes. Obviously, not using those in a punitive way, but if you are not hitting those, go back and figure out where are the barriers and what needs to be done to overcome those.

So, this slide shows some additional resources as well. There are - there is no one right way to do this. So, we provided all of these additional resources so that folks can look through these, find what resonates with you, and kind of borrow and pull together an implementation plan that will work for you.

Before we wrap up for the afternoon, we wanted to just kind of present what our help from the healthcare authority is, from the vision of shared decision-making in Washington state going forward.

Of course, we would like to continue the promotion of shared decision-making and the use of certified patient decision aids. As we have talked about many times today, reducing unnecessary variation in healthcare. The goal is not necessarily for a specific outcome with shared decision-making, there is not a one right answer of what you are supposed to get, that is a point of shared decision-making.



Making sure you are honoring the patient's values and preferences and getting the answer that works for them. And then figuring out ways, I think this is one of the most challenging parts of shared decision-making, of how you actually measure the quality, as we have talked about several times today. Particularly with electronic records your contracts being used or lease was being looked at but do we know for having the impact that we want. I think that's an area that's right to continue thinking about and discussing.

From the Health Care Authority's perspective we are interested in continuing to get submissions for patient decision aids so we can certify those. So, if there are patient decision aids with vendors that you are working with or if you have ideas and you would like to go through that process we are very interested in receiving more and working with you on that.

And then ultimately the point of this discussion today is to engage patients. It's about patient centered care and really trying to get at what is meaningful and important to patients in ways that can impact their health more positively, both in getting to the clinical outcomes they want and also just patient experience that's more positive for them.

So, this slide shows the email address if you have additional questions after today or if you have thoughts please shoot us an email. We also included the link for shared decision-making website on Health Care Authority website it's got all sorts of great information including not only the history of shared decision-making in Washington state, but a list of currently certified patient decision aids as well as a link to virtual online training that is excellent and runs through some different primary care and orthopedic scenarios that you can work through and get continuing CME credit for.

And that is it for today. I am going to just give some next steps on what to do after we leave today. So, we will send out, so many people were taking pictures of various slides today but we are going to send out all of the slides that you guys saw today. We will also send out links to resources that have been mentioned. There are different additional virtual training opportunities in addition to the one that's online on HCA website so make sure to get those two folks. And then we'd really like today to be the start of an ongoing conversation.

One of the goals of the workshop today was to get people engaged so that we can have a shared decision-making learning community that would be virtual, and what we are hoping to do with that is HCA will be the convenor. We will have some virtual meet ups and people can come in a more informal discussion mode, either possibly with specific topics of discussion that we wanted to do, perhaps in a quarterly fashion or more often, the details are still being worked out but the idea would be people who have had successes with shared decision-making would be able to share those successes and people who are

having difficulties or struggling so that we can learn from each other and keep that conversation going.

We have an online survey that we are going to send out. Please look in your inbox for that and make sure to get that back. We would love to get feedback on what worked today, different things that would be interesting to do particularly in this virtual learning community we are interested in getting implemented.

And then just as a housekeeping item for those people who have parked and have a parking ticket there's a second parking ticket we can give you that will get you out that is paid for. If you need that I believe shall be? Yes, Shelby is the holder of the tickets and she will be able to get those to you.

I want to thank everybody. Our presenters, all of the attendees for the engaging and inspiring discussion information that was shared today. I feel ready excited going back and I took copious notes as people were talking, and I am excited to see what we can all do next. Thank you.