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DECISION-MAKING STEERING COMMITTEE WEBINAR
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00:00:01 MOD: Good morning and thank you for participating in the Decision-Making Steering Committee speaker series. My name is Amola Surya and I will be moderating today's webinar. I'd like to introduce this morning's speaker, Dr. Jeffrey Williams, Director of the Healthy Living Center at the University of Rochester. Dr. Williams will discuss his personal experience as practitioner and what he identifies as the most challenging issues in cancer prevention and treatment.

00:00:29 At this time, all participants will be in listen-only mode. We will then open up the floor for an open discussion format. Please note that this webinar is being recorded. If you have any technical difficulties or questions, please enter your question in the chat window so we may help you. I will now turn the call over to Dr. Williams.

00:00:56 DR. WILLIAMS: Hello, everybody. It's a real pleasure to have the opportunity to present today. It's also quite an honor to be able to participate on this steering committee. This is one of my very favorite things to do, which is putting on my

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clinician hat. My background is that I'm an internist, and I'm a health psychologist, and I have too many fellowships, but one of them I conducted with the National Cancer Institute actually studying brief intervention models for physicians and have done a lot of training for that, but eventually found that intensive interventions in our research were in many ways needed to detect some of our effects across the models that we were using.

0:01:54.3 So where I've ended up is that I see people in consultation for intensive treatments around tobacco dependence. I am also board certified in lipids and hypertension, and I work with people about diabetes prevention and weight loss as well, so physical activity and nutrition. So it's a rich and complex group of things that I will be asked to work with patients about. We also study our interventions as well and research them.

0:02:27.1 But the clinician hat is a special hat, and here the advent and the development of the endorsement of lung cancer screening with viral CT scan has been endorsed

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by the U.S. Preventive Services Task Force on a B-level evidence and what I find, I find it very interesting and challenging to work with smokers and ex-smokers about this issue as it comes up. And I'm going to talk a little bit about my experience with that without definitive answers and also about how I apply, try to apply theory and models into the actual care of the patient.

0:03:19.5 And so if you go to the next slide. So the overview here is I'm going to discuss what I think are some opportunities and dilemmas that relate to the health of the patient and how clinicians and systems may best support and improve that health. And very interesting to me about this particular test is that we're talking about a lot of risks and benefits and opening up a new area that smokers I think value greatly to understand more about their risk for lung cancer and to be able to have the opportunity to do testing on this.

0:04:01.7 And this relates for those that continue to smoke their abstinence from tobacco, but it also relates to their possible risk to relapse. In addition, this

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particular test provides an opportunity because we don't often always get to see smokers so often; they don't come in as frequently as other people and they suffer more with other diseases. And so this may represent some particular opportunity to talk with them also about cardiovascular disease and COPD that this test identifies. And I'll talk just a little bit more about that later.

0:04:37.0

I decided to provide—actually there's—I ended up with four models, I ended up saying three models; sorry, I meant to change that in the slide. But informed decision making has an interesting perspective on this, medical professionalism and medical ethics, which actually informed the practice of medicine. And then what I want to comment a little bit about what I've learned from smokers themselves in talking with them over the years and then self-determination, self-determined motivation, which is based on a theory of motivation and change. And then try to sum up at the end of that.

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0:05:11.5 So next slide. I like to start with a case. I've probably met, I'm not sure, 40 or 50 smokers since the guidelines came about, but this is a particular person who is a 56-year-old woman who smokes a pack per day, so she has 40 years of smoking and being over the age of 55 and with more than 30 pack years qualifies her for this recommendation. It turns out that she also has prediabetes and we found in—I've been tracking this for some time but that 2014 Surgeon General's report identified that smoking is a cause for diabetes and insulin resistance.

0:06:06.6 And she also happens to have rheumatoid arthritis, which is also linked now to smoking. So those are interesting clinical features in the background. She has hypertension, which is controlled on two meds and hypercholesterolemia. And we recently had headline changes in that area. We're not actually supposed to set an LDL goal according to the U.S. guidelines. But all the other guidelines in the world on cholesterol have retained that for this person probably we would want an LDL to be less than 70, which is where this

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reading starts. I'll come back to that more in the future.

0:06:41.4 So she may be at twice the level of LDL cholesterol that's healthy for her. She is up to date on immunization. She saw me in the context of tobacco dependence treatment, so she had some motivation around that. But discussion about the spiral CT for lung cancer screening was unexpected to her. And her results showed no suspicious lesions for cancer, which was very positive, but interestingly enough it identified that she had a coronary calcium in her coronary arteries, which gives her a diagnosis for the first time of atria [ph.] sclerosis and coronary artery disease.

0:07:25.9 And it also identified emphysematous changes. So most smokers with this many pack years are going to have some level of emphysema even if they haven't been clinically diagnosed. And so that was also a new diagnosis for her as we went through this. So my question is there's a lot of territory here to cover with patients about this particular test, one of which

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is about the level of cancer. And you can go to the next slide.

0:07:57.0 So she agreed to start atorvastatin and she's on 20 milligrams, her LDL came down to 64, which is pretty close to her target. You might argue to go a little bit lower, but I'm not going to get into those details. This is a very positive response to the atorvastatin. And her blood pressure remains well controlled, and with all of this information she did stop smoking and has maintained her abstinence now for 10 weeks.

0:08:28.7 And so in summary, here is a woman with 40 pack years of smoking, she needs to continue the lung cancer screenings, so she needs to be motivated to continue and follow through with this, at least over the next 2 years to complete the protocol, but probably we're going to be going on with doing screening over a period of time, up to even 15 years before her risk falls to that where it stops declining for risk of lung cancer.

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0:08:55.6 Her cardiovascular risk interestingly probably falls as best I can estimate from 11 percent in the next 10 years to 2.5 percent within a 2-year period of time as long as she stays on the statin and she remains smokefree. She's already noticed less leg and joint swelling when she walks, her emphysema and symptoms are stable, coughing has more or less resolved and she really does not notice much in the way of shortness of breath. And she is now increased her walking to 40 minutes per day and is working to increase fiber and other changes in her diet to be healthy. So that's the net effect of our entire work with her.

0:09:36.7 Next slide. I think we went two—so I posed a series of questions, for instance, it's interesting to me, I wasn't sure that she would agree to the screening, and I think the very first introduction of this when it's new to patients and for clinicians for the first time going through this, they're going to be seeing them in primary care or perhaps for other reasons like I was, and presenting the concept to them, and I think we want to attempt to understand what the meaning to this smoker is around getting these tests and what the

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meaning to us as clinicians around getting this test is, and then you can also ask the question of what does it mean to be offering this test from the health care system's perspective or even from society's perspective about why we would be offering these.

0:10:35.0 I'm curious about which part of this assisted her in her motivation to stop smoking. She said this quit attempt is very different than all the others that she's had before. She's never maintained any period of time of abstinence before, but this one really qualitatively was different for her; she's much clearer about why she's doing it. And then to discuss what potential benefit and what limitations may be put on this test. So. Next slide.

0:11:05.9 So a few thoughts about why she agreed to the screening and presenting this to her. We know that there's a 20 percent increase in length of life across the population of people who get this, but that doesn't mean that she's going to get this. And in fact, only one of several studies that have been done on the CT scans have shown this benefit. It happens

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to be the largest one—the national lung cancer screening test here in the United States with over 50,000 patients in it.

0:11:36.2 But that kind of message to her, I mean we might find an advanced cancer, but I think that this test operates very well because if you get a negative result it has a very high negative predictive value. That means it's very unlikely that she has cancer at this time. And that's the result that she got. I suspect that that is more what she's looking for is to feel better about reducing the threat that goes on in the back of her mind all the time from this continued— from her smoking.

0:12:10.9 So the function of the test is best with a noncancerous test result. But when you do this screen, only 2 to 5 percent are found to have cancer. But of the cancers it has to be the nonsmall cell for the person to get the benefit from it as I understand this test as it goes out. So there's a lot of nuances to how we might present this that might relate to why she would agree or disagree to this test. And I'm

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listening very careful to the patients as I talk to them about this to see how that might be best presented. Next.

0:12:55.7 And why do we recommend it? I mentioned this before; I think it's particularly important that this is a B-level evidence. That means that we have a few studies or one large study that shows a benefit. It's possible that we are not—you know, over time with additional evidence—not sure that there will be many more studies with 50,000 people in it, but this level of evidence has a potential for change. As we mature and get more into the studies behind it, and into the practice of it we're going to learn a lot more about this.

0:13:33.3 And I think that it's also important to recognize that the way this test works is it identifies more nonsmall-cell cancers at earlier stages; it has to do that in order for them to be resectable for people to get the benefit. There are small-cell cancers that don't respond to the surgical option and we're getting a bit better with those treatments, but if you happen

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to fall in that category, this test doesn't necessarily help them.

0:14:05.6 I just mentioned in the large study the T1, the first year, 27 percent of the scans were positive, meaning they found abnormalities that needed to be followed. Smokers have a lot of abnormalities in their lungs, but only 2.4 percent were found to be cancer. And then at Time 2, 17 percent found to have some abnormality, but only 5.2 percent to be cancer. So this kind of detail in a B-level evidence is important for us to keep in mind as we're counseling our patients.

0:14:37.8 The cost effectiveness is, you know—it's 200,000—I believe it could be per life you've saved. I'm sorry I didn't identify that distinction. But the sensitivity analysis of this suggests that it may be pretty important for the person to quit smoking as part of this in order for the cost effectiveness to really be improved. And so I've included what's in our national guidelines for intensive cessation services is about \$3,500 for quality-invested life you've saved. Our own intervention costs about

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\$1,500. That's the one that I use when I work with our smokers.

0:15:24.7 I'll present a little bit on that later on. So another interesting question is do we bundle the smoking cessation services for those that are continuing to smoke. And remember, even if they're saying that they're not smoking, they are at risk for some time, for a period of time I will say at least for 2 years, but maybe up to about 5 years for going back to smoking under distress. So we can't lose sight of those former smokers that would be getting this test, they may be starting to smoke again. We need to be asking again about that. Okay, next slide.

0:15:58.0 Why did she stop smoking? She was in treatment for cessation. She was already motivated to do that. And there's discussion in the literature here that this test result, you know, she might have looked at this to say oh, wow, I've quit smoking and I don't have lung cancer and I really don't want to continue to smoke because I don't want to be faced with that

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anxiety or as much anxiety in going through this test again and again and waiting for those results.

0:16:29.5 Another side of this that's been identified and discussed in the literature is there's fear that if smokers get this test and it shows that they don't have a cancer; that gives them permission to go on and smoke. And I haven't heard that yet from anybody, but they may not be willing to tell me that as a clinician. But I do think that how the patient is interpreting these results is important for us to follow.

0:16:52.6 I mentioned here the Danish Lung Cancer Screening Study, which is an annual screening for 5 years, they found 17 percent of their active smokers stopped in that period of time. And when they, and this, at baseline they asked them how motivated they were on a five-point scale. And those people that were motivated or very motivated, this was even a higher result. They did not find in this study of about 5,000 people randomized to receive this test or not,

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they did not find an increase in quitting in the group that got the test.

0:17:27.2 So the test itself didn't seem to motivate them. I wonder about the framing of this and how we—if we can attend to motivation within the time and the way that the results are presented and the test is being performed might make a difference there. There is a small study, just 18 subjects, half of them got counseling before getting the lung cancer screening versus getting it after, showed a slightly higher rate of quitting if they got it before that. That makes some sense to me, so that they can begin to integrate and use that information. It may be a teachable window. So I think that's something to be explored further.

0:18:17.8 The PDF, by the way, that I'm referring to here, we're making up a bibliography and we'll send them in so that you can look at them. Next slide. So the last specific question that I have here is what benefits come from the test? Well for her, I think maybe some reduced anxiety might be important as anything that

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might relate to the quality of her life. I don't know exactly how an individual experiences when they go through a test like this when the rationale is given that a population lives longer we see an increase in life expectancy, you have chance for that, how the individual experiences that. And I'll comment a little bit more on that later.

0:19:05.2 This test also identifies that she had cardiovascular disease and we could make a big improvement in that risk over time, which she was very interested in and very willing to follow along with. And then the information about the emphysema may also be important. In talking with smokers over a long time, they frequently will ask, well, I need to see that I have some problem before I'm going to take this seriously. And this is one of the places where we can give them that information. And I think I've covered the last two points here. Next slide.

0:19:45.9 I'm a little out of order from what I said I was going to do in the overview, but the smokers' model, one of the things that I've found over the years that was

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articulated well in this commentary in the Archives of Internal Medicine entitled Live Fast, Die Young, was a good-looking corpse. I have found most of the times smokers are not very responsive to length of life arguments about why they do this. They are, however, very interested in quality of life arguments. And I suspect that that's where the greater meaning is. I'd like to see more research on that be brought forward. But the action for me clinically very much has moved to talking about what would be important to know for you to hear about or find out about how you're going to live going forward that would be meaningful for you in your decision here to stop or not.

0:20:48.2

I mentioned that many smokers are very dismissive of these risks and, in my opinion, I think that's denial in many ways, but it may be a variety of other things. But if we can talk to them concretely about what we see in this test, I think that helps them and it may be that we can show them risks in several areas that that adds up to be more meaningful, particularly if these risks can be reduced over time. Okay, next slide.

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0:21:23.2 So another one of the models, this is from Clarence Braddock [ph.] and others. This is published in JAMA back in 1999. They audiotaped about 1,500 physician/patient encounters and divided them into simple, moderately low, complex, and very complex decision making and set up a criteria for what they felt would be—how much information do we need to provide people to understand that they are informed? And in this particular study, the thing that we did the least was to invite the patient in to make the decision, identify the patient role. It was only found in about 5 percent of these cases.

0:22:09.3 The nature of the decision was covered fairly well. I think we do that in clinical practice reasonably well. Whether the alternatives are laid out, we weren't doing very well at this time discussing the pros and cons, and is again less than 20 percent of the time in these studies and something that we can improve on. We did not check for patient understanding. And I think that is really important. I think this sort of model can inform the clinicians a lot about what our

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task is and how we need to do this. That's why I'm going over it.

0:22:45.8 But we obviously don't cover all these dimensions. And I think this could be explicated for this intervention as a package for people to know what we need to cover. I would consider this lung cancer screening decision making to be a moderate complex, could be very complex though. And the one that's labeled as uncertainties here is only included and required for the complex decision making. And the reason I bring that up here is that this is only B-level evidence. So there is some uncertainty in this field. And how much we reveal to patients around something they're very anxious about is, I think, needs attention and we need to be paying attention to how our patients go through this.

0:23:39.7 So I like the sort of model. I wanted to present it here. It could be applied in the circumstance and I don't know currently if there's such studies underway. So next. Clinically, I use and teach for our medical students and residents and attendings when we're going

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over what are the goals of your intervention, what are we trying to do here, I use the document that came out in 2002 around medical professionalism that's an integration with biomedical ethics, I'll go into just a little bit more on the next few slides, but the ABIM published with organizations around the world that we need to move beyond just do no harm and beneficence.

0:24:29.2 We need to move beyond just the primacy of patient welfare, although that is still a highest level goal. That is felt to be, we need to be dedicated to serving patients' interests, both related to their physical and mental health, both to the quality of their life and length of life. And that is what our—whether it's from a health perspective or from an individual patient/physician interaction, we need to be dedicated to providing the best outcome here.

0:25:42.8 But at the same time, patient autonomy has now been promoted to an equivalent level outcome. And that is to empower patients to make informed decisions and to also to eliminate discrimination, are the two ones that were most recently added. And I think that these

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are interesting. Right now, our outcomes do not credit patient autonomy as an outcome in itself. In other words, if we go through all of this information provision and the patient decides to not follow through with our recommendations, but they're more autonomous, that should be categorized as a positive outcome.

0:26:22.4 And right now, our research base that's informing our clinical practice categorizes that as a negative outcome and the pay per performance pressures that are getting put on physicians are seeing that as a negative outcome. We need to bring those into alignment so that the actual practice that we're doing around autonomy and informed decision making and patient welfare, such as what goes on in the lung cancer screening, needs to be worked out very clearly so that we keep both the clinicians and the patients motivated. All right, next slide.

0:27:00.6 The biomedical ethics that lie behind the medical professionalism is that we are working with patients in a free-choice environment and that is critical to

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understand, that's why autonomy is so important because patients in the real world don't have to do what we say. But we need to establish relationships with our patients that leave them feeling that we are competent and trustworthy. And those are some of the basic aspects of our ethics.

0:27:38.3 Next. This also applies at the society level as well, even the decision to rate this as a B-level recommendation and to bring this forward to be recommended is one of those at the society level. If you look at the specific contract with society, the ethics are nonmaleficence. That goes back to Hippocrates: Do no harm. Beneficence I think is important and relevant to the lung cancer screening. But it's a group of norms pertaining to relieving, lessening, or preventing harm and providing benefits against risks and costs.

0:28:24.4 And I think this is required in this counseling, particularly this coronary calcium score. Right now, I think if we find it there, and this test is good at finding this, we need to provide that information, and

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right now I think there's discussion nationally about whether those results are going to be included in these test results. As I understand, the radiology societies are considering not providing the coronary calcium scoring. But I think that as an individual clinician that it's important that that test result, if that result is in this output that we have, we need to be discussing that. And that makes it a broader intervention than just the lung cancer screening.

0:29:02.0

Just this in respect to autonomy appeared around 2000. That's a very interesting history in itself, and how it evolved. First of all, was the first person to write the modern medical ethics, that was in 1802. Around 1950, when our intervention started getting better, health psychology was born because we had effective interventions, but we realized the patients weren't doing what we were recommending all the time, and so very observant clinicians like George Engel and others started listening to patients to hear why they might not be doing that.

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0:29:44.1 And we recognized indeed that they had different motives and they were thinking about this differently than us, so about 50 years later bringing that discussion out to the fore was brought to our medical professionalism and biomedical ethics. Okay, next slide. This is just a timeline. The respect for autonomy and ethics in 2000. I'm going to date the psychological needs for self-determination theory as autonomy being identified actively as a research area of 1970. There's a whole informed decision-making literature that also started to address this. We can put that on the timeline as well.

0:30:15.0 Practitioner competence in 1802 and trustworthiness back to 400 B.C. These are the three psychological needs that STC thinks are important for people to be motivated, and we try to attend to them in our study interventions. And I think these are entirely consistent with clinical ethics and informed decision making, so I'm doing this clinically, I'm actively trying to support these needs as well. Next slide.

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0:30:52.0 So what is self-determination theory? Well it's a theory that is an organismic dialectic. It looks at the individual and their social surround. So here's the smoker with many pack years of smoking, and now they're out in mid-life, and now a recommendation is made to get a test for lung cancer screening. So that would be the dialectic is how does society present information about that test, how does the individual do that and so forth? Self-determination also defines motivation as human energy directed toward a particular goal.

0:31:26.3 And in medicine, we're really good at identifying these goals, and what we don't do so well is identify the energies that people have around achieving them. Another way to look at motivation is that it's the integration of affect or emotions with our cognitions, and that's another interesting way to look at it and how things change over time. Another reason that self-determination theory is so I think relevant to clinical practice and why I use it sort of off the shelf is that its studies include a free-choice period.

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0:32:19.4 And it uses a free-choice paradigm to determine whether someone is autonomously proceeding, are they doing this for themselves or not? And that makes it ready for clinical use because we practice in a free-choice environment. So I think this informs that. There are other models that do that as well, some of the ones we've talked about you may all know others. This theory also assumes that humans are innately motivated toward well-being and personal growth; that is, that they will move toward their health. And I think what I see in my conversations with smokers around the lung cancer screening, probably 80 percent of them don't bat an eye and agree to do this test because they perceive something in here is going to be helpful for them, either about their psychological health or their physical health, or both.

0:33:14.3 So I was a little surprised. I thought there would be more hesitation from them. But they seemed to want to do this. But we need to be talking with them about that. Next. As soon as you get into the issue of both autonomy and competence, you get into this interesting

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discussion. As soon as I ask people what they want to do, more than half of them in a few studies have been found to turn around and say but you're the doctor, why don't you tell me. And then if you make a recommendation, then you find the other percentage of the people who feel like they really want to do this themselves. So we have a tradeoff back and forth here. So far, I'm finding smokers, at least the ones I'm speaking to, be very open to this idea, but I'm not working so much with smokers who don't want to quit at this point. And so I think that's one of the areas that we need to study better about this.

0:33:50.5

And at the same time, while we want to illicit the patient's perspectives about this, we also want the physician and the U.S. Preventive Service Task Force recommendation, but we want that voice to be heard. That seems to move people along as long as they feel that we are trustworthy and competent. So next slide. I mentioned the three psychological needs. I'll just go very briefly into them. Autonomy is the perception the patient feels choiceful and volitional about one's behavior.

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0:34:13.0 I think this is particularly relevant. We want to be sure that's in place about lung cancer screening, particularly for them to follow through with the cycle of at least three of these and perhaps longer to get the benefit from this. So this has something to do with the immediate time, but also about the future test and whether they're wanting to do it or feeling pressured to do it. Next.

0:34:47.2 There's a perception of competence and that is do they feel capable of achieving the outcomes? If we do the test, but there is no hope for benefit, why do it? Here we can say there are benefits, and the better we articulate that I think the enhanced competence a patient feels. And also, physicians, that importance of being perceived as competent, we're sort of a surrogate for their competence; we close that competence gap, so their confidence in us can help substitute and support their own perceptions of competence in a healthy relationship. Next.

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0:35:23.3 And then the third source of energitization here is relatedness. They feel the need to feel connected and understood by important others, including their clinicians, family, bosses, friends, and so forth. Relatedness leads to energitization. A higher sense of competence leads to energitization and a sense that people are doing it for themselves leads to energitization. These are keys in all clinical encounters that I have. That's what I'm trying to foster and bring about and be supportive for patients. Next.

0:36:14.3 Internalization is the active process for change. This doesn't say that reinforcement is not a mechanism for change. But internalization is a process by which people initially may feel controlled by a new recommendation, imagine just giving someone a diagnosis of diabetes or a cancer of some type, it takes them a while to organize those energies and to begin to feel autonomous. Most of the time, it's difficult for them at the beginning and they need to learn to regulate within these. That happens over days and weeks; it doesn't generally happen over

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minutes within the interview, so our outcome for change in this is over the couple of few days or weeks after the visit as opposed to all happening right in the time we're seeing them.

0:36:57.4 I think this is somewhat relevant to the issue about— I think the counseling around the smoking cessation is probably best targeted before they get these test results so that they can begin to organize these motives over the long-term. Next. These are the behaviors that we think in any interview that elicits more autonomy, more competence, and more relatedness. Elicit and acknowledge patient's perspective, explore their values, provide a clear rationale for advice given, give them effective options for change, acknowledge the option of not changing is important, support the patient's self-initiations, and minimize control.

0:37:19.6 Be positive they can get an effect from this, accurate, identify barriers, develop a plan and reframe failures to short successes. We use that in the behavior change strategies. And relatedness

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support is empathetic, warm, interpersonal relationships, and remaining nonjudgmental. Next slide.

0:37:51.0 We've studied this, and there is now 184 data sets included in one meta-analysis. This is the general model. The extent that the health care climate, important others support these needs leads to that needs satisfaction and the middle column of autonomy, competence, and relatedness, think of those as energizers. And these have been associated with the various outcomes here over to the righthand side, mental health, less depression, less somatization, less anxiety, greater quality of life, less suicide attempts actually in college students.

0:38:30.3 Physical health has improved. The ones in orange represent randomized control trials that have changed at interventions trying to target supporting these needs and the context of treatment change those mediators. And the change in those mediators accounted for change in the intervention group over the control group for the outcomes listed. So there's

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about 10 of these randomized control trials of the 184 causal level of a pattern for change within this model. Next slide.

0:38:54.7 And this is one of the specific studies. There were a thousand patients in this. I'm not going to give a lot of detail, but just wanted to show you the model. What was interesting to me is that this model worked, and we did get more autonomy and more competence in the intervention group than the control, and they had higher rates of quitting that was sustained a full year after the intervention ended up to 18 months. And then again out to 30 months. So over 2 years, this was maintained.

0:39:25.8 One of the other things is this was done—we compared the control group to the intervention group and found that their process for change was exactly the same. This is in a variance model in testing. And their pathway followed the same mechanisms, but they had a lot less of the motives in some place, and so they didn't change as much over time. So I won't say more about that. Let's go onto the next slide.

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0:40:17.8 This is a prospective nonintervention trial with all the diabetes patients, type 2 diabetes patients, at Henry Ford Hospital, they have about, I think about 2,500 of them that participated, where we followed their glucose control and non-HDL cholesterol change in adherence to medications through pharmacy refill over a 12-month period of time. But we had their motives recorded at the very beginning of that year. And my point here is that all of the health care climate questions that need support in this, autonomous, motivation, and perceived competence all have a moderate relationship to quality of life and a weaker relationship through adherence to the physiologic outcomes, and there was almost no relationship between quality of life and the physiologic outcomes.

0:40:38.9 And so when we look at these quality of life adjusted life years, I think it's very important to pay attention to issues of autonomy, welfare, anxiety as they go through these tests. That's what's going to

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be helping inform their quality of life, and we may also be supporting their length of life. Next slide.

0:40:48.9 MURIEL CUMMINS: Hi, Dr. Williams, this is Muriel Cummins [ph.] from the National Cancer Institute. I just want to remind you that we hope to have a little bit of a discussion at the end and we are ending at 11:30.

0:41:24.6 DR. WILLIAMS: I'm about to be quiet. [LAUGHTER] Sorry, of course, I got into my favorite stuff and got carried away. So let's just briefly go through—there's a lot of implications for this. I think—I may just—I'll do two slides here, and then if you want to read the others, you can. I think what these models are saying is that we need to establish autonomy as an outcome of care here. We need to respect this issue of free choice in our studies that we're doing around this, and we need to train clinicians about how to work with free choice.

0:41:56.2 And also to start to include and inform us about how to work with people who don't want to change. Next

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slide. And that will be my last one that I will offer any comment about. Some of the questions about the lung cancer screening itself is you know if we have someone with a lot of pack years do we really want to limit this only to people to 55 in clinical practice or should we broaden this? How do we present the potential benefit of a decrease in mortality by 20 percent, which is the rationale given in our literature?

0:42:35.8

How do we have that discussion with people in a meaningful way? Or do we need to include quality of life discussion? Do we bundle cessation with it? I'm firmly on the side of doing that. I think that only makes sense to do that. And I think that we need to address the other findings that are in the lung cancer study itself because I think that they're very powerful for motivation and for health improvements that actually occur faster than the lung cancer risk reduction that occurs. So with that, I'll be quiet and open it up. And thank you very much for your attention.

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0:43:31.6 JERRY SULS: This is Jerry Suls, and I'm the chair of the Decision-Making Steering Committee here at NCI in the Behavioral Research Program. We very much appreciated your talk, Dr. Williams. I thought it was great and covered quite a bit of ground in a short amount of time. Just to kind of anticipate where we might be going in the discussion is the Decision-Making Steering Committee was formed to try to help us identify and promote areas where we thought that decision science can make contributions to cancer prevention and control, and more particularly, we're interested in identifying what the most pressing issues might be with regard to the public health, which might be addressed effectively by decision science.

0:44:11.7 And our first goal, our first kind of part of the plan is to try to identify those issues. So I guess I'm going to start with a question. I guess it's a two-parter. When you initially presented the slide which had to do with Braddock et al. about the dimensions that need to be covered during conversations between physicians and patients, I actually thought that was

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going to be your most—what you would identify as the most pressing question that the trying to get to all those dimensions is important.

0:44:43.4 And you seemed to highlight, and I might be wrong about this, but you seemed to highlight at that point the fact that there was little structure got described in these discussions. I wonder whether—would I be right in discerning that you think of a general question of covering all the dimensions as one of the more pressing issues or did I kind of lose focus of your talk?

0:45:23.3 DR. WILLIAMS: No, I think that's remarkably important, particularly in primary care. If we're going to leave this to the primary care physicians, let's say a doc has 2,000 patients, and maybe 20 percent of them smoke, or 15 percent of them smoke, and they're going to start to get EMR messages to tell them they've got to call these patients and get them in for this screening. And being able to cover all of those dimensions at the same time—first of all, at that point, we didn't do a very good job of that, and

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yet there already isn't enough time to have these indepth discussions.

0:45:57.4 So how do we do that in a timely way? We might need to create systems that for instance, when this gets initiated that there is a systematic way that people are informed about this with other care practitioners in the medical home or at the radiology screening site to get them to contact them and start this interview process and informed decision-making process before they actually have the test.

0:46:21.4 So we've got to solve that. And I think right now, we don't do that well enough in primary care, that I'm going to guess is a 15-minute discussion to do all those things. And if you get to all the levels that makes the discussion longer. So, yes, that is—and Jerry you said you had two parts to your question. Maybe I missed the second part. But—

0:46:53.4 JERRY SULS: You kind of answered part of it, of what I was going to get to. So the other question for me is this is an ongoing—I see this as an ongoing

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discussion, and I wonder if all dimensions are relevant to after the results are in contrast to talking to patients about the possibility of doing this and whether they agree. And I wonder if you'd comment on that?

0:47:02.2 DR. WILLIAMS: If I understand you, the question is about do we do everything before or do we save some of it for after.

0:47:05.6 JERRY SULS: Yes, that's the question.

0:47:38.8 DR. WILLIAMS: Well, I think that since this is a decision note it's a yes or no, do they go forward? You need to cover, or we need to be clearer about what the basic package is that needs to be covered. I would suggest that uncertainty probably doesn't need to be covered so much now, I wouldn't do that. That's the way I see this right now. But one could argue that we need to do that. I think we certainly need to check in with people afterwards, which we weren't doing very well before.

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0:48:08.3 And inviting them into making the decision, that's sort of giving them a signal at the beginning that says look this is a decision for you to make, I'm here to support you and to set that up in a context where they actually feel supported in that. But I think it's not just a single decision; it's like any cancer screening, are you going to get into the sequence of these things. So there is more to do afterward. That will facilitate the internalization process if you ask me.

0:48:35.3 And they probably have a lot of emotional effective experience when they get these test results both waiting for the test results and getting the test result that we want to be eliciting and acknowledge that's going to help them move through this going forward. So that's—I see most of it needing to happen before, but I see your point: This is not done with just one visit.

0:48:35.9 JERRY SULS: Thank you.

0:48:37.6 Are there others who have some questions? Okay.

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0:48:57.4 DR. WILLIAMS: Should we inform them of their risks of not asking questions? [LAUGHTER]

0:49:09.0 JERRY SULS: Mary, is everybody connected that they can do the video? The audio, they can talk?

0:49:18.1 STEPHANIE LAND: This is Stephanie Land. I'm connected. I found the talk very, very interesting and provocative. I'm sorry that I don't have any specific questions though. But I certainly valued this discussion.

0:49:34.9 JERRY SULS: So I wonder whether you could say something about the whole question of people quitting smoking after receiving a negative test as opposed to receiving a positive test. Do you have any thoughts about that, and how regular an effect that might be, how that might interact with issues of autonomy and self-determination, and what the physician says is a function of the feedback?

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0:50:12.7 DR. WILLIAMS: So the Danish study was about 5,000 people that were followed over 5 years, and they were randomized to receive five of these screens in a row. And they did not find that there was increased quitting in the group that received it. So both groups quit, about 17 percent of them quit. That's higher than what you'd expect in the background of that. But they were in a study about lung cancer, so maybe there was some motives there. So my first thought is this—that we can measure autonomy and any increment or any prevention of it going lower should be considered to be a benefit here is what I'm arguing for.

0:50:54.6 And we can do that, but we haven't done that. Yet. So to me, this is pulling for the opportunity to climb in there and see that. I think that when the smoker quits who does not have lung cancer, their risk gradually reduces to about 50 percent of what it was before by 10 years. It takes 10 years for that risk to fall in half. And I think that we, I think that they have—smokers are really very fearful of lung

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cancer. That's one of the things they're most concerned about that stirs them up.

0:51:34.0 Stroke is the other thing that I think really—diabetes is somewhat disconcerting as well, and I think we can talk about all of them with them because all of those risks go down considerably. So, yeah, I think some discussion afterwards to let them know what an important pathway this is putting them on to reducing risk going forward. For those diagnosed with cancer, there's also a message there. They've got, they've just been told the major thing or that they might have cancer if they have to be followed over time.

0:52:10.0 But I'm working with [unint.] at our cancer center here about how we deliver this message. Smokers have an increased risk for secondary cancers; they can get—excuse me, second primary cancers related to smoking. They're much higher in people who have had a first cancer. And so additionally, it would be a reason why they might wish to quit and talk with them about that. And smoking also affects the immune system dramatically. That was a big part of the Surgeon

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General's report, and the increased risk for infectious disease is almost as high as the cancer burden risk.

0:52:51.8 And I think we need to tell that when people are in chemotherapeutic agents or they're getting radiation or they're fighting cancer, and they're stressed, they are going to be more susceptible to these infections. And so helping them actively quit smoking and providing intensive support around doing that I think is particularly important. And I think that's what facilitates this internalization. They feel more autonomous. I'll go back to our patient, she felt much clearer about why she was quitting this time. Her motives became much clearer to her. She commented on that several times.

0:53:24.6 I'd ask her what's different about this. I don't know, but I just know this is much clearer to me about why I'm doing this. So I think those are all opportunities. I think there's important messages on both sides of that, all of which we need to pay attention to what the affective experience of what

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it's been for this person to go through this testing.
Okay?

0:53:47.7 JERRY SULS: So I have another sort of two-parter for you, which really has to do with what you mentioned about—that in terms of people thinking about quitting and its effects that the quality of life is actually the more critical concern for a large proportion of patients as opposed to how much of their life is left. And I wonder if you would comment about the extent to which you think there might be a disjunction for patients versus health care professionals about what patients are really concerned about and whether that influences the way they talk to patients and try to carry through some informed decision making conversation?

0:54:41.1 DR. WILLIAMS: I'll just say yes, there's a huge disconnect here. And I'll be a little provocative here or maybe very provocative, our study base for this stuff is based on length of life and has not—we're starting to incorporate quality of life, but we have not started to address the issue of people's

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autonomy as a separable outcome that we go toward. And this gets very confused when pay for performance comes in, when docs are paid if they reach certain goal, they make their patients reach certain goals. That sort of poisoning or undermining the patient's free choice here because it's pressuring from the doc to get that length of life outcome, different than the autonomy outcome.

0:55:41.1 And I think it's a potential problem for us and I think that we need to pay a lot of attention to it. Our research studies need to be broader and inform both quality of life as well as autonomy and length of life to fully inform patients about this. The other point that I was making is that the cardiovascular benefits here—I want us to get out of our silos. The cardiovascular benefits and the COPD benefits for this population may be more noticeable for them when they go in for the screening.

0:56:17.6 So this is an opportunity to improve quality of life there even though it's in the context of lung cancer screening. We need to be talking with smokers about

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their health and the benefits they get. So I think there is a definite threat if we are only talking about length of life. And we need to learn to have these discussions better. So it's a great question and deserves a lot of attention.

0:56:42.0 JERRY SULS: Thank you.

0:56:48.0 If we don't have any other questions, I guess I would just ask Dr. Williams if you have any final comments you'd like to make.

0:57:55.2 DR. WILLIAMS: Yeah, I think that this is a very interesting advent and opportunity for cancer screening and ways to work with patients to make their lives better and for us to learn about how we can do that as health care practitioners. And I think really, that's the opportunity. There's many options for how to address these issues, but they're all challenging issues is how to get this into the brief period of time that we already don't have enough of to do this. But sorting that out is going to make a more cost-effective and a more satisfying experience for

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patients going through this. So very interesting area, and I want to thank you for the opportunity to bring this up as a topic.

0:57:59.8 JERRY SULS: Well, thank you.

0:59:00.4 MOD: Thank you to Dr. Williams for providing today's information. If you have questions after today's webinar, please e-mail NCI.BRPwebinars@icfi.com or call 301-407-6608. Thank you for joining us. This concludes today's webinar. You may disconnect at this time.

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