

**National Diabetes Education Program
Engaging the Disengaged Patient Webinar
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Joanne Gallivan, M.S., RD—Director, National Diabetes Education Program (NDEP)

Welcome, everyone. I am Joanne Gallivan. I'm director of the National Diabetes Education Program at the National Institutes of Health, and thank you for all joining us today. I think we have a very exciting program. Today our program is called "Engaging the Disengaged Patient," and we are featuring Dr. Bill Polonsky, who I'll introduce in just a second or two. As you know, the NDEP is a program of both the National Institutes of Health and the CDC, and we have periodic webinars with all of you to help you learn more. The NDEP's mission is to facilitate strategies and provide tools and resources to help people with diabetes and people at risk make and sustain lifestyle changes to live long and healthy lives.

So we are very excited today to have Dr. William Polonsky as our guest speaker. He is president and founder of the Behavioral Diabetes Institute, which is actually the world's first organization that is dedicated to studying and addressing the unmet psychological needs of people with diabetes. Dr. Polonsky also serves as associate clinical professor in psychiatry at the University of California in San Diego. He received his Ph.D. in clinical psychology from Yale University and has served as senior psychologist at the Joslin Center in Boston, a faculty member at Harvard Medical School, and chairman of the National Certification Board for Diabetes Educators. He's an active researcher in the field of behavioral diabetes. He has served on the editorial board of *Diabetes Care*, *Diabetes Forecast*, *Clinical Diabetes*, *Diabetes Self-Management*, and *Diabetes Health*. His most recent research projects have focused on quality of life and diabetes, diabetes-related distress and depression, and emotional behavioral responses to the diagnosis of diabetes. He has also authored several books for lay audiences, including *Diabetes Burn-Out: What to Do When You Can't Take It Anymore*, published by the American Diabetes Association. And he's co-authored publications to health care professionals, including a *Core Curriculum for Diabetes Education*, published by the American Association of Diabetes Educators. So as you can see, he's very, very busy, so we are very, very glad to have him today.

Just a few logistics about today's webinar: He will lead a discussion on patient engagement, sharing with us research findings concerning issues related to motivation in diabetes care, techniques for assessing contributions to patient disengagement, and methods for overcoming patient disengagement in diabetes clinical practice. And then after this discussion, he will answer some of the most commonly asked questions all of you submitted to us in advance of this call. So please note that all your lines are muted. If you have a question, please submit it during the webinar using the questions panel in the control panel. If time permits, we'll address these additional questions. But any questions that we have not answered, we'll share with Dr. Polonsky after the webinar.

Remember this webinar is being recorded. We will post the video recording and presentation slides on the NDEP web page in the next 3 weeks and notify all of you when the files are available. You'll also receive an email from us that asks you to evaluate this webinar; please give us your feedback, because we really use it to plan future events. And if you would like to receive a certification of completion for this webinar, please email the program—and we'll show you this email at the end, but it's ndep@hagersharp.com. Again, thank you for joining us, and we will now turn it over to Dr. Polonsky.

William H. Polonsky, Ph.D., CDE—President and Founder, Behavioral Diabetes Institute

Okay, well, thank you, Joanne. This is Bill Polonsky; I'm talking to you from San Diego. Again, as you heard, I'm a professor here at the University of California at San Diego and also run the Behavioral Diabetes Institute. If we have time, I'll tell you a little more about those. But we're here to talk about this particular subject, which you see here on your screen, "Engaging the Disengaged." And I'm hoping that everyone here is familiar with this issue—that everyone who is listening and watching has met at least one person with diabetes who wasn't taking perfect care of themselves all the time. That might be your patients; it might be your family members; it might be you. But we know that this can happen for all sorts of reasons, but we know that whether it's because of—well, we'll get to some of those reasons. But we know that there's a lot of people who despite being bright and interesting and involved in many aspects of their lives—they become either partially or very completely disengaged from their diabetes, where diabetes becomes their last priority. We want to think a little bit about what the problem is but really focus on putting forward some strategies about what to do. Hopefully, some of these strategies are things that many of you are already doing, and we'll just reinforce that, and perhaps you'll just think creatively with me about new ideas. Again, I'm going to be relatively brief so we get to the questions.

So first of all, let's all understand and agree that this is indeed a sizable problem. Let me click one more time, just to highlight what I want on the screen. Just to let you know, hopefully you already know this, but in some of our very large United States–based surveys, we know that—we see the problem. On the screen, if you look at the red column, we know about half of the folks with diabetes in the United States are reaching ADA targets, meaning an A1C of 7 percent or less. About half—close to half have reached ADA-recognized blood pressure targets; about half, lipid targets. But again, what you see circled over there on the right is the percentage of people, almost 19 percent, who, as I like to say, are in a safe place with all of these—are in a safe place with their A1C, blood pressure, and lipids, meaning they've reached those ADA targets. So 19 percent, that's fairly dismal, isn't it? It means, again, that 81 percent of our patients aren't there; they are, if you will, not in a safe place. Now, the good news is, because that means, again, more than 80 percent are not there yet, it does mean—and I hate to be sarcastic about this, but it does mean that all of us probably will have jobs for the rest of our lives. There's a lot of work to do.

But the other good news is that this is a large survey project that does get done every 5 years or so, and 19 percent is up from the last time this was done; it was about 13 percent, and it was in the single digits the time before that. So things are getting better, but boy, do we have a long way to go. And again, we understand there's all sorts of contributors to why this is. We have a terribly fragmented health care system; we know we have lots of, actually, physicians and other health care professionals who aren't up to date and aren't aggressively titrating medications and working together with their patients in a way that really would be effective.

But then there's this other big category that people are disengaged. And we can kind of understand why. I mean, as you know, the day a person learns they have diabetes, it means the universe has just handed them a new job. It's a job you can't say no to, there's no vacations, there's no pay, and you've got to figure out how to fit it in with everything else you're doing. And when we think about living every day with diabetes, it can seem relatively easy if you don't have diabetes; but if you talk to folks who do, we know that living with diabetes looks a little like this: It is a balancing act. It requires vigilance, and then we're tal—that's true for type 1 or type 2 diabetes. There's a lot of things you need to pay attention to and you need to balance, and it's hard to get a break.

And there's three major things you're trying to balance. On the one hand, you want to have the best blood sugars possible—best blood pressure and lipids, of course, as well, as we understand now. Now, you want

to balance that, of course, with, on the other hand, not wanting to have any big issues with severe hypoglycemia, of course. And there's a third arm of this stool you're trying to balance, which is, you also want to have a life. You want to have a life where you can do what you want and be spontaneous and not have to think about or worry about diabetes all the time. And to do all three of these things perfectly is pretty much impossible. So what we see is that people compromise, and that's reasonable and understandable. Unfortunately, people sometimes compromise unconsciously and make bad compromises, and it's our job to help people figure out how to do that. So we want to be thoughtful and reasonable from the patients' perspective about why diabetes is tough and why people get disengaged and understand it's not necessarily how all health care professionals approach this problem.

In fact, several years ago—let me see if I can share my next slide here—with my colleagues Dr. Edelman and others from *Taking Control of Your Diabetes*, we actually surveyed health care professionals from around the United States—and this is from an abstract we presented at ADA—and the top five complaints about patients that we heard were these: “Oh, patients say they want to change, but they're not willing to do so,” or number two, “They're not honest; they only tell me what I want to hear; they don't listen to my advice, or they're unmotivated or in denial or don't care. They just don't take responsibility.” And you know, what lurks behind these attributions is the idea that diabetes and taking—not taking good care of your diabetes is somehow a sin; it's a biblical sin; it's to be—you should be shamed and blamed for it. And that's not fair—not reasonable.

There's another way to think about what the problem is here. And I think we need to put aside these typical attributions, because they don't help us, and really consider what we're talking about when we think about engagement and we think about motivation. And here's what I mean by that. And again, if you've ever heard me give a talk, I apologize, because I'm going to repeat something I always say, which is that, when you think about it, you know, almost nobody is unmotivated to live a long and healthy life—I mean, not our patients, not anyone listening to this call right now and not me. No one's unmotivated. And I do say “almost,” because I don't really like working with teenagers too much anymore; they're kind of a different story. But at least with adults, I feel comfortable saying this. And if you can believe this, then it means that we and our patients are on the same side, and we can deal with the other problem. If no one's unmotivated, then what's getting in their way?

And the problem, of course, is that even though people may be aware of the powerful positive benefits of taking good care, they can be kind of abstract and in the distance and in the future, and immediate obstacles just outweigh that. And as you can see from the last bullet point in this slide, you know, the underlying theme to so many of the obstacles that our patients face—what it really comes down to is what I like to think of as this lack of perceived value. It's a lack of worthwhileness. People come to the conclusion, consciously or unconsciously, that what we're asking them to do in terms of managing diabetes day to day, compared to everything else their life demands of them—it's just not that worthwhile. And it's that issue, and that's conversation that we need to have. Now, as some of you know, I've written a whole book about the obstacles patients face; there's many of them, many more than we're going to cover and we can think about. But again, so many of them come down to this eventual feeling that people have that it's just not worthwhile. So, having said that, let's reverse course and think about what to do about it.

Now, again, just to set the stage, and because our time is limited, I'm going to focus with you on just a—whoops, let's see if I can undo this—focus on just these four reasons why people come to the conclusions that it isn't worthwhile to put out the effort to manage one or more aspects of their diabetes. And those four reasons, those four contributors to worthwhileness or lack of perceived value, what you see on the

left side of the screen: They can have a lot of emotional distress, not perceived benefits; the cost, meaning emotional cost or medical costs, are too high; and unrealistic expectations. And we'll take the rest of our time focusing on these strategies on the right of the screen, and we're going to do these one at a time.

So we're going to start with emotional distress as the first one. Now, when we think about emotional distress, I want to be clear with you what I mean. For years, we've talked about the importance of depression in diabetes and how people with diabetes are at elevated risk for depression. And I have to say, the most recent evidence that we've seen over the past few years suggests that, well, that may not be true. There's some nice work from one of my colleagues in New York State and some work that my colleagues and I have done here at UC San Diego and UC San Francisco that suggests that people with diabetes might not be at elevated risk for depression. They're at elevated risk for depressive symptoms, and I'm not meaning to split hairs here. It means that they have a lot of things that may look like depression but aren't solvable with an antidepressant medication. Really, the broad category—they have a lot of emotional distress, and a lot of that distress is about living every day with diabetes. So I don't think, for those of you who are not mental health professionals, you want to get a couch in your office about this; but the most important solution we want to think about, if you're running into people with a lot of significant emotional distress, whether that's depression or diabetes distress or something else, is to just be alert for it, talk with our patients about it, and refer as needed and as possible, because we do know that's common.

Now, again, I want to be clear: Depression and diabetes is a very bad combination, and it leads to very, very bad outcomes. I don't want to make that any less powerful than it actually is. It just may not be as common as we think it is. but we want to do pay attention, because oftentimes, we'll meet patients who just—you know, they don't really seem to be with us, they don't seem to be engaged with us, and it's because they're, if you will, preoccupied. They're profoundly distressed about, well, life. So it could be depression, could be other things.

So again the most important issue I just want to highlight is the importance of assessment, and that means doing, of course—asking people questions about depression, which—and again, this is really getting at just depressive symptoms. This is the PHQ-2. I'm sure many of you are familiar with this. We tend to ask people these two questions: “During the past month, have you often been bothered by feeling down, depressed, or hopeless? Just yes or no. Or during the past month, have you had little interest or pleasure in doing things?” And if people say yes to either one of these, that's enough to pass our simple depression screener, and it suggests that we should ask more.

But what we feel strongly about is that, if you really want to get at the important elements of emotional distress that so many of our patients are struggling with, these two questions aren't enough—that we really want to ask about diabetes distress. And while we have psychometrically valid questionnaires that we can give people and encourage folks to use, really, for busy practitioners, we just recommend asking one question. And the one question is this, you know: “Can you tell me one thing about diabetes that's been driving you crazy?” And again, because we know clinicians are so busy, that's why we suggest you say one thing, and not even the most important thing, “Can you just tell me one thing about diabetes that's driving you crazy?”, as a way to open this conversation with folks.

Again, I've been using this question in talking with patients, now thousands and thousands, for almost 30 years now, and I still have never met anybody who thought about that and said, “Hmm, something about diabetes that's driving me crazy—gee, I can't think of anything.” Everybody can tell you something, and the depth and the sense of that can give you a sense of whether, again, diabetes distress might be a really

critical issue that's leading people to feel disengaged. And we want to, again, chat with people and get people the help they need.

Now, having said that, I'm going to speed on to these other issues, where I think we can be a little more directly helpful. So the second point you hear, the second contributor, is this idea of no perceived benefit. And again, we have all sorts of patients who just don't believe it; they just can't believe there's any tangible benefit to putting out the effort to managing diabetes. Sometimes that's because they just feel doomed by this disease, they've seen terrible things happen to relatives or they've heard stories on the news or whatever it might be; they think that diabetes is a death sentence or that, you know, it's all just up to fate anyway. Or they've made efforts to try and make changes in their lives and nothing really seems to work and they lose weight and it comes back or they take medications and they don't feel any better. So it's this lack of a sense of tangible benefit that's unfortunately so common in chronic disease, especially in diabetes, where so much of our interventions are based on prevention, that this occurs.

So there's a number of strategies we recommend. The most important thing I want to mention to you—and again, if you've ever heard me speak, I apologize, because it's something else I like to make sure I talk about all the time—is this issue of people feeling doomed by diabetes. So we think it's critical to make sure people are very, very clear about some basic facts and have the most up-to-date information about one topic in particular. And we usually do this through true and false questions.

So this is my favorite true and false question: We ask patient groups; we ask physician groups—other health care professional groups, you know, “Diabetes is the leading cause of adult blindness, amputation, and kidney failure in America. True or false?” And I can tell you, from doing—using this with audience response systems around the world, about 96 percent of folks on average agree this is true, whether we're talking about patients or health care professionals; and those other 4 percent have either heard me present this before or just think this is a trick question, which of course it is.

So, of course, this isn't true, and what we want people to understand is why. This is false because, as we all know, to a large extent, it's not diabetes that's the problem; it's poorly controlled diabetes that's the leading cause of these issues. Now, it sounds like we're splitting hairs, but this difference is critical, and it leads to the corollary, and the corollary is this: Well-controlled diabetes is the leading cause of nothing.

The point is, we want to give our patients another perspective, especially when they feel doomed by this disease. We want people to understand that what our evidence tells us here in the 21st century is really about what we like to refer to as evidence-based hope, which really is this point at the bottom of this slide: Well-controlled diabetes is the leading cause of nothing. That's why they're hopefully working with us and why we hope they will engage with us about managing this disease. Now, a fact check, of course, I should mention is that when we make a statement like this, it doesn't guarantee that good care will prevent you from developing complications. We can't make those kind of guarantees. But the second bullet point is true: that with good care, you know, odds are pretty good you can live a long and healthy life with diabetes. Now, you know, we couldn't have said that 50 years ago; but with what we have now, how we understand diabetes, our tools and technology—we can say this, because this is true: With good care, odds are good.

Now, when I present this to patients, this isn't enough. I want to give them something more solid they can get their hands around. So we'll show them, you know, pictures of Joslin Diabetes Center 50-year medalists; we'll talk about how there's more and more of them every year. But what really seems to be even more powerful is when we can show them data that's understandable, and we've put together some

new ways of doing that. So, for example, I usually start by saying, “Well what’s your risk of running into complications?” And you know, our best data is with type 1, so I usually try to focus on the type 1 data.

So here’s an example: So I’ll usually start with this slide and say, you know, “After you’ve had type 1 diabetes for 30 years, what percentage of people run into really scary complications?” And so I’ll run through this slide; I’ll say, you know, “Here’s data from one of the best medical centers in the world. People have had really good care. And as you can see, 30 percent have had severe vision loss or gone blind. More than 10 percent have had significant amputations. Again, more than a third already have significant kidney problems.” And then I remind people—I say, “Oh, I forgot to tell you: This is from 1978. Would you like to know what your likelihood of running into complications or the percentage of people who run into these complications after 30 years of type 1 diabetes is now? And again, well, let’s look at people who have had pretty good medical care. We’ll look at people, for example, who’ve been through the long-term DCCT or the EDIC Trial, and we’ll look at these same three columns: severe vision loss, amputation, and nephropathy. Now we’re going to look at 2009, not 1978; here’s the data from that, from today. You ready? It looks like this.”

So again, the risk of severe vision loss or blindness from the EDIC trial—well, very low, about 1 percent; amputations, about 1 percent; nephropathy, again, only about 5 percent. Things have changed dramatically, and we want people to understand this: that with good care here in the 21st century, odds are good you can live a long and healthy life. We have so much good news to share with our patients, but we often get so focused on wanting to scare them with complications, we forget about the other side of this.

So—oops, I meant to back up if I can; let’s see if I can do that. You know, we can—we also—although the data isn’t as great, we can talk about this same sort of good news with type 2 diabetes. So this is just from a large study just completed a few years ago. And again, what they showed in this large primary care program, this lovely randomized controlled trial—when you provide people with good, comprehensive—in this case, type 2 diabetes—good, comprehensive metabolic care, the risk of mortality is no different than people who don’t have diabetes. I mean, here’s the conclusion, as you can read with me: The study shows a normal life expectancy in a cohort of subjects with type 2 in primary care when compared to the general population.

To be fair, this is from the Netherlands, so I always tell my patients it might be best if you just moved to the Netherlands if you really want to have great medical care. But you know, things are getting better in the U.S.; we’re almost there. But we have good news. And then, usually, I like to wrap this up with the—in the words of our greatest physician from the end of the 19th and early 20th century, Sir William Osler, who said it so clearly: He said, you know, “Remember, to live a long and healthy life, develop a chronic disease and take care of it.” And we’re seeing more and more patients who are doing this. So again, it’s really what we would call “cognitive reframing,” but it’s good news we need to share with our patients. This is so enlivening. And trust me: Our patients never, ever get to hear this enough.

Now, the other issue about perceived benefits or lack of perceived benefits I want to mention is what steps we can take to help people see, in the short term, that what they’re doing is making a difference. And there’s a number of different approaches. One of the ones that we’ve been practicing and using for years is looking at structured blood glucose monitoring for our type 2 patients, as one way to do that.

And here’s my favorite example; we’ve done this many, many times, but I always like to go back to one of my first cases. This is Mr. Samuels. You can see he’s 42 and married. He’s a school teacher—had type 2 for not very long. He’s overweight. His A1C is relatively high, 7.9 percent. I’m not going to read all this

to you; the bottom line is he used to be very active and athletic, but he's run into injuries, so he stopped. Like so many of our patients, he doesn't really bother checking his blood glucoses very much; you can see that fifth bullet point, "no longer checks BGs." And he's very clear about why: He says, "Trust me, you know: Whenever I check, it's always too high." He takes a big old shot of glargine every day. And he and his physician have been talking a lot about exercise, and Mr. Samuels is not very interested, but his doctor just keeps saying, "Look, I promise you, just—if you just even walk regularly, it would be so good for you." And they've been arguing about this for months and months.

And I finally had a chance to meet Mr. Samuels; his doctor asked me to see if I could be of any help. You know, I made him a deal: I said, "Look, Mr. Samuels, if you will try a home experiment for 1 week, whatever the results are, I promise I'll get your doctor to stop bothering you so much." And he went, "Ah, that would be great." And I told him—I said, "The experiment's very simple: All I'd like you to do is, for the next 7 days, I want you to get up in the morning and check your blood sugar, which I know you don't like to do, but check your blood sugar, and then make sure you have enough time and go for a walk around the block." And he lived out in the country, so a walk around the block actually was pretty far for him. "And when you get back from your walk, I want you to check your blood sugar again and just write that down. And do that 7 days in a row, and then bring those numbers in to me. I don't care what the numbers are; don't worry about it; just bring those numbers in. Let's talk about it. That's all you need to do." And he said, "You know, I could do that."

So he did, and he showed up a week later with these numbers. And the numbers aren't as important as what happened next, but just to be clear with you, you can see from the second column—those were his blood sugars before he went for his walk; you can see in the second column—those were his blood sugars when he got back from his walk. Again, it's 7 days in a row. It turns out Mr. Samuels was good at arithmetic. You can see on the far right how his blood glucoses had changed—quite a bit of variability. And down there at the bottom, you can see his average blood glucose change. And again, we like asking people to do this multiple days in a row, like 7 days, because there is a lot of variability in one's life—a lot of error in our blood glucose meters, so it's looking at change over days that's really very useful.

But what's important about this is, Mr. Samuels came in and took this sheet of paper and put it on my desk and said to me, "You know, Bill, look, you better sit down; I have something extraordinary to tell you. You know, I've discovered something that I don't think anyone's ever known: that exercise lowers blood sugars." And I said, "Well, you know, Mr. Samuels, that's what your doctor's been talking about, and I've mentioned it to you, and the diabetes education class you took—" and he said, "Yeah, yeah, yeah, but those were just words. This is real, you know."

And this is the principle of discovery learning. I think I probably first heard this from my old friend Betty Brackenridge, I hope many of you know, from Arizona: the idea that, in discovery learning, we help people to discover things for themselves and to help make diabetes and diabetes efforts tangible in a way that can turn people on, to help people to feel engaged, like this did for Mr. Samuels. In psychology, we would call this the principle of perceived treatment efficacy, when we can help people to see that their own actions can make a difference, people get more interested. So Mr. Samuels actually became quite interested in regular physical activity and started walking regularly and soon was doing more, because he knew it was making a difference. In fact, he got pretty interested in blood glucose monitoring for the first time in many years, and we began to talk about what else it could do. So I said, "Let's do some other experiments."

And the first experiment we did was “I wonder how breakfast affects me.” We did another 7-day experiment to look at why he was so tired in the evening—was related to perhaps his blood glucoses going up after a carb-rich dinner. But his very, very favorite set of experiments—and again, I started with what he wanted to know and how blood glucose monitoring could help him—his favorite experiment is when he said to me, “Gee, I wonder which type of beer would have the least negative impact on my blood glucoses.” And he was pretty excited about that. So we had weeks and weeks of blood glucose experiments all about trying to find the right beer to drink.

So let me move on, because I know our time is limited. The third element I want to mention to you is about this—about the cost being too high. Now, sometimes that’s just the actual cost of medication, which can be a big contributor of why people would not be taking the medications—want to, again, give up on their diabetes care more broadly. But one of the major costs I want to mention to you—why people get concerned is, you know, they may not be that distressed, they may believe in the benefits, but they’re concerned that what we’re asking them to do might be bad for them. And oftentimes that’s around medications, people having a lot of concerns that the medications we’re recommending can harm them.

So just a few words—when we asked people about that, you know, people usually, if we approach it correctly, are more than willing to tell us about their suspicions and their concerns. You know, maybe they’ve seen some late-night infomercial from some law firm: “Have you or your loved ones ever taken this medication? Please call us.” So it’s understandable people would be concerned. So we want to make sure we can chat with people, understand their perspective, and share with them some of the critical medication “secrets.”

And there’s really five. One is, we want people to understand that if you have out-of-control diabetes mellitus, you know, this can harm you, even if you feel okay; it’s important to help people understand that. We want to make sure that, well, there’s hundreds of things we’d like to recommend that people can do to help manage their diabetes more effectively. We want to let people know that in terms of bang for your buck, taking your medications every day, making sure you’re on the right medications and taking them, is clearly one of the most powerful things you can do to positively affect your health—more than many of the other things that we often talk about. Just having that discussion with patients can be so powerful. We want people to understand that your medications are working for you, even if you can’t feel it—and helping people to chat about that and explaining that. We want people to understand, especially if they have type 2 diabetes, that if and when we need to talk about increasing medications, increasing dosages, adding new medications—it’s not your fault. And I think number 5 is the most important: We want people to understand that if you’re taking more medication or need to take more, it doesn’t mean you’re sicker, and taking less medication doesn’t mean you’re magically healthier.

And this is imbued in our conversation so much, and I think many of us are susceptible—believing this as much as our patients—that it’s what we think of as the subjective metric: “How healthy am I? How sick am I?”—as often we measure it with “how many pills am I taking, or am I on injections or not?” And that’s why we hear from our patients comments like, you know, “Hey, look, what’s it going to take for me to get off this insulin? Or what do I need to do to take fewer pills?”, the idea being that that may mean I’m healthier. And we want people to understand that, look, if your blood sugars are high, if your blood pressure is high, your lipids are high, you’re not in a safe place and taking more medication to help you get to a safe place is a good thing. And we have this other powerful way to help measure those metrics, which is key.

So I'll try to get to my end of this quickly here by talking about this last point. Oftentimes, people get disengaged not because they're distressed, not because there's no perceived benefits, not because they're worried that costs are too high, but they simply are set up—that they have expectations about what they're supposed to be doing and what they're supposed to be achieving that are so unrealistic or vague, they end up feeling discouraged, and they'll, again, give up. And the keys to what we need to do are just to check in with people about those expectations. So we want to make sure that they understand that they don't have to be perfect with their blood glucoses—that that isn't necessary, nor is it possible.

You know, boy, I meet patients all the time who say, you know, "I don't have—any time I have a blood sugar that's, you know, less than 70 or more than 130, then I'm a failure." Now, they didn't make that up; that came from somebody else. So oftentimes, it's our job to help them to understand that if you have diabetes, you are going to have wacky blood sugars from time to time, and make sure they have goals and expectations that are reasonable. In fact, one of the things that we think is so important is not to over-focus on blood glucoses at all as outcome measures but to really focus on A1Cs and, again, make sure that people have concrete and achievable A1C targets. So I'm always asking my patients, you know, "Do you and your doctor have a specific goal for your A1Cs that's possible for you, that's reasonable for you, that can help you get to as safe a place as you can? And do you understand that?" Again, that's often a new idea for folks, so it's important to bring up.

Now we know for so many people, just automatically, they'll say, "Well, you know, I understand that I should have an A1C of less than 7 percent, period. You know, that's what I believe; that's what my doctor told me. And I'm not there, I've never been there, and I just feel like a loser." So while that's a reasonable goal, I think it's important to let people know where everybody else is. So especially for my type 1 patients, you know, I can turn to the data from the type 1 registry and say, "You think you should have an A1C under 7 percent. You aren't there. You feel like a failure. Let's look at how everybody else is doing."

So here's what that is on the next slide. Again, this is a nice study from Roy Beck and his colleagues. So if we look in this large, large type 1 diabetes exchange registry, now over 25,000 patients with type 1, broken down by age groups—so on the far left, you can see patients who are under 6; on the far right, you can see type 1 patients who are over 65—and all the other brackets in between. And I'll just say to my patients, "Okay, well, let's—these are the average A1Cs in these groups. Now which, if any, of these groups have an average A1C under 7 percent?" And of course, you look, and you realize, well, nobody. So if you're not there yet, even though that's your goal, if that's a good goal—a right goal for you, then just give yourself a break, you know. You're—if you're not there, you're in the majority of folks. And it doesn't mean you shouldn't shoot for it, but there's no need to feel like a failure.

We find this so critical—I do this a lot with patients who I work with in other countries; I'll often do—I'll meet with them via video Skype, and we'll check in every month or two. And we use this as an opportunity to say, "Get an A1C done, if possible, every month, if doable; graph it, and let's make that where we start our conversation." Now, we never use that A1C and talk about it as good or bad; it's really about being in a safe place or an unsafe place. "Have we reached a place that's comfortable for you?" We use it to inform our conversation.

So here's just an example of one of my patients. This is someone who, when I first met, had an A1C of a little over 10 percent, and it had been 10 percent for several years. And that's the number you see over there in the far left, when we first met. And she was pretty good at getting that A1C done almost every month, and we would use that as an opportunity to have a chat and to continue to graph it. Now, her last

A1C isn't even on this graph, I forgot to update it; she's at about 7.3 percent as of about 2 weeks ago. But you can see the ride she's been on, and in our conversations, it was about trying to find this compromise between how much she wanted to let diabetes be a part of her life—this is a young woman with type 1 diabetes, by the way. How much was she willing to be vigilant and give it her attention? Now, again, part of why she'd become so disengaged is because she thought she had to be perfect, and if she couldn't be perfect, she might as well just ignore her diabetes, which she had done for years.

So our conversation over this whole period of time was about, how do you find that point of compromise and comfort for herself? You can see, at one point, she got below 7 percent. And she was clear with me; she said, you know, "That's too much." It was too much time and effort focusing on diabetes, given the other pressures and strains in her life now. And she's fairly now well-balanced in the mid-, now low, 7 percent range. And I think that's where she needs to be for a while—is the place she can maintain and she is to be congratulated. So think about how we can use these sorts of numbers to make the invisible a little more visible for our patients, to do so in a non-blaming way, and to really make a difference.

So let me wrap up quickly here so we can get to the questions. You know, the bottom line is this: You know, our patients are not unmotivated in any way. Even the most disengaged patient would prefer to live a long and healthy life, and that means we and our patients are on the same side. The problem is that what we're asking people to do—this is that third bullet point—the problem is that diabetes self-management is a really tough job and that people often come to the conclusion that what we're asking them to do, those self-management efforts, just aren't worth the effort.

And we've talked about some of these core intervention strategies, which pertain to these four contributors to worthwhileness or lack of worthwhileness or lack of perceived value. So think about the importance of just asking about—assessing about emotional distress. Make sure we help people to know about the good news—evidence-based hope that you're not doomed—that with good care, odds are good you can live a long and healthy life. And think about structured blood glucose monitoring or how we can do that now with continuous glucose monitoring for many of our patients. And remember to talk about people's concerns about medications, when we think about how the costs are too high—or real medication costs. And finally, make sure, in terms of unrealistic expectations, that we talk about goals that make sense for our patients and targets that are reasonable.

So that's really all I had to say. Thank you all for listening. I hope you'll come visit us in San Diego at the Behavioral Diabetes Institute at some point—actually hoping to start our own live CME programs here in the fall or early next year, so if you want to get in touch with us, we'll be glad to send you information when that comes up. But thanks very much. And with Joanne's help, we're going to talk about some questions now. So thanks. Joanne, what do you think?

Joanne Gallivan

Bill, your presentation was great. I mean, I think that you've opened my eyes to a lot. And I think, from a communication standpoint, as one that develops communication programs, the fact that we really need to emphasize the good news more—you don't hear that a lot, and I really, really appreciate that reminder, so thank you. So taking small steps and looking at it from the patient's perspective, because it's so overwhelming—I think those are things that we can really use as we go out and develop messages for our patients.

So I'm going to—we asked people to send in questions to you ahead of time. So this is the first question, and we tried to group them together, so it really affects—it's practical approaches for identifying disengagement and helping a person to become and to stay engaged in diabetes self-management.

Are there tools or approaches? What are some open-ended questions that we can ask? And how can I best encourage clients to log their food intake and increase their physical activity? And I think the third question really—one of the answers is how you helped that one patient, you know, just make—just try a small experiment and see, you know, how it affected their blood sugar. So I will be quiet and let you address these questions.

William H. Polonsky

Sure thing. I purposefully didn't read any of these very carefully, because I wanted to make sure we could just be spontaneous about this. So the first question about are there particular tools and approaches—well, hopefully, it's just the stuff I just talked about. There have been efforts to do formal randomized control trials [cough]—excuse me—to try to see how we can go about this. We have some colleagues who are working on some proposals to NIH right now.

There's nothing really formally that I could say we're pretty confident or excited about, other than the things I've already talked about. I will mention one thing that people should be cognizant about, and that's one approach that we think or thought was very useful, which is motivational interviewing. Now, I'm an enormous fan of motivational interviewing. I've been a motivational interviewing trainer for more than a decade. But unfortunately—and this is one of the other things we've been trying to write up—there's been six/seven good randomized controlled trials, all of which have shown that motivational interviewing in diabetes have not been shown to be particularly useful in improving metabolic control; it's been very disappointing. I still find it hard to believe, but you see them in study after study. And all I can say is, we think there's something we're missing, and it may be—as I gave in a lecture to ADA last year, it may be that we're using an approach to motivational interviewing that's pushing people towards behavior change too soon—what are you going to do? what are you going to do?—and not spending enough time with folks respectfully addressing—of how mixed they feel—how unworthwhile they're thinking diabetes is—that we need to spend more time appreciating that, thinking about it from their perspective. So other than that, I'm not sure what else to say about it, other than—I hope they'd consider some of the things that we've talked about here.

We think the most important thing is, as you mentioned, Joanne, we need to share the good news with patients. This is a—I've been chatting about this. I've learned probably most of this from my colleague Dr. Richard Jackson, who's an endocrinologist at the Joslin. And we've been talking for years about wanting to write an article called “The Good News About Diabetes,” because no one ever has, but hopefully we'll get there soon.

Okay, about the second question, “What are some open-ended questions that are useful in identifying patient disengagement?” Well, again, I would say the most important question is the one I listed in one of the slides, which is—just ask people, you know, “Can you tell me one thing about diabetes that's driving you crazy?” And I would really make sure I phrased it that way: “Can you tell me one thing about diabetes that's driving you crazy?” It opens up everything. “Can you tell me what living with diabetes is like for you?” might be another way to do it. But it's a gift when you ask people that question. The usual response I used to get—I still get over time—is, “Wow, thanks for asking.” It really opens the door to understanding what's making this tough for people and how you can then go about—to address it.

I'm going to zip on here and just mention something about the third point. Joanne, you actually already said this: We think the best way to encourage people around physical activity, at least, is to use this structured blood glucose monitoring approach, like we did with Mr. Samuels. I've done it many, many times, and it's very effective. In terms of logging food intake, this is a tough one. You know, I was surprised after asking so many of my patients to do this that I finally said to one of them, "I'll tell you what: If you'll keep food records for 3 days, I'll do it as well." And it was the first time I had ever done it. And I realized when I collected my own food records and looked at them, and even though no one else was ever going to see the records I had written down except me, that I had lied. It is so easy to begin to shift things around, because there's so much sort of blame and shame around it. So, you know, I'm not sure what to do about logging. I think we just have to talk with people a lot about how just uncomfortable it is and how much shame there is around that. No matter how much time we say to folks, "Hey, we're just going to be objective about this, and there's no blame and shame," we're dealing with a long history of how we think about that and talk about that in our society. So I really don't have anything else brilliant to say about that.

Joanne, what about you? Maybe you have some comments about any of these, though.

Joanne Gallivan

You know what, I've been—as a registered dietician, I've asked people to keep food records, and I've had the same issues as well. I think that people think they're going to get scolded, because they write something down that, you know, we don't want to them—they don't want us to see. So, you know, it could be a learning tool, and even if they just don't—even if they keep it and they just look at themselves and they don't share it with us, maybe that's what they could do—you know, just use it on their own and don't ask them to share it with anybody else but use it on their own, and maybe they could just use it as their own learning tool and not worry about turning it in to anybody, because I think when people have to turn it in, they think they're going to get graded or reprimanded for having a bad food record.

William H. Polonsky

Yeah. You know, I think one way that—make it just more practical—the one way I've ever had any effectiveness with that is when I'll ask people to just do it at the end of the day, you know. "Right before you go to bed, take out a piece of paper and, to the best you remember, write down what you ate during the day and approximately what time, as best you can." It won't be exact, but it's not onerous.

Joanne Gallivan

Mm-hmm.

William H. Polonsky

And maybe that's a good compromise, but I wish I had something more intelligent to say about that one; that's a tough one, really tough.

Joanne Gallivan

It is. Can we go to the next question—next set of questions?

William H. Polonsky

Please.

Joanne Gallivan

State of—and I think you addressed a little bit about this, though—state of denial about having diabetes: “How can we help about a patient in denial about poorly controlled diabetes in accepting their diagnosis?” And dealing with a difficult patient that’s a know-it-all—this is a hard one—argumentative, is denying their diagnosis or need for self-care.

William H. Polonsky

Yeah, let’s think about this. I guess I would start with—at least with the first question, except in extremely rare circumstances, I just don’t think anybody is in denial. And I think we should stop accusing people of being in denial—that if people are not doing what we ask them to do, then, you know, we just need to think about it a little bit differently. And we need to ask them about what’s been tough about this. Now—and again, it goes down to—“Can you tell me what’s driving you crazy about living with diabetes every day?” is a place to start.

Now, to be fair, again, I’m assuming this is—that’s really what’s going on and the person will respond. If the point is, you actually are talking to someone who’s saying, “Oh, no, I don’t have diabetes,” I’d—again, that’s very, very rare, but I would just say, “Well, why do you think you’re here?” I guess. I mean, we—you know, “You’re here because your blood sugars are high? Are you concerned about—we’ll give it another name.” You know, I think, in many ways, because we still talk so much about prediabetes these days, it’s become a bit confusing.

You know, we’ve put together a little booklet that’s, by the way, available at our website for free if you ever want to download it. It’s a booklet for people newly diagnosed with type 2 diabetes, and we called it the “Don’t Freak Out” booklet. And we said, “What are the top 10 things we hope people—we want people to know walking out the door?” And the most—the first thing was—is always “It’s probably not a mistake,” because that’s the first thing people say: “Well, I should get this, you know, OGT done again,” or “let’s check my blood sugars again,” or “something’s wrong with this meter.” But it’s—at least when you first hear about it, it’s understandable that there’s a lot of people who say, “Oh, it’s just not possible.”

So if people are having truly trouble accepting the diagnosis, and again, I just think that’s very rare, I would just engage in a conversation about “what do you think that would mean if you had diabetes?” And again, for many people, they say, “Well, you know, gee, my mom had it, or I had a cousin,” and they think it’s a death sentence. So we’d want to have this conversation about what—if you had diabetes, what that means—that it isn’t a death sentence and that it doesn’t mean you are guilty of the cardinal sins of sloth and gluttony. It is a metabolic disease—you know, we would explain this—we’d typically explain it. But this is really tough.

So it’s so tough, let me skip to the next one: “What are some ways to deal with a difficult patient, i.e., know-it-all, argumentative, denial of diagnosis or need for self-care?” Ah, well, another tough one. Let’s see. You know, this is where I think there are principles of motivational interviewing that are very, very valuable. And one of the things that—one of the elements that one learns when you’re practicing and doing your initial training in motivational interviewing are the use of summary statements, where you’re hopefully doing a good job of listening carefully to what your patient is telling you, and then you’re bringing it together in a paragraph-like summary statement—you know, “Mrs. Smith, let me make sure I understand what you’re telling me. On the one hand, you’re concerned about this; on the other hand, this isn’t a big deal,” et cetera. But you’re bringing it together in a summary statement. And we find that summary statements are an incredibly valuable way to regain control of the conversation. So when I’m dealing with someone who likes to interrupt or is tangential or wants to be argumentative, I like to just

stop and say, “Hey, let me make sure I understand what’s going on here and where you’re coming from right now.” And so I just will use a summary statement to say, “You’re pretty sure you understand what’s going on. It sounds like you’re pretty sure you know more about this disease than I do. You’re concerned that maybe I’m leading you down the wrong path. On the other hand, you’re sitting here, so I imagine you might be thinking I could be of some value. Let me make—is that correct?” So—and just providing a summary statement, when it’s done well, can kind of reset the conversation—can ask the individual to sit back, step back, and go, “Well, wait a minute, what are we doing here?”

So I would ask people just to consider those kinds of elements of motivational interviewing and why it becomes useful to get training in motivational interviewing. The use of nothing else, just the summary statement, is a powerful way to have an impact.

So that’s one thought. Joanne, how about you? Any other thoughts about that?

Joanne Gallivan

Well, Bill, in terms of the first question, I think it goes back to—people hear so much negative news about diabetes that—or they think they did something wrong, so maybe that, you know, so they need to be, to me they need to be assured that it’s nothing that you did that’s making you have this disease. And again, emphasizing the good news and it’s not, like you said, a death sentence. They probably saw family members that suffered from many of the complications, but we really need to educate them about, you know, with well-controlled diabetes, you can lead a long and healthy life. And again, I think those messages haven’t been—don’t come across as much as they need to. I mean, they see all the negative stuff on diabetes about medications and so on, and we need to really give them, you know, hope and give them, you know, some reasons to take care of their diabetes.

William H. Polonsky

Yeah. Yeah, thank you. Yup, yup. Absolutely.

Joanne Gallivan

Okay, and I think this will probably be the last question that we can get to—a series of questions. But—and again, it goes back to low motivation engagement in diabetes self-management due to competing priorities. Comorbidity and other barriers, you know, are difficult, because people have so many other things going on, such as what you mentioned: limited income, lack of transportation, low health literacy skills, which we know is a huge problem. And then they don’t often have support in their community. How do you manage people who are disengaged because they think that they lack financial resources to manage their disease? And again, you know, many of the patients that are participants—they live in poverty, without transportation—have so many other competing factors going on; it’s not in their top 10 concerns. You know, how can we bring it to their attention and put it higher on their priority list?

William H. Polonsky

Sure. Okay, great. These are—it makes sense we’d stop—end with these, because this is the hardest ones. By the way, before we get to these questions, there’s something in that paragraph up at the top I want to mention. It’s about low health literacy skills. And allow me to cause a little trouble here. This is going to sound a little funny, but I don’t really believe in low health literacy, and I think the way we talk about it is troublesome. And what I mean by that is, oftentimes, when we are talking about our patients as having low health literacy, it has become a sort of polite way of saying, “Well, they’re not very intelligent.” And if you look at health literacy in populations, I would prefer—and someday I’ll get this written up—if we called it something else; like, I’d like to call it “health clarity.” And the reason I mention that is because,

Joanne, I don't know about you, but oftentimes, I will leave my own doctor's office and feel overwhelmed and forgetful and confused and realize I didn't really absorb everything I heard. And I don't think I'm stupid, and I don't think I'm unknowledgeable about health. But what we see is that people may leave their physician's office and not be able to absorb stuff. And it may be partly due to what they know and what they don't know, but a lot of it may have to do with how well that's been communicated. So I don't like to think—the reason I don't like “health literacy”—I don't like to think of it as a problem of the person; I like to think of it as a problem between the individual and the health care provider. That's why I'd rather think of it as “health clarity.” So anyway, that's just my soapbox for the moment.

Let me get to these extremely difficult questions, and maybe we won't even—well, we'll just focus on the first one because of time. You know, it says, “How do you manage patients who are disengaged because they think they lack financial resources?” Well, first of all, they are the experts; they probably do lack financial resources, and this is unfortunately extremely, extremely common and very real. And it is—to some degree, of course, it's an impossible issue to deal with, because, you know, if one can't afford one's medications, our job is to help them find some way to make that more affordable or to find other choices.

But I will say we have one tiny opportunity here, and it's—I'll go back to—well, let me say it this way: When people tell us they can't—I think I hear the frustration behind this question. People say, “Oh, I can't afford my medications,” and “Oh, by the way, I just bought a new, you know, huge television.” Or people will say, you know, “I can't exercise, because I don't have time.” Really, what both of those statements are—underneath that, people are saying, “Compared to the other things in my life, what you're asking me to do isn't as important.” So I can't win an argument with someone about, you know, “Why don't you get up at 4 a.m. to walk if you're having trouble with time?” or, “Why don't you dig deeper in your purse—that's empty—to find the money to pay for your medications?” But we can have conversations with folks about, “How important is taking care of your health and your diabetes compared to everything else, and can we help that to shift?”

And to highlight that, I want to mention, just quickly, one study from one of my colleagues, John Pate in Michigan. And what he did is, he looked at folks who—looked at their relationship between, well, poverty and medication adherence, where, of course, you always see a relationship. But he found there was one powerful moderating factor, which was the degree to which patients trusted their physician. And this has been seen in other studies now. When you trust your physician, even in situations where medications are very costly, because you don't have much money, it turns out adherence isn't as bad. When you trust your physician, in other words, you're more likely to agree and see that your health really is that important, where you might want to compromise, unfortunately, other aspects of your life in terms of putting money in other places so that you can put money toward needs. You're more likely to believe in the importance of your health when you're working with a physician or other health care professional that you really trust. So I would say trust is so key, and that's our only real leverage here—only opportunity. When we are good at listening to our patients, when we arrange our offices and talk to our patients in non-blaming ways so that they understand and perceive that we are on the same side and that we wish them well and that we are competent, everything starts to change, even when you're dealing with concerns around cost of medication, which is amazing.

So I can see our time is just about up, so I figure we should probably just stop here, but—unless you have some other comments, Joanne.

Joanne Gallivan

No, I don't, and I don't want to keep everybody or you over the hour. So I do want to say thank you to everybody. Unfortunately, we didn't get to any additional questions, but I think a lot of the questions that people asked, you have already answered. So if you have additional questions that Dr. Polonsky could not address, you can always send them to us at ndep@hagersharp.com. You could also get a certificate of completion from us as well.

Thank you again, Bill. This has been really, really an enlightening presentation. It's made me think about diabetes and counseling patients in a whole new way, and I think that our participants have a lot to think about when they go back to their practice. And just to put in a plug for NDEP, remember, we have lots of resources that can help you with your patients. In the beginning of June, we actually have a new resource called Medication Adherence. We've collected resources and tools with the help of medication adherence experts from across the country, and we'll have that up on our website, and hopefully that can help you with your patients when it comes to medication adherence. And I mention that because Dr. Polonsky just talked a little bit about medication adherence.

So thank you, everybody. Please fill out the evaluation form that you're being sent after this webinar. And thank you so much, Bill, for this wonderful presentation.

William H. Polonsky

Thanks for letting me; I appreciate it.

Joanne Gallivan

Thank you.

William H. Polonsky

All right, see you later.

Multiple speakers

Bye.