

This transcript was lightly edited for readability.

Introductory Remarks

Moderator, RTI International

Great. Thank you, everyone. So, good to see you today. I appreciate you joining. My name is **[MODERATOR]**. **[REDACTED]** I work for a company called RTI International, and I also want to introduce a colleague with me today, **[SECONDARY MODERATOR]**, who's also with me today, who's going to be helping me. You will hear from her for a couple of times today.

So, the Centers for Medicare & Medicaid Services, or CMS, is convening these patient-focused roundtable events and others as part of the Medicare Drug Negotiation Price Negotiation Program. The purpose of today's event is to hear from you all, and just so you know, you're a group that includes patients, caregivers, and patient advocates, about your experiences with the conditions and diseases treated by the drug we're discussing today and with other medications for the same conditions.

Today's group is more patient-focused about the experiences living with diabetes and obesity and so forth. If you want to share your input on other topics, more policy-focused, we do also have an email address that you can email comments to. That email address is IRARebateAndNegotiation@cms.hhs.gov. You don't have to remember that, you'll see a slide at the very end with that email address. But again, today is more focused on the patient experience.

Today, just to avoid confusion, I want to note that I'll be referring to the drug, Ozempic, Rybelsus, and Wegovy by the generic term semaglutide.

I'm going to say that just so I don't have to mention all three names at once. I'm just going to say semaglutide today, just for make things easier for all of us. But you can refer to the drug however you would like.

The information shared during the events will help CMS understand patient experiences with the conditions and diseases treated by the drugs, patient experiences with the selected drugs themselves, and patient experiences with other drugs that are used to treat the same conditions. CMS may use this information in negotiating Medicare pricing with the manufacturers of the selected drugs. Your experiences and perspectives are very important to us, and we genuinely appreciate your time today.

Let's watch a brief video from CMS leadership so that you can hear from them about how much they value your time and input today.

CMS Remarks

00:02:27

Steph Carlton, Deputy Administrator and Chief of Staff, Centers for Medicare & Medicaid Services

Greetings, everyone. I'm Steph Carlton, the Deputy Administrator and Chief of Staff at the Centers for Medicare & Medicaid Services, or CMS. CMS administers Medicare, our country's federal insurance program, for more than 65 million older Americans and people with disabilities.

I deeply appreciate each one of you for taking the time to join us today. Lowering the cost of prescription drugs for Americans is a top priority of President Trump and his administration. As the second cycle of negotiations begins under the Trump administration, CMS is committed to engaging with stakeholders for ideas to improve the Negotiation Program.

In January 2025, CMS announced the 15 Medicare Part D drugs selected for the second cycle of price negotiations. Medicare's ability to negotiate directly with drug companies will improve access to some of the costliest drugs while fostering market competition and continuing innovation.

Our priority in negotiating with participating drug companies is to come to an agreement on a fair price for Medicare. Promoting transparency and engagement continues to be at the core of how we are implementing the Medicare Drug Price Negotiation Program. And that is why the process for negotiation engages you, the public.

This event is part of our effort to hear directly from a range of stakeholders and receive input that's relevant to the drugs selected for the second cycle of negotiations. Thank you again for joining us. Your input matters. And next, stay tuned to hear from the event moderator to give you more details on what to expect during this event.

00:04:22

Moderator, RTI International

Also, I want to make you aware that staff from CMS will be sitting in on this event so they can hear your experiences and opinions directly from you. Let me hand it over to, I think it's **[CMS STAFF]**, for a moment, just so they can say, hello. Hey, **[CMS STAFF]**!

00:04:35

CMS Staff

Hey, everyone, thank you so much for being here and welcome. We do have staff here today from the Medicare Drug Price Negotiations team. And we want to take a moment just to thank you all for participating, and to let you know that we're very much looking forward to learning from you and hearing the discussion today. I want to let you know that we are going to have our cameras off to let you all focus on the discussion, but that we will be here and listening. So, thank you.

Housekeeping

00:05:02

Moderator, RTI International

Thank you, **[CMS STAFF]**. So, before we begin and we're almost there, I promise, I do want to go over just a couple of housekeeping items and ground rules so that every everyone knows what to expect.

First, I'm going to ask some questions, and I hope that you can share your experiences. If, however, a question arises that you don't want to answer, that is totally okay. You don't have to answer any questions you don't want to today. Please minimize background noise and silence your cell phones and other devices, and mute yourself when not speaking.

This discussion is not open to the press or the public, and for today we will use first names only during the discussion to protect your privacy.

Please do not share any unnecessary personally identifying information about yourself or personal health information during our discussions. We are going to audio and video record today, which we are now. But these recordings will not be shared publicly. Following the event, CMS will prepare transcripts that have your names and identifying information removed, and these transcripts will be made available to the public.

I also want to highlight a few of the things for our discussion today. One, thanks in advance for keeping your video on throughout the discussion. This discussion will last about an hour and a half, and I do have a lot of questions to ask, and it's possible that we may be in a good discussion, but I may have to move us on to another point. That's not me being rude to you. That's because we have a lot to discuss today.

If you get disconnected, please attempt to rejoin, and if you can't connect, please reach out to the email address shown here, IRADAPStechsupport@telligen.com, and someone will help you get reconnected. If you need to take a break or step away, that is totally okay, just turn off your camera and your microphone. Step away and come back as soon as you can.

Please try to speak one at a time. If there are multiple people speaking, I may have to play traffic cop and call on people, but for the most part we'll keep this free flowing. And finally, also, if you want to speak, and you can't get a word in edgewise, you can also use the raise hand function in Zoom, and that lets me know to call on you. Finally, your opinions and experiences will differ. We want to know what each of you thinks honestly about the topics we discussed today.

Okay, that was a lot of me talking. I'm going to pause for a moment to see if you all have any questions for me before we begin.

So, for the first part, what I'm going to do is I am going to ask you all to do some quick introductions, and these introductions will be about 30 seconds. So, pretty quick.

Just tell me your first name. Tell me the condition or conditions that semaglutide treats that you have experience with, and then whether you'll be sharing personal experiences as a patient, the experiences of a loved one, like as a caregiver, or you're sharing the perspective as a patient advocate, and it's totally possible you're wearing two or three hats as well. And that's totally okay.

And I want to go in the order that they appear on my screen, and the first one I have is **[Participant 1]**. Hey, **[Participant 1]**.

Discussion

00:08:18

Participant 1 (registered as a patient and representative of a patient advocacy organization)

I'm **[Participant 1]**, and I am here speaking on my own experience, the experience to friends and loved ones, and as a longtime advocate in the realm of obesity in particular, but also diabetes insofar as it relates to obesity.

00:08:40

Moderator, RTI International

Great. Thank you so much, **[Participant 1]**. And **[Participant 2]**. Hey, **[Participant 2]**.

00:08:46

Participant 2 (registered as a patient and representative of a patient advocacy organization)

Hello. I'm **[Participant 2]**. I have type 2 diabetes, and I'm on Ozempic, and I just thought it would be a great thing to sit in on these meetings and get my voice heard.

00:09:00

Moderator, RTI International

Wonderful, thanks, **[Participant 2]**. Happy to have you here! And **[Participant 3]**?

00:09:05

Participant 3 (registered as a patient)

Hi, I'm **[Participant 3]**. I'm actually on Zepbound for obesity. And it's been really wonderful, lost 100 pounds. And so, I'm here as a patient. Thanks.

00:09:20

Moderator, RTI International

Thanks, **[Participant 3]**. **[Participant 4]**?

00:09:24

Participant 4 (registered as a patient)

Hi! My name is **[Participant 4]**. I check all your boxes, **[MODERATOR]**. I have type 2 diabetes and have had it for over 40 years. I have been on both Byetta, Victoza, Ozempic, Wegovy, and now I'm on Ozempic again. I am a caregiver for my mother and my father, who passed away, type 2 diabetes. And I've been a patient advocate for over 35 years with four or five different diabetes organizations. I'm also a heart attack survivor. So, I check just about every box you have.

00:10:04

Moderator, RTI International

Oh, goodness, all right. Thanks, **[Participant 4]**, I appreciate you being here. **[Participant 5]**?

00:10:09

Participant 5 (registered as a patient, representative of a patient advocacy organization, and as other)

Hi, all. My name is **[Participant 5]**. I have type 1 diabetes. I've been living with it for almost 20 years. I do take Ozempic as a patient and have also used it for PCOS [polycystic ovary syndrome] and high cholesterol as well. I also wear another hat that I am an **[REDACTED]** with **[REDACTED]**, an organization that fights for affordable and equitable access to medications. And we don't take any pharma funding.

00:10:36

Moderator, RTI International

Great. Thanks, **[Participant 5]**. And **[Participant 6]**?

00:10:42

Participant 6 (registered as a patient and representative of a patient advocacy organization)

Hi, I'm **[Participant 6]**. I'm here speaking on behalf of myself as a patient living with obesity, who has taken semaglutide. In addition to obesity, I also have the cardiovascular risk reduction indication, and, as **[Participant 1]** mentioned, I also do have close friends and loved ones who have taken the same medication, but they took it for type 2 diabetes and obesity together.

00:11:13

Moderator, RTI International

Thank you, **[Participant 6]**. And **[Participant 7]**?

00:11:26

Participant 7 (registered as a patient)

I'm **[Participant 7]**. I'm a Medicare patient, and I'm living with high blood pressure, diabetes, and metabolic syndrome and some other medical conditions. And I live in **[REDACTED]** California and so, everything's far away from me. So, in the meantime, what my background is, as far as the drugs itself is, I tried metformin, didn't work. I tried Jardiance, didn't work. They said Rybelsus, and it worked, and yay, except I couldn't afford it because it was too expensive. It was \$425, and then they even got it down, but I still had to pay the deductible and the donut hole, and I just couldn't do it.

So, there's that, the pricing. I guess that's it. My background is, I work in the educational media industry, and I'm also a small business owner. I have a grief support and grief decluttering business. So, it's sort of behavior change, basically.

00:12:57

Moderator, RTI International

Thanks for that. And **[Participant 8]**, last but not least.

00:13:03

Participant 8 (registered as a patient)

Thanks. I'm **[Participant 8]**. I'm here primarily as a patient. My own experience is that I've had obesity since childhood, and it grew more severe in adulthood. So, I've been dealing with it virtually my entire life. I also have a very strong history for type 2 diabetes. I'm also here on behalf of loved ones and friends.

And I've become a patient advocate, too. As far as my own usage of any of these drugs, I've been on a couple. I've had experience with both with semaglutide and with tirzepatide and have had good success. I'm excited to be here.

00:13:50

Moderator, RTI International

Thanks, **[Participant 8]**, we're happy to have you here as well. So, now that you've all had a chance to introduce yourselves, I want you to use the chat feature for just a moment, and you can put yes or no. And what I want to know is, if you have personal experience or a loved one has personal experience using Ozempic, Rybelsus, or Wegovy. So, just yes or no. Seeing quite a few yeses.

00:14:21

Participant 7 (registered as a patient)

Nope.

00:14:28

Participant 3 (registered as a patient)

Did you say anyone?

00:14:29

Moderator, RTI International

Yeah, anyone in that group. Any semaglutide. So, Wegovy, Ozempic, and Rybelsus. Okay, awesome. It looks like mostly yeses I'm seeing.

For just a moment, I actually don't even want to talk about the treatments for these conditions. And, by the way, you probably all know this, but semaglutide is indicated for a number of conditions. It's indicated for type 2 diabetes, type 2 diabetes and cardiovascular disease, type 2 diabetes and chronic kidney disease, and then also obesity.

But for the moment I want to talk about just these conditions. And first, I want to talk about type 2 diabetes in general. How does type 2 diabetes affect your life or your loved one's life or people's lives on a day-to-day basis? Again, how does type 2 diabetes affect people's lives on a day-to-day basis. **[Participant 4]**, you want to go first I see your hand is up.

Go ahead, **[Participant 4]**.

00:15:46

Participant 4 (registered as a patient)

I'm sorry. I didn't hear you say my name, **[MODERATOR]**. Diabetes is a 365-day, seven-days-a-week, 24-hours-a-day disease. We don't take a vacation. We don't get to ignore it. It's a disease even with type 2 diabetes. Now, my mother and father with type 2 were both on insulin. I have never been on insulin. However, I have been on injections, and a handful of medication that makes me look like a drugstore twice a day with all the medications I take. My son had type 1 diabetes, and he never took a vacation day until he died. It's a disease that you have to manage. You can't ignore it.

And how does it affect my day? I think about it all the time. I think about it when I eat. I think about it when I exercise. I think about it when I take my medications. I think about it when I take my blood sugar. It's a disease, you don't get to not think about. And it's a chronic disease that affects everybody. Everybody in this picture that you see, **[MODERATOR]**, this disease affects them differently.

Nobody is the same. It's an individual disease that has to be treated and managed individually. Important thing, it is manageable with the correct tools. But as somebody put in the chat, they didn't have access to the tools to manage their disease, and that makes it difficult, and I'll hush.

00:17:22

Moderator, RTI International

No, that was that was helpful, **[Participant 4]**. Thank you, **[Participant 7]**.

00:17:27

Participant 7 (registered as a patient)

Well, for me, before I realized I had diabetes, when I had a 13 A1C, and my doctor said, this has gone far enough. You need to do something. And I was like, okay. So, I tried, as I said before, I tried a couple of things that didn't work, and then I tried Rybelsus, and it did work. I had been before that, passing out during the day. I work remotely, and I would pass out. And my husband would just go "timber." There I go. I would just pass out during the day. It was beyond being tired, it was just all of a sudden, I had no strength. I didn't have a continuous glucose meter at that time, so I'm pretty sure I had high blood sugar, but I didn't know it. I just thought that was the way I was.

When I had Rybelsus, that stopped. I lost 20 pounds. My face got thinner. And the only thing was I was really having terrible stomach problems. But they got better over the three months that I was trying it out, and I thought, I'll step into it, and they said, and that was like they give you three, I think it was 3 milligrams or something, and then they said, it'll go to seven now. And I'm like, oh, I just got used to three. But I thought, okay, I could do this. And then, I went to go get the Rybelsus from the pharmacy. And it said \$425, and I'm like, what? And they said "it's not in the formulary." Then I had to go back and work on the formulary and they got it down. They got the monthly payment to \$40, but they still had a \$425 starting point. I don't have \$425, and they said "And by the way, it will come again, you'll have \$500" I said, "here you can have them back." I can't afford that, not now, and probably not in the foreseeable future. And so that's what happened with that.

00:20:22

Moderator, RTI International

Actually **[Participant 7]**, we'll dive more into the drugs themselves. But at the moment, I want to focus on how diabetes affects people's lives day-to-day. But we'll come back to that for sure, **[Participant 7]**, don't worry. **[Participant 1]**, how does type 2 diabetes affect people's day-to-day lives?

00:20:48

Participant 1 (registered as a patient and representative of a patient advocacy organization)

In the case of my father, he died from complications of type 2 diabetes. So, in terms of affecting his life, it ended it. For myself, I live with a diagnosis of type 2 diabetes, and you might say that it is a shadow that largely defines how I think about my health, and what I can and should and might do about it, and what my prospects are for future health.

00:21:27

Moderator, RTI International

And when you say "a shadow," tell me what you mean, **[Participant 1]**.

00:21:32

Participant 1 (registered as a patient and representative of a patient advocacy organization)

Well, I look at my patient record and the stuff that's in the health tracking app from my primary care physician, and there it is, up top of my problem list. I just went and got blood work for my upcoming physician visit. And one of the first things I wanted to see is where is my A1C sitting? And that's kind of where it is. It's there. It is a risk that I am mindful of, and that I really, really, really want to stay back from a diagnosis of full type 2 diabetes and either hang on to or erase that diagnosis of prediabetes.

But I don't really have access to the medicines that I believe could reverse the prediabetes diagnosis, and that's because of cost and access issues.

00:22:46

Moderator, RTI International

Great. Thank you, [Participant 1]. [Participant 5], go ahead.

00:22:50

Participant 5 (registered as a patient, representative of a patient advocacy organization, and as other)

I won't speak on behalf of the type 2 community, because that is not my experience, though my father died from complications of type 2 diabetes. And so, I have an intimate window of what that looks like, and I also think that the types are more closely joined together than they are separate.

I just want to reiterate what [Participant 4] and [Participant 1] said about this being a 24/7 disease. I was diagnosed when I was 15, and I think it irrevocably changed my brain and how I operate in the world and how I look at the world, because I cannot go without insulin. I cannot go without my medications, and that is a really stark thing to learn when you're 15 of having that experience. I have had to ration my insulin in the past, and so it was an incredibly shameful experience of not being able to afford your own medications.

But then I learned that that is not a rare experience. About one in four people have that experience, and it's even higher in the Medicare population. And so, it encompasses our whole daily lives, our food, our activity, how we move through the world, but, as others have said, if you don't have access, and you don't have affordability, everything else is moot. That is really the sticking point for me.

00:24:26

Moderator, RTI International

Thanks, [Participant 5]. And, [Participant 2]?

00:24:31

Participant 2 (registered as a patient and representative of a patient advocacy organization)

I agree with everybody else. It is 24/7, but it also puts another thing on us that we have to see different kinds of doctors. I see an ophthalmologist every year, because they have to check to see that the diabetes isn't affecting my eyes. I have an endocrinologist, of course, who prescribes me these drugs and helps with looking at my feet, looking at my thyroid, all that good stuff. I also am a chronic illness patient. I started first with rheumatoid arthritis and psoriatic arthritis, and the

diabetes developed through inactivity and gaining weight and prednisone, and things like that. It is every day, 24/7, and then also more money comes out of your pocket when you go to these specialists.

00:25:33

Moderator, RTI International

There's lots of treatments available for diabetes. And we're talking about some today. But we're going to focus on all the different treatments out there.

To you all, thinking about treatments for diabetes, what aspects of type 2 diabetes are most important to you and your loved ones or patients to have managed or treated? Again, what are the most important aspects of type 2 diabetes for people to have managed or treated?

Yeah, **[Participant 2]**?

00:26:11

Participant 2 (registered as a patient and representative of a patient advocacy organization)

I'm not sure exactly what you're asking of us. Maybe making sure that we're eating the right foods, making sure that we have access and money to get the medications we need. Many people can't afford anything past metformin, which is a shame because Ozempic is a game changer for me, at least. It brought my A1C way down. That's what I think. I wasn't sure exactly what you were asking, but I think that's what you're asking.

00:26:47

Moderator, RTI International

Yeah, that is helpful.

00:26:55

Participant 4 (registered as a patient)

Just real quickly. If I understood your question, you're asking what, as a type 2 diabetes patient, what part of that disease is most important to me, and frankly, it's being here to be on this Zoom call. Frankly, it's being here, to be here. I'm **[REDACTED]** years old. I'd like to see **[REDACTED]** years old. It's living a long life, managing your disease, as **[Participant 2]** talked about, is exactly correct. But what's important?

What's important is seeing grandkids, seeing children. I lost my son with type 1, and you're not supposed to outlive your kids. That's not the way it works. It's making sure you've heard the word "cost." I know you don't want to get into that yet, but nobody brought up the stress and the worry of this disease of you not being able to get the tools you need to manage it. And what happens if you don't get it? **[Participant 5]**'s exactly right. She goes 72 hours without insulin, she dies.

Okay, [if] I'm not on insulin. I die slower, but I still die. The stress that you go through, you've heard of diabetes and depression. It's real. The stress you go through is important, and worrying about money, I know that we're talking about price negotiation here and drug negotiation, and you'll get to some of that later. I love that idea, as long as it lowers the price for patients, as long as it helps me afford the medication. I am blessed to have a great job, and I can afford \$900 after **[REDACTED]**, when I go pick up my medication the first time. Not everybody can do that, so the stress of people having that worry about their disease cannot be discounted. I realize I preach, **[MODERATOR]**. I should have been a preacher, but I'm not, so I'll hush now.

00:29:07

Moderator, RTI International

That's okay. [REDACTED] No worries.

I focused a little bit on type 2 diabetes. And I also want to tell people who have both type 2 diabetes along with cardiovascular disease and chronic kidney disease, to think about those conditions as well. Is there anything else you want to add to the discussion about cardiovascular disease and chronic kidney disease? If not, I'm going to go to obesity next.

Okay. I want to talk about obesity as well. So, that's one thing that semaglutide can also help treat. So, again, thinking big picture, not thinking about the treatment set for a moment. In general, how does obesity affect people's lives? How does it affect them on a day-to-day basis in their lives?

[Participant 6], go ahead.

00:30:00

Participant 6 (registered as a patient and representative of a patient advocacy organization)

Sorry. I'm going to try to say this without getting too emotional. Let me just give you an example. I traveled today. That traveling required me to purchase an additional seat on the airline. My mobility is limited. The airport I flew out of, I was able to walk. The airport I flew into, I needed to get wheelchair assistance. At one point the pusher quietly asked me if I could get up and do the moving sidewalk because there was an incline, and he wasn't able to push me up the incline. This is something that's typical to me.

Two weekends ago, my bed broke, so, that interrupted my sleep for the weekend. It is also a 24-hour disease. It is one that is heavily stigmatized, also. When it comes to my other health care, it keeps me from getting the health care I need because of the weight restrictions and limits on equipment or doctors just judging me. I won't get too into it, but the reason I started these medications was because I needed a cardiac procedure, and I was over the weight capacity for the procedure table.

And honestly, the cardiologist said, come back when you weigh 390, and that was it. The medication I was given for the heart condition wasn't working, and I was just told, go and come back whenever you weigh less. And this has been all my life. On a daily basis, it impacts me. I typically don't have any other ways to do it. It's a chronic condition. I have other conditions that contribute to the excess weight, but it is every day navigating a world that isn't built for me.

00:31:59

Moderator, RTI International

Appreciate that, **[Participant 6]**.

00:32:01

Participant 6 (registered as a patient and representative of a patient advocacy organization)

If I could just add, I know it was mentioned earlier, but part of that is having, I'm on Medicare at my age, because I haven't been able to work full time for most of my life. I've been on Social Security disability, which is another stigmatizing hardship to live as a young person. I feel like my career was stolen from me.

00:32:27

Moderator, RTI International

Thank you, **[Participant 6]**. I appreciate that. **[Participant 8]**, go ahead.

00:32:33

Participant 8 (registered as a patient)

Thanks, **[MODERATOR]**. For me, living with obesity is being blamed for my disease every day and everywhere in society, even though I've tried everything I can think of to manage it.

You know we're all told that weight is all controlled by what you eat and how much you exercise. There's much more going on with weight that we don't have volitional control over in our bodies, and every time I try to diet, I'd lose some weight, and then I'd stop losing, and I would end up regaining that weight, and usually a few extra friends came along back with it. I'd even be heavier than when I started the diet. I've done that since junior high school. I'm a Medicare recipient, so gives you an idea, we had junior high schools back then. They weren't all middle schools.

I've been on and off diets my entire life. Now, there are actually some science-based treatments available for the disease like semaglutide. But you can't access it, or a lot of people can't access them. And it's so frustrating that, here's something that might help. It's not going to help everybody, but a tool you can't have. It's out of reach for so many people, and it is a day-to-day struggle. It's akin to diabetes in that, having obesity and trying to control your weight, is an everyday thing and every minute thing. I once had somebody ask me, "how long has it been since you thought about your weight?" I looked at my watch, and I said right now. Because it is a constant stress. It's a constant thought on your mind. And the stigma we face in society, it is a disease we wear on our sleeves. The stigma we face in society, it does untold damage.

00:34:57

Moderator, RTI International

[Participant 2]?

00:35:03

Participant 2 (registered as a patient and representative of a patient advocacy organization)

It is something that every time I look in a mirror, I'm a little bit shocked at how I look, because this is not how I started out. I was always, what they used to call "skinny **[Participant 2]**," because I was the skinny one when I was younger, and when I became chronically ill is when the weight gain started for me.

I work every day with plus size ladies. I'm a **[REDACTED]** for Lane Bryant, which is a plus size ladies clothing store, so I see the toll it takes on my clients, as well, because my clients have a hard time finding the right size. For the ladies, right size bras, right size panties, right size pants and shirts and things that they like to wear. I see it every day. In fashion, of course, that is the one thing is the hardest to find, clothing.

00:36:07

Moderator, RTI International

And **[Participant 3]?**

00:36:11

Participant 3 (registered as a patient)

Thank you. I liken it to taking one or two or three bags of peat moss and attach them to your body and walking around with them. You take them in the shower, you take them to bed, you take them everywhere you go, and you don't get to take them off. They're very heavy and they hurt, and I hurt when I was obese.

There is a lot of fat discrimination in society. There's a lot of fat discrimination in the medical community, and the reason that I spend \$500 a month, which is very hard for me on Social Security disability and a small job, is because I could not get a knee replacement, and I was suffering, and I probably would have put a bullet in my head. I said, "you know what, I'm going to do this because I have to." And so, I did, and I'm getting my knee replacement. But I shouldn't have had to, I should not have had to do that. And I shouldn't have to do it today just to get the care I need. This wasn't a vanity project. This was a knee replacement.

00:37:22

Moderator, RTI International

[Participant 4], and then I will ask another question. Go ahead, **[Participant 4]**.

00:37:26

Participant 4 (registered as a patient)

I tell people I've lost two or three tons in my lifetime.

And weight gain and weight loss was a seesaw up and down scenario until Ozempic came out. Ozempic, Wegovy.

It not only helps appetite, but it also helps alcohol intake. I am a Bourbon aficionado **[REDACTED]**, and I will tell you that it severely restricts. I now believe it ought to be given to everybody that's an alcoholic, because it would absolutely restrict not just your food intake, but your alcohol, which is a sugar, which does put on weight.

Everybody made great salient points on this, that it's not a choice drug. It's a drug that we need to manage obesity, which is a disease separate from diabetes, but is a causation action for diabetes. As **[Participant 5]** said, there's type 1s on Ozempic as well, and they're not using it for obesity in most cases; they're using it for management of blood sugars. It's important. For the government not to do everything in their power to put it in our hands is a mistake. I'll step off my soapbox.

00:39:18

Moderator, RTI International

Okay, thanks, **[Participant 4]**. I appreciate it.

Okay. I want to focus now, we've been talking big picture. But now I want to talk specifically about semaglutide, again Wegovy, Ozempic, and Rybelsus. And we'll talk about type 2 diabetes, first.

To you all, thinking about you, your loved one, or patients' experiences with semaglutide for type 2 diabetes, what do you think are the main benefits that you or your loved ones have experienced by taking semaglutide? And we'll talk about drawbacks later. But first, I just want to focus on the benefits of the drug for type 2 diabetes. **[Participant 4]**, go ahead.

00:40:09

Participant 4 (registered as a patient)

I didn't want to control the conversation, but, the benefits are what I kind of talked about. It does help you lose weight. It does help manage your A1Cs. I can talk about the side effects that aren't great, but the positive effects of it outweigh the side effects, and that's why I'm still on it. The side effects of these medications allow me to manage my disease in a way that metformin and the other drugs that I take didn't do.

I'm still on metformin. As I said, I look like a drugstore twice a day with all the medications. But these type of drugs are the benefit of years of research that scientists put in to help us, to help everybody on this call. And what they do, once again, is what our ultimate goal is, which is to manage our disease well, to improve our life.

00:41:27

Moderator, RTI International

Awesome. And then again, the main benefits that you or other people have experienced taking the semaglutide for type 2 diabetes. **[Participant 5]**, go ahead.

00:41:39

Participant 5 (registered as a patient, representative of a patient advocacy organization, and as other)

When I was diagnosed with type 1 diabetes when I was a teenager, around the same time, I was also diagnosed with PCOS, and so that's why I've started adjunct therapy. I've taken metformin Victoza, and finally Ozempic. I say this because, it's had such cross-relational benefits for me, in that as a type 1 diabetic, you're pretty much given insulin and said, okay, go off and do your own thing. That's it. But for many folks, especially women, also have other metabolic considerations that are going on at the same time, that make it really difficult to manage my diabetes. For me, being on Ozempic, I was able to cut my insulin usage, my total daily dose by a third. I went from about 90 units to 30 units, and there's a lot of benefits from cutting down insulin usage and having that sort of circulating in your body. My cholesterol are now all in range. For the first time ever, my menstrual cycle has been regular with my PCOS, and I know that there's a lot of studies going on about this drug, specifically for PCOS. My A1C has been perfect. Just a few points higher than a non-diabetic at this point. Those positives have really been life-changing.

00:43:19

Moderator, RTI International

[Participant 7]?

00:43:22

Participant 7 (registered as a patient)

I'm pretty much saying the same things. Basically, I did lose weight, even in three months, I lost, I think it was about 20 pounds, and those pounds have not come back. And they haven't gone down since either. My face got thinner. My A1C went from 13 to 7 in three months. I feel like it kind of reset my metabolism, so I was on a better path even though I didn't get to continue. I would have probably liked to continue, but that was not to be. But I think it did a good thing, even in that time.

00:44:21

Moderator, RTI International

Yeah, **[Participant 2]**, the benefits of the drug?

00:44:26

Participant 2 (registered as a patient and representative of a patient advocacy organization)

The benefit has been that my A1C has drastically dropped. I went from like a 9 down to a 6.7, so that has been the benefit. I haven't lost much weight with Ozempic, unlike other people who I've seen that have lost like 40, 50 pounds. I've only gone down like 10 pounds, but to me the benefit of getting my A1C down is probably the best thing.

00:44:52

Moderator, RTI International

And then, **[Participant 1]**, I'll let you wrap up, and then we'll move on to another question.

00:44:59

Participant 1 (registered as a patient and representative of a patient advocacy organization)

Two things I'd like to add. One is with the caveat that I can't afford semaglutide, so I don't have the direct experience, but from friends and loved ones who take it, I know that one of the benefits that has not been mentioned is the effect of quieting what is referred to as "food noise," these are intrusive thoughts that you just can't escape. People describe it as like a cacophony of voices telling you, where are you going to get your next meal? Where is the food? Do I need to drop into this or that food outlet? It's intrusive and disturbing thoughts about food that prompt a person to eat, and the fact that it quiets that, people have told me that even if I didn't lose a single pound, just having those voices go away is a huge benefit to me, and I would pay for it they say.

The other benefit that I see kind of across the board is that by repairing the broken physiology that is at the root of obesity by fixing that root problem, it has served to snap people out of the thinking that this is a disease of bad behavior, that this is somehow the fault of the people who have it, and that alone has made a big difference in the quality of the discussions, and to a certain extent the bias that people face when they seek treatment for obesity. Oh, you have to get medicine? Oh, you have to have surgery? Well, couldn't you just eat less and move more? And I do not for a minute underestimate the importance of that.

00:47:12

Moderator, RTI International

Thanks, **[Participant 1]**.

Now, we've been talking about type 2 diabetes for benefits. In addition, with type 2 diabetes, you can also treat cardiovascular disease and chronic kidney disease, and I wanted to see if people have noticed benefits there as well. Like **[Participant 5]**, you mentioned it lowered your cholesterol, I believe, but others, have you seen benefits in terms of cardiovascular disease or chronic kidney disease? **[Participant 3]**?

00:47:36

Participant 3 (registered as a patient)

I had chronic kidney disease. I was stage 3. I still couldn't qualify for these medications, but they say it's resolved since I've been on it. I don't have chronic kidney disease anymore. My glomerular filtration rate [GFR] has been consistently over 60 for the last six months, so I don't have it.

00:47:56

Moderator, RTI International

When it comes to the treatment of type 2 diabetes with semaglutide, what have been some of the drawbacks or the challenges that people have faced with the drug?

[Participant 8]?

00:48:20

Participant 8 (registered as a patient)

I didn't take semaglutide for diabetes, but one of the challenges I faced when I tried Ozempic to help manage my weight. Two things. One was cost, huge challenge, but the second was I had a very bad reaction to it, and I'm not saying it's a bad drug. I think it's a very good drug for some people, and I have friends who have had absolutely no side effects and done really well with it. Dropping their A1C from 13 to 6 in two months, and he had absolutely no side effects. But for me, it was a drug where I was sick for a month, even though I started on a microdose.

But that's just a reason of why we need more options. We need options because our bodies are, and I think **[Participant 4]** made the point earlier, we are all different. Our bodies are all different. We need really personalized treatment. That's just an example of why we need that in both diabetes and obesity.

00:49:35

Moderator, RTI International

Great. For obesity, for benefits and drawbacks, I will come back to that, I promise, **[Participant 8]**. Don't worry. But for type 2 diabetes, some of the drawbacks or challenges that your loved ones or you've experienced? **[Participant 7]?**

00:49:51

Participant 7 (registered as a patient)

The drawbacks from Rybelsus was it just tore me up as far as digestive. The digestive everything was just awful, but it started getting better towards the end of the three months, unlike the metformin so, I was willing to give it a chance. But the digestive was just awful. I mean, I was very sick most of the time. But, believe me, I didn't want to eat anything, so it really helped in losing the weight. True story, you don't feel like eating. You don't have that feeling like you must eat. That was helpful, too, for losing weight, which is important when you're trying to manage type 2 diabetes. Got to handle the weight, so, that was really important, but I would say that was the worst thing, the digestion.

00:51:14

Moderator, RTI International

And then **[Participant 5]** and then **[Participant 4]**, and then actually, **[Participant 2]**, I need to move on to another question, just for time sake. But **[Participant 5]**, if you could, just quickly. And then **[Participant 4]**.

00:51:25

Participant 5 (registered as a patient, representative of a patient advocacy organization, and as other)

I think a lot of the side effects are pretty well documented. I will say that having been on Victoza before, I do get low blood sugars, but they're not nearly as bad as they were on Victoza, which I had some really dangerous low blood sugars on. And similar to **[Participant 8]**, I microdosed it, starting at 0.1 rather than 0.5 and still had pretty much all the same symptoms as everyone else.

00:51:56

Moderator, RTI International

Okay. And **[Participant 4]**?

00:51:59

Participant 4 (registered as a patient)

All the things that were talked about, **[MODERATOR]**, are common, and I had many of those. I had to move to an extended-release metformin, which helped with them. The high doses of Wegovy was 2.4. I went back to Ozempic at 2.0 to help relieve those symptoms, and we're talking gastro symptoms. It is the issues. I didn't have many of the other symptoms that other people have had, but I have not talked to very many people who have gone on one of these semaglutides, or GLP-1s [glucon-like peptide-1], and not had some type of side effect. Once again, as I think **[Participant 3]** said, I'm not sure who said it, but it's worth it. The side effect was worth the effects you got.

00:52:54

Moderator, RTI International

Now I want to talk about using semaglutide for obesity. We can do benefits and challenges together, just for sake of time. For obesity, what are some of the benefits and the challenges you've experienced with semaglutide for the treatment of obesity? **[Participant 8]**, already mentioned cost was one challenge. **[Participant 3]**, go ahead.

00:53:19

Participant 3 (registered as a patient)

The number one for me is that I can get my knee replacement. But I must say, I don't know if anybody else has experienced this, but sometimes it's emotional. I want to eat because I'm having feelings, and I can't do that now. Is it a major problem? No, I'd rather be on the medication and not have the chatter, someone mentioned voices, that chatter. But it can be hard sometimes, because I don't have that, I don't want to call it a crutch, because I don't believe it's a crutch. I don't have a better word. Maybe somebody else does. But sometimes I just pout, because I can't stuff it down, and I had to feel the feelings and go to therapy.

00:54:08

Moderator, RTI International

And, **[Participant 6]**?

00:54:10

Participant 6 (registered as a patient and representative of a patient advocacy organization)

The benefits for me, were I was able to lose the amount of weight I needed to, to have my cardiac procedure but in addition to losing weight, I noticed I have a lot of stiffness. I have lymphedema in both my legs, and I had a lot of stiffness in my left knee, and I realized getting in and out of my car, that stiffness had gone away. I was having longer periods of time in between cellulitis, which is a skin infection that lymphedema patients often get. I was getting it about every three months from 2020. The longest stretch now has been almost more than a year, so that was quite of a thing.

The downsides, I will say I have some IBS [irritable bowel syndrome] issues. For me, the medications have actually improved my GI [gastrointestinal] symptoms versus worsening anything. It might be also because I take other things to help those symptoms. But the downside was I originally was able to get this for a diagnosis of insulin resistance. My Medicare Part D covered that. Suddenly, in January of 2024, they said, “no more.” You can’t take it because you don’t have type 2 diabetes, so I lost coverage. I was on Ozempic. As I mentioned, I have the cardiovascular risk reduction. I’ve had two mini strokes in my lifetime, so I should have been able to qualify for Wegovy. I lost coverage in January, March I should have been able to qualify for Wegovy, but it was denied, and it took me to the end of June to get that coverage back. I had to start over again. I regained about 20 pounds, but what bothered me was within a month of stopping Ozempic, the knee pain came back, and I thought the knee issues were resolved because of the weight loss, and it was something else in the medication that was helping me.

I still haven’t recovered because I had to start on the lower dose again. I still haven’t recovered what I had gained being on Ozempic for nearly two years. That is upsetting to me because I don’t want to have to my health to get worse in order to get the access to what I need. The only way I was able to afford it was I’m on Medicare, but I get the extra help and that was the ability to have it covered. Ozempic was covered for insulin resistance, and when they cut that off, I got Wegovy. The price actually was going to be too high, because coverage still left a large out of pocket, but I had extra help through Social Security. But that took a battle. I had to go through administrative law judge to get coverage for that, despite having the indication that was supposed to be indicated for.

00:57:19

Moderator, RTI International

[Participant 8], you want to finish this up and then I have a different question?

00:57:24

Participant 8 (registered as a patient)

On the benefit side, there have been so many benefits for me from the GLP-1s. For the first time in my life, I feel like I have a good handle on weight management. I, too, like **[Participant 6]**, have experienced far less knee pain. I’ve been told that I need double knee replacements, but frankly, they’re not bugging me that much right now, and I notice that when I’m at the end of the cycle of the dose of the GLP-1, my knees get a little sore. But, combined with good obesity care, I’ve lost about 30% of my body weight; 20% of that resulted after I started the GLP-1.

I've also seen reduction in my cholesterol. I'm on a statin, but we've cut the dose in half. And we're looking at cutting back my high blood pressure medication now, too. I've seen major health gains, and the ability to move again. I'm not Twiggy. I'm never going to be Twiggy, but I am so much healthier at this weight than I was. I'm like **[Participant 3]**, over 100 pounds ago.

00:58:48

Moderator, RTI International

Thanks, **[Participant 8]**.

There are other drugs that can treat both diabetes and obesity. We're just going to go through this quickly. But what are some of the drugs that you all have taken or you're familiar with to treat first type 2 diabetes?

[Participant 2], you can just shout them out.

00:59:15

Participant 2 (registered as a patient and representative of a patient advocacy organization)

I've taken metformin, then Trulicity. I've taken a pill, and I can't remember the name of it now, and then Ozempic, and then I was also for a little time on an insulin shot at one point.

00:59:38

Moderator, RTI International

And **[Participant 2]**. And then **[Participant 4]**, just real quickly. Oh, sorry, **[Participant 4]**. I think you're next.

00:59:48

Participant 4 (registered as a patient)

I mean, if you have type 2 diabetes you're normally, even if your blood pressure is fine, you're on blood pressure medication. Even if your cholesterol is fine, you're on cholesterol medication. Because I'm a heart attack survivor that my doctor said was caused by diabetes, I'm on two different pills for my heart. So, it's varied, I mean, it's huge. I'm better living through pharmaceuticals, I tell people all the time. I can tell you that there's no end in sight as they come out with new things that will help us treat our disease. It's hard to pin down exactly any one couple of drugs other than the classes that we're looking at.

01:00:44

Moderator, RTI International

I want to just for a moment kind of compare the therapeutic alternatives that you may be familiar with to the semaglutide and discuss a bit about how the therapeutic alternatives are better, how they have better benefits, and also how they may have more challenges or drawbacks compared to semaglutide. So, again, how they do better, and maybe how they do worse than the semaglutide. Does that make sense?

01:01:30

Participant 4 (registered as a patient)

Can you give us an example of therapeutic alternatives?

01:01:33

Moderator, RTI International

The ones that you have already mentioned, like insulin, and so forth. All the other drugs that treat diabetes other than the semaglutide.

01:01:47

Participant 4 (registered as a patient)

I'll start. If it wasn't helping my diabetes, if I could have done it just with those other medications to get an A1C [hemoglobin A1C] of 5.1, which was my last A1C, I wouldn't be taking it, because it's a shot, and I bob and weave at wasps and bees. I hate needles, always have. Pricking my finger for 40 years has killed me. And so, I hate needles, have hated since a kid. I hate anything that bites or stings, I would not be taking a shot.

Insulin tends to have weight gain, not weight loss, which is why teenage girls sometimes that have type 1 diabetes will not take it so that they can lose weight. It's a scenario where we take it because it helps, and it helps in conjunction with those others, **[MODERATOR]**. Not on stand alone. I'm not speaking for everybody here, but I can tell the rest of you, if it didn't help me, I wouldn't take the shot, plus it's expensive and a pain in the behind, no pun intended.

01:02:55

Moderator, RTI International

Literally. Thanks. All right, **[Participant 1]**?

01:03:01

Participant 1 (registered as a patient and representative of a patient advocacy organization)

My father took Avandia for his type 2 diabetes, which of course, made him gain weight, and my suspicion is that that contributed to the long-term complications of his type 2 diabetes, because, as a **[REDACTED]**, which I am, it never made sense to me.

There are medicines for type 2 diabetes that cause you to gain weight, which causes type 2 diabetes and causes complications that are common to both type 2 diabetes and obesity. The differences with these GLP-1 medicines like semaglutide is they don't cause you to gain weight. They cause you to lose a little bit of weight, which improves your overall metabolic health.

01:04:00

Moderator, RTI International

And, **[Participant 5]**?

01:04:03

Participant 5 (registered as a patient, representative of a patient advocacy organization, and as other)

As I mentioned before, I've been on metformin. I've been on metformin extended release, Victoza, and now, Ozempic. Nothing has given me more holistic benefits than Ozempic. But prior to the last five years or so, those medications were cheaper. However, now even metformin is becoming increasingly harder to access. I hear all the time from endocrinologists that they require prior authorizations. I have an intense story about not being able to afford Ozempic, but even trying to get

some of the [sodium-glucose linked transporter] medications and some of the other classes, you can't substitute for it. It's still ridiculously expensive and requires prior authorizations. The hurdles to get those medications seems to be mounting.

01:04:58

Moderator, RTI International

[Participant 5], when you said that the semaglutide was a bit more holistic in its treatment, can you speak more about what you mean?

01:05:06

Participant 5 (registered as a patient, representative of a patient advocacy organization, and as other)

I would say, like with the metformin I saw a small reduction in my insulin needs and my blood sugars. But because it's a daily medication, the ebbs and flows of it were more frequent, and less predictable than say, Ozempic. Victoza, I noticed blood sugar drops, but none of them seem to really help with cholesterol, PCOS symptoms, some of those other things that are going on that contribute to the care and management of diabetes.

01:05:45

Moderator, RTI International

Let's talk about obesity for a moment.

Aside from the semaglutide, what medications, if any, have you or your loved ones taken in the past, or currently to treat obesity? **[Participant 3]**?

01:06:01

Participant 3 (registered as a patient)

I took phentermine, and something begins with a "t," I can't remember what it was, and I thought I was going to have a heart attack. Then I tried taking Alli, which is an over-the-counter medication, and my hemoglobin within two weeks tanked, and I needed two units of blood because of it. So that was not a good medication for me. I don't know how common that is, but I was very, very ill.

01:06:34

Moderator, RTI International

Okay, **[Participant 1]**.

01:06:37

Participant 1 (registered as a patient and representative of a patient advocacy organization)

I've been taking Orlistat for a couple of decades now. I've also recently started taking metformin, although metformin has modest effects on weight. My doctor has been kind of slow about titrating the dose upwards, I'm really not getting much of an effect from that. But net, the Orlistat has helped me back off from a level of obesity that is mild to just being right at the border of overweight and a healthier weight. It has side effects that a lot of people find intolerable in terms of excretion, in passing fat in your stools. But for me, after 20 years of taking it, it's just not an issue.

01:07:39

Moderator, RTI International

[Participant 6], I'm going to move to another question, but I think you can probably answer what my next question is. So, these drugs that you have all mentioned for obesity, so, these are the therapeutic alternatives to treat obesity.

What I want to hear from you all now is, how do the benefits of these therapeutic alternatives differ from the semaglutide? And also, how did the drawbacks of these therapeutic alternatives compare to the semaglutide?

[Participant 6]? Do you want to go ahead and answer that also?

01:08:12

Participant 6 (registered as a patient and representative of a patient advocacy organization)

One of the drawbacks I was going to mention was the phentermine and the cardiac effects of being on phentermine. And that was one reason it wasn't an option. I'd taken it in college, but it wasn't an option when I needed assistance, because I already had a cardiac issue. There have been some alternatives that have come through the course, typically when those were brought up by either myself or my doctor, the percentage of weight loss, I wasn't willing to take the risk of a medication based on the estimated percentage of possible weight loss. I can't remember what one it was. But I think it would have been like 16 pounds for me, and I was like, I have a lot more to lose. I'm not going to risk the side effects, not even, you know, giving a try or the expense of having it. The effectiveness of the semaglutide versus previous ones was the main benefit I see and even giving it chance to try it, because there had been several that came out, and didn't want to try it, because didn't think it'd be worth it. And this actually seemed like it was worth taking the risk.

01:09:47

Moderator, RTI International

So they're more effective than the alternatives?

01:09:49

Participant 6 (registered as a patient and representative of a patient advocacy organization)

Yeah, very much more effective than the alternatives.

01:09:52

Moderator, RTI International

Okay. And **[Participant 8]**, go ahead. I saw you nodding your head a couple of times.

01:09:55

Participant 8 (registered as a patient)

Definitely. Another drug I took for a while was called Belviq. It was marketed as Belviq. Belviq was pulled from the market right towards the beginning of the pandemic, because it threw up a cancer signal, and the manufacturer pulled it from the market, and it had been helping me successfully sustain about 120-pound weight loss. Wasn't helping me lose more, but it was helping me maintain that weight loss, so that when I lost that drug I started to gain again. But it didn't have the same impact. Something **[Participant 5]** said really rang true with me as well, the GLP-1s are more comprehensive. They seem to take care of multiple facets of obesity, and it sounds like diabetes

and related conditions. And that's different. The earlier drugs I had been on didn't have that same sort of comprehensive impact. For me, the GLP-1s are much better drugs.

01:11:14

Moderator, RTI International

And [Participant 8], from the perspective of obesity, can you talk to me more about the comprehensiveness of it?

01:11:23

Participant 8 (registered as a patient)

Yeah, it's not just your appetite. You know, there are appetite suppressants that people have used for years, and that they've used to help manage weight, things of that nature. There are anti-anxiety medications that some people have used, but those types of things that address just one piece of the puzzle, but the GLP-1s seem to address a variety of pieces. It addresses appetite, they address satiety, they address inflammation, which is known to be an underlying problem with obesity as well. It's multifunctional. It addresses the food noise in your head. And all these thoughts about food. It has a broader impact than the other drugs I had experienced.

01:12:25

Moderator, RTI International

Just for the sake of time, **[Participant 1]**, I won't be able to hear from you, I'm sorry. But I do want to hear from **[Participant 7]** just really quickly, and then I have another question.

01:12:37

Participant 7 (registered as a patient)

When I first took Rybelsus, it wasn't for the aim of losing weight, but it did have that weight loss effect, and that was partly because of losing interest in food, but it just kept dropping like crazy. It kept it off, and I know that's good for the diabetes. I also have a fatty liver, and I know it had to be good for that too, although more would be better. I feel like it was more well-rounded, like **[Participant 8]** was saying. With metformin, I had that feeling of illness, but I didn't do anything for the weight. The weight was still the same, even though I felt ill and not really wanting to eat, because I felt ill. So, I think there's more to it than just the taking away the taste of the food and stuff. There's something else going on. And I appreciate that because it kept on after I couldn't afford it. The weight kept off, and my face got thinner, so there was that.

01:14:10

Moderator, RTI International

And I wanted to actually circle back around one question also on the type 2 diabetes.

Again, these drugs can treat type 2 diabetes and cardiovascular disease. Thinking about the treatment of type 2 diabetes and cardiovascular disease, how do the benefits of these therapeutic alternatives compare to semaglutide and also the drawbacks?

And there may not be anyone who's actually taking it for both type 2 diabetes and cardiovascular disease. **[Participant 6]**, go ahead.

01:14:48

Participant 6 (registered as a patient and representative of a patient advocacy organization)

I take it for cardiovascular disease and obesity. But I think the overall thought I'm having with this question is the indication for cardiovascular disease, I think for both is risk reduction. I guess we could say, I haven't had another one since I've been on it. But that's the only comparison, as in the other medications didn't have that scientific backing behind it. For me, the other medications typically had a cardiac risk indication that prevented me from taking them. I believe semaglutide does say it could possibly increase heart rate. But then, in comparison, it has the cardiovascular risk reduction for patients who have had a previous event, either a heart attack or a stroke, and I'm not sure what else might be involved in that. So, obviously, it's been studied to make sure it is good, it won't cause heart failure, heart damage, whereas other medications have that potential to.

01:15:54

Moderator, RTI International

Let's talk about what life would be like if there were no treatments available. So, what would it be like for someone who has diabetes if semaglutide or other medications for this condition were not available?

[Participant 4], go ahead.

01:16:19

Participant 4 (registered as a patient)

I think that I would be heavier. I think that I might have had a second heart attack. I had two arteries that were, one was a hundred percent blocked, and one was 90%. I have two stents. I may have had a second heart attack and died. The only reason I didn't die was I had my heart attack in the emergency room.

My A1Cs would not be as good, and that causes a variety of different things, such as neuropathy. I have hearing aids. My audiologist says it's a result of my diabetes that has caused my hearing to deteriorate. I may not be here, **[MODERATOR]**, you may not be talking to me. I truly believe that these medications help us manage our disease to the point that extends not just our life, but our livability. Our ability to enjoy life. I think it's important, and I know we're closing in on our time. I think it's important to realize when you start talking about drug price negotiation, that it comes from a patient perspective. And **[Participant 1]** being a **[REDACTED]**, knows what I'm talking about.

It comes that it benefits me. Insurance companies negotiate through rebates all these price reductions from drug companies. But I still, during my deductible period, pay a fortune for my medication, because it doesn't benefit me. We need, in drug negotiations, to pass it straight down to the patient, that these people you see get the benefit of these drug negotiations to help them live a longer life, that I get the benefit. It infuriates me to get my insurance, I'm on Medicare and private insurance, and it infuriates me to get my statement, saying you saved this much money, but we have tried to bankrupt you while you saved it.

So, as you all in the government talk about drug price negotiation, don't forget why we do this in the first place, the patient. The patient is where the central focus always needs to be, because that's the lives that you're affecting. And I'll take an amen from **[Participant 1]**.

01:18:55

Participant 7 (registered as a patient)

Amen from me.

01:18:57

Participant 1 (registered as a patient and representative of a patient advocacy organization)

You read my mind. I was going to say, Amen.

01:19:01

Moderator, RTI International

[Participant 7], go ahead.

01:19:04

Participant 7 (registered as a patient)

I was so swept away by that, I forgot what we were asking.

01:19:08

Moderator, RTI International

It was, what would life be like for people who had diabetes if there was no treatment available?

01:19:15

Participant 7 (registered as a patient)

Well, so, like I said, the Rybelsus gave me a great kickstart—what did I do afterwards? Because that for me was life without medicine? I turned to alternative medicine, and it was good. I am now down further, but I would have liked to have just stayed on the Rybelsus, because it was easier. I have to take handfuls of different kinds of medicines just to keep stabilized with the alternatives.

But with the Rybelsus, it's one in the morning and boom, you're done, and on you go. Also, the Rybelsus got me over the timber thing, where I was just passing out during the day. Metformin didn't do that. Jardiance didn't do that. Basically what I was saying, it gave a good kick start, but I wish I could have stayed on it, because it was easier.

01:20:27

Moderator, RTI International

And, **[Participant 5]**?

01:20:29

Participant 5 (registered as a patient, representative of a patient advocacy organization, and as other)

I don't have to imagine it, because I've had to do this. I was forced off of Ozempic. I've been on it since 2021, approximately a year and a half later I was kicked off of it by my insurance, even though it was covered for the same exact reason prior.

And immediately, saw my blood sugars go up. Immediately, had to double to triple my insulin intake, which is, for a diabetic, is actually an emergency, because we're already so tight on how

much insulin we're allowed by the insurance company. So, if I'm doubling and tripling it, you're creating a dire emergency for folks if they're running out of their insulin.

It took me four months of fighting my insurance, over 60 hours of phone calls, over 100 emails, to finally get it reinstated. And that's only because I had the time, and I was so angry about it that I was able to do that. Most people do not have the time, the resources to fight this. I think the big elephant in the room is that we're looking at Ozempic and Wegovy and Rybelsus. Medicare can't even cover Wegovy, and the main reason for that, I've done panels with Senator Bernie Sanders and other officials at the U.S. federal level, and they all want to see it be covered. But one of the reasons that most of these places aren't covering it is price. Because by covering it, it would bankrupt states or bankrupt the federal government. And I think it creates a really, really bad precedent to say, we're not going to cover a medication because it's too expensive.

Even though we've heard today about all of these really great benefits that people are seeing in their lives for obesity, for type 2 diabetes, for heart issues. At the end of the day, the price is the key. If people can't afford the medication, then what use is that? All these great benefits are no use if we can't afford it, and the fact that so many of us on this call have said that we can't afford the medication speaks to one, that we need the price care negotiations to work and to have this, but we need it to work really well; \$1,200 a month is not attainable for most of the world. I really want to see this being anybody who needs it and can access it, has access to it.

01:23:08

Moderator, RTI International

I see hands up. I do need to skip to the next question, which you may want to be able to answer also, which is, what would life be like for someone who has obesity if these drugs or other treatments were not available? And I have about two minutes, and then I need to go to the next question. But what would it be like if treatments were not available for obesity? **[Participant 6]**, I see you have your hand up.

01:23:28

Participant 6 (registered as a patient and representative of a patient advocacy organization)

I guess I did foresee that. Honestly, I think I wouldn't be here right now. I needed a cardiac procedure and wasn't able to get it and was just being brushed off. And that's scary, especially having, I didn't really share this. But, I did mention my mother had diabetes. I have had the fear of, what could happen if I didn't try to manage my health the best I can? I had my mini strokes in my twenties. I had that wake-up call very early. I've been trying to do the best I can, and if it wasn't for this medication, I wouldn't have been able to lose the weight I did to have the procedure I needed.

I'm just going to say it. So, I had lost coverage, too. I mentioned I could afford the medications on Medicare because I was getting them covered, and I had extra help. In January of this year, I lost the extra help. I went to refill my Wegovy, and it was going to be like \$893, almost \$900, and that was with coverage. I was going to be paying \$900. And my plan supposedly was paying \$1,600. That is well over the retail price. That doesn't make sense. I thought, oh, obviously, there's a mistake, because if it's, everyone says \$1,200 a month, and I was paying \$900. No.

There's definitely some negotiation we need to do there. And actually at this time, because I also have sleep apnea. I switched to tirzepatide in January of this year, because if I was going to be paying something out of pocket, I was going to be paying \$700 for that. So, amongst even, I know we're not talking about all of them, but even amongst what's available, there are lower cost options

than that. And so, there's something that has to be done with that pricing. It doesn't make sense that Medicare plans are paying almost three times as much as what we should be.

01:25:46

Moderator, RTI International

[Participant 3], I have about one minute. Let me give you one minute. Then I need to start closing things. Go ahead, **[Participant 3]**.

01:25:51

Participant 3 (registered as a patient)

I was going to say that I probably would be dead myself, because and I was being serious earlier, I was extremely suicidal. My knee is really bad. I have zero cartilage. The femur hangs off my knee because it is just slid over. I mean, I barely do anything. I can't go to church, I can't. I just sit. I'm like the story, the old lady in a shoe. I'm like the old lady in this chair. And I probably would have died by suicide if I could not get this surgery, still trying to get it scheduled. But it is going to get scheduled, so I feel like we have to look at more than just weight. But on the back end, how much we're going to save, because I would end up probably in a nursing home, and that would cost a lot more.

01:26:45

Moderator, RTI International

All right. So, I want to wrap things up here, and those are all the questions I have for you all today. But I did want to pause for a moment and ask if there was anything that wasn't covered today in our discussion that you feel is important to share with CMS?

01:27:05

Participant 7 (registered as a patient)

No.

01:27:08

Moderator, RTI International

Now, **[Participant 8]**.

01:27:11

Participant 8 (registered as a patient)

We have sort of a unique position with drug coverage. I'm fortunate, I have the federal employee drug insurance or health insurance. I'm a retired federal government employee, and for those of you from CMS on this call, I want to thank you for your service to the government and to all of us in the country. I appreciate all of you, and I know how hard you work. But because I have federal employee health insurance combined with Medicare, but my drug coverage is through the federal employee health insurance. I now have coverage for GLP-1s. And it's at \$150 a month for me, is my copay on it, and that's because OPM required federal health insurers to cover anti-obesity medications. So, I feel very, very lucky, and I think a lot of people could afford that amount. Some people still wouldn't be able to afford that much, but we could cover a lot of people if these drugs can come down to that level or close there, too. It's certainly important that we make these available as we've all talked about this afternoon.

01:28:41

Moderator, RTI International

And, [Participant 7]?

01:28:43

Participant 7 (registered as a patient)

The last thing I want to say is just, we pay for the research for these drugs with the National Institutes of Health [NIH] and such, we pay for them. We're also paying for the advertising. You don't pay for that, you don't pay so much in, say Canada, because they don't allow advertising. But we have to pay for the marketing, and we have to pay for the research that we already paid for. I feel that there could be something in the negotiation pointing that out, pointing the ways that they're padding that, when you look at other countries you don't see at that high of price.

01:29:31

Moderator, RTI International

Great. Thanks, [Participant 7].

01:29:32

Participant 7 (registered as a patient)

Okay.

01:29:33

Moderator, RTI International

Thank you again to everyone for participating in today's groups. We appreciate your time to talk with us today. And your experiences and input were extremely valuable, and will help to inform CMS' negotiations for these drugs. As I mentioned, CMS staff have been listening to the roundtable and will be able to bring your perspective back to their teams. CMS team, did you want to say something before we end?

01:29:59

CMS Staff

Yeah, I do. I just want to say thank you to everybody for sharing your experiences today and all of your knowledge with us. On behalf of CMS and my colleagues, just want to send a huge thank you to all of you for your participation. Thanks.

01:30:16

Moderator, RTI International

Great. Thank you.

And if you have any questions following today's session, you can submit those to the mailbox that's on your screen, IRAREbateAndNegotiation@cms.hhs.gov, and then just put the subject line, public engagement events. Again, that email address is there on the screen if you want to send any questions following today's session.

But we are just a tad over the hour. Thank you again, everyone, for your time. I really appreciate it, and you all have a good rest of your day.

01:30:46

Participant 5 (registered as a patient, representative of a patient advocacy organization, and as other)

Thank you.

01:30:47

Moderator, RTI International

Bye, everyone.

=== END OF TRANSCRIPT ===

For a list of the drugs selected for the second cycle of the Medicare Drug Price Negotiation Program, click on the following link: <https://www.cms.gov/files/document/factsheet-medicare-negotiation-selected-drug-list-ipay-2027.pdf>

For more information on the Medicare Drug Price Negotiation Program, please click on the following link: <https://www.cms.gov/priorities/medicare-prescription-drug-affordability/overview/medicare-drug-price-negotiation-program>

Appendix

Participant 1: Registered as a patient who has experience with the condition(s) treated by the selected drug; a patient with experience with other treatment(s) similar to the selected drug for those condition(s); a representative of a patient advocacy organization

Declared Conflicts of Interest	
No	Receipt of financial payments (e.g., gifts, funding, research support, honoraria, travel, or other expenses) from a company with direct/indirect interest in the Negotiation Program, in excess of \$10,000 by you, your spouse, or an immediate family member
No	Direct assistance preparing your remarks from someone who is NOT a family member, caregiver, friend, or your healthcare provider
No	You, your spouse, or an immediate family member is employed by or holds equity interest (stock or ownership interest) in excess of \$10,000 in a company or related association with direct or indirect interest in the Negotiation Program
No	Any other personal or professional relationship or interaction with a company or related association with direct or indirect interest in the Negotiation Program that may be considered a financial conflict of interest

Participant 2: Registered as a patient who has experience with the selected drug; a patient who has experience with the condition(s) treated by the selected drug; a patient with experience with other treatment(s) similar to the selected drug for those condition(s); a representative of a patient advocacy organization

Declared Conflicts of Interest	
No	Receipt of financial payments (e.g., gifts, funding, research support, honoraria, travel, or other expenses) from a company with direct/indirect interest in the Negotiation Program, in excess of \$10,000 by you, your spouse, or an immediate family member
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Participant 3: Registered as a patient who has experience with the condition(s) treated by the selected drug; a patient with experience with other treatment(s) similar to the selected drug for those condition(s)

Declared Conflicts of Interest	
No	Receipt of financial payments (e.g., gifts, funding, research support, honoraria, travel, or other expenses) from a company with direct/indirect interest in the Negotiation Program, in excess of \$10,000 by you, your spouse, or an immediate family member
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Participant 4: Registered as a patient who has experience with the condition(s) treated by the selected drug; a patient who has experience with the selected drug

Declared Conflicts of Interest	
No	Receipt of financial payments (e.g., gifts, funding, research support, honoraria, travel, or other expenses) from a company with direct/indirect interest in the Negotiation Program, in excess of \$10,000 by you, your spouse, or an immediate family member
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Participant 5: Registered as a patient who has experience with the selected drug; a patient who has experience with the condition(s) treated by the selected drug; a patient with experience with other treatment(s) similar to the selected drug for those condition(s); a representative of a patient advocacy organization; other

Declared Conflicts of Interest	
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Participant 6: Registered as a patient who has experience with the selected drug; a patient who has experience with the condition(s) treated by the selected drug; a patient with experience with other treatment(s) similar to the selected drug for those condition(s); a representative of a patient advocacy organization

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No	Any other personal or professional relationship or interaction with a company or related association with direct or indirect interest in the Negotiation Program that may be considered a financial conflict of interest

Participant 7: Registered as a patient who has experience with the selected drug

Declared Conflicts of Interest	
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No	Any other personal or professional relationship or interaction with a company or related association with direct or indirect interest in the Negotiation Program that may be considered a financial conflict of interest

Participant 8: Registered as a patient who has experience with the selected drug; a patient who has experience with the condition(s) treated by the selected drug; a patient with experience with other treatment(s) similar to the selected drug for those condition(s)

Declared Conflicts of Interest	
No	Receipt of financial payments (e.g., gifts, funding, research support, honoraria, travel, or other expenses) from a company with direct/indirect interest in the Negotiation Program, in excess of \$10,000 by you, your spouse, or an immediate family member
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