

This transcript was lightly edited for readability.

Introductory Remarks

Moderator, RTI International

Thank you so much for coming today. I'm **[Moderator]**, and I am from RTI International. I also want to introduce my colleague, **[Secondary Moderator]**, who you may hear from during the discussion today as well. The Centers for Medicare & Medicaid Services, which we will refer to throughout today's event using the acronym CMS, is convening this patient-focused roundtable event and others as part of the Medicare Drug Price Negotiation Program. The information shared during these roundtable events will help CMS understand patient experiences with the conditions and diseases treated by the selected drugs, patients' experiences with the selected drugs themselves, and patients' experiences with other drugs that are used to treat the same condition as the selected drug. The information shared during these events will also help CMS identify other medications used to treat the conditions treated by the selected drug, what matters most to patients in managing their conditions, and other important factors CMS may consider in negotiating Medicare pricing with the manufacturers of selected drugs.

The purpose of today's event is to hear from you all, a group that may include patients, caregivers, and patient advocates about your experiences with the conditions and diseases treated by Cosentyx, including ankylosing spondylitis, enthesitis-related arthritis, hidradenitis suppurativa [HS], non-radiographic axial spondyloarthritis, plaque psoriasis, and psoriatic arthritis, with Cosentyx itself, and with other medications for the same conditions.

I want to emphasize that our focus today will be on the patient experience. If you wish to share input on other topics related to the Drug Negotiation Program that are not directly focused on that patient experience, we ask that you send the input to the mailbox at IRARebateAndNegotiation@cms.hhs.gov instead of sharing it during today's discussion.

Your experience and perspectives are very important to us, and we genuinely appreciate your time today. Along those lines, let's watch a brief welcome video from CMS leadership, so you can hear from them about how much they value your time and input.

CMS Remarks

00:02:30

Dr. Mehmet Oz, Administrator for the Centers for Medicare & Medicaid Services

Hi, everyone. I'm Dr. Mehmet Oz.

I'm the Administrator for the Centers for Medicare & Medicaid Services, also known as CMS. CMS is the Federal agency that oversees Medicare, which provides health care coverage for more than 69 million older Americans and people with disabilities. We also oversee the Medicaid program and the Health Insurance Marketplaces.

I wish I could join you today in person, but I want you to know I am eager to hear your feedback and am deeply grateful for your participation in today's discussion.

It is a crucial conversation.

No one in America should have to choose between buying groceries or paying for their medications. But many are forced to make this choice. It's a choice that comes with a personal cost in addition to a financial cost. I started my health care career as a cardiothoracic surgeon, so I know firsthand what happens when people can't get their medicine, like the ones that lower their cholesterol or blood pressure. Left unmanaged, these conditions can be dangerous.

CMS is doing incredible work reigning in the skyrocketing cost of prescription medications, and we need all of you to help us make real, lasting change.

Right now, we're working on the latest cycle of Medicare drug price negotiation.

We announced the drugs selected for this round earlier this year. Some of them are covered under Medicare Part D, and others are payable under Medicare Part B. For every drug, our priority is to reach an agreement with the manufacturer on a fair price for Medicare.

We are committed to being fair and transparent throughout the negotiation process. And that's where you all come in.

It's my goal to get input from people across the health care ecosystem. We want to hear your perspective about the drugs selected for the current cycle of negotiation and renegotiation.

Your input makes a difference – a big one. Thank you for taking the time to join us today. I'll turn it over now to our event moderator.

00:04:21

Moderator, RTI International

Great. I also 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. I'm going to hand it over to them for a moment so they can say hello. **[CMS Staff]**?

00:04:36

CMS Staff

Hello, welcome everyone. My name is **[CMS Staff]** from the CMS Drug Price Negotiation team. There are other members of the staff today on this call. We work on policies on getting the public input and negotiating the Medicare negotiation drug prices. On behalf of CMS, I want to thank you for participating in the session today. We look forward to hearing about your experiences, and we are going to go off-camera now, just to focus on the discussion. Thank you.

Housekeeping

00:05:03

Moderator, RTI International

Thanks, **[CMS Staff]**. All right, before we begin, I want to review some housekeeping items and ground rules so everyone knows what to expect. First, as far as technical assistance goes, if you get disconnected, please attempt to rejoin. If you cannot connect, please reach out to IRADAPStechsupport@telligen.com.

Also, regarding privacy, this discussion is not open to the press or the public. We are using first names only during the discussion to protect your privacy, and we ask that you please don't share

any unnecessary protected health information—for example, your doctor's name or the name of a medical facility where you received care—or personally identifying information—for example, your employer's name, the city you live in, or names of schools you attended—during the discussion. Following the event, CMS will prepare transcripts that have participant names and identifying information removed, and those will become available to the public.

You can see, of course, that we're video recording. These recordings will not be shared publicly. Recordings are only being used for internal program documentation and to produce the redacted transcripts for public release, consistent with Federal privacy guidelines. By participating, you consent to being recorded for these purposes.

As far as participation goes, we hope that you'll feel comfortable and will contribute your perspectives throughout the discussion. However, if questions arise that you don't want to answer, that's okay.

We ask that you minimize your background noise by silencing your cell phone and other devices if you haven't already done so, and we ask that you mute yourself when you're not speaking. Of course, we also ask that you keep your video on throughout the discussion.

We've reserved up to two hours for this session. However, it is possible that we may not need the full two hours to discuss all of the planned topics. If that happens, we can let everyone go a little bit early. You'll see I am looking down occasionally. I do have a discussion guide in front of me to help me keep us on track. We have a lot of topics to cover, so I may need to redirect our conversation or cut a conversation short at times to make sure we're able to cover everything and that all participants have ample opportunity to share their perspectives.

If you need to step away briefly during the discussion, that's totally fine. Just turn your camera and microphone off and rejoin when you're able to, and you don't need to tell me that you will be away from your computer, just return to the discussion as soon as you're able.

We ask that you try and speak one at a time. I may occasionally interrupt you if two or more people are talking in order to be sure everyone can be heard and that everyone's comments are accurately recorded. We tested out that raise hand feature. If you can use that, when you would like to speak, that's great. If you're not able to, if you just want to raise your hand, that's also fine. And this helps us know when someone would like to add to the discussion. While we're hoping that everyone will focus on the oral discussion, you can also add your comments in the chat if you don't get a chance to share them orally. This may be the case, for example, if we don't get to hear from you before we need to move on to the next question, or if you think of something else to add later on, just please be sure to note what question or topic you're responding to when you add those comments. Any questions about that?

Discussion

00:08:24

Moderator, RTI International

Okay, wonderful. All right, we'll get started with a little bit of warm-up and introduction. And we're going to go around our virtual room here, and if you could take a moment to tell us your first name, or what you'd like to be called, if it's something different than what's on the screen; whether you'll be sharing your experiences as a patient, a caregiver, or from the perspective of a patient advocate; and then the condition or conditions that Cosentyx treats that you have experience with. I'm going to start with **[Participant 1]**, if you don't mind going first. Again, your name, whether you're sharing

experiences as a patient, caregiver, or as a patient advocate, and then if there [is a] condition or multiple conditions that Cosentyx treats.

00:09:12

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

Hi, everyone. My name's **[Participant 1]**. I have psoriasis and psoriatic arthritis. I've had it for going on 22 years now, so I'm a patient and eager to share my story.

00:09:31

Moderator, RTI International

Thanks so much, **[Participant 1]**. **[Participant 2]**?

00:09:36

Participant 2 (registered as a patient)

Hello, good morning. My name is **[Participant 2]**. I'm a patient, and Cosentyx is being used to treat ankylosing spondylitis.

00:09:47

Moderator, RTI International

Thank you, **[Participant 2]**. **[Participant 3]**?

00:09:51

Participant 3 (registered as a representative of a patient advocacy organization)

Hi, I'm **[Participant 3]**. I'm a patient advocate with the Arthritis Foundation. I'll be representing the experiences of patients living with inflammatory arthritis, like psoriatic arthritis and axial spondyloarthritis as well.

00:10:06

Moderator, RTI International

Okay, thanks. **[Participant 4]**.

00:10:11

Participant 4 (registered as a patient and representative of a patient advocacy organization)

Hi, my name's **[Participant 4]**, she/her pronouns. I am a patient and a patient advocate. I'm the **[Redacted]** of Chronically Informed. I take Cosentyx to treat hidradenitis suppurativa, which I may be pronouncing incorrectly. I usually just say HS. I also likely have psoriatic arthritis. We're in the process of diagnosing that right now, so it is likely that Cosentyx is treating both of those things for me.

00:10:38

Moderator, RTI International

Thanks, **[Participant 4]**. **[Participant 5]**?

00:10:42

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

I'm **[Participant 5]**, she/her pronouns. I have hidradenitis suppurativa. I do not take Cosentyx, but I also work in patient advocacy full-time, so I'm doing double duty here.

00:10:54

Moderator, RTI International

Okay, wonderful, thanks. **[Participant 6]**.

00:10:58

Participant 6 (registered as a patient)

Hi, I'm **[Participant 6]**, patient advocate. I previously took Cosentyx, and I live with hidradenitis suppurativa.

00:11:06

Moderator, RTI International

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

00:11:24

Participant 7 (registered as a patient)

Hi, everyone. My name's **[Participant 7]**. I'm a psoriasis and psoriatic arthritis patient. I've been diagnosed for about 25 years. And I am on Cosentyx and have been on it for about ten years.

00:11:44

Moderator, RTI International

Thank you, **[Participant 7]**. And **[Participant 8]**!

00:11:49

Participant 8 (registered as a patient)

Hi, I'm **[Participant 8]**, and I'm being treated with Cosentyx for ankylosing spondylitis. I was diagnosed at 24. It's been 34 years, and I'm excited to be here.

00:12:06

Moderator, RTI International

Thank you all so much for being here and for sharing.

00:12:09

Participant 8 (registered as a patient)

Oh, and I'm a patient.

00:12:10

Moderator, RTI International

And a patient, yes, okay, wonderful, thank you, **[Participant 8]**.

As you heard, we have participants here with experience related to a number of conditions that are treated by Cosentyx. We realize that the experiences may differ by condition, so I'd ask that when you speak, it would be helpful if you could please remind the group which condition you're discussing. For example, you might say, "When I was considering treatment options for psoriatic arthritis, I thought about XYZ," et cetera. And I might remind you, too, during the discussion, so we can make sure we've got that recorded.

All right, first, we're going to talk a little bit about patient experiences with the conditions that are treated by Cosentyx. Thinking about different ways that these conditions treated by Cosentyx affect patients' lives, what would you say are the most important aspects of the condition to have managed or treated? These could be things that affect patients in the short term or in the long term. And you can raise your hand or just go ahead. Yeah, **[Participant 5]**.

00:13:19

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

For hidradenitis suppurativa, because it can often progress quickly, depending on the patient's stage, and there's permanent damage done to the skin. When it comes to hidradenitis suppurativa, there's the daily debilitating pain. But once it progresses to Stage 2 and 3, the scarring is irreversible and then will often require surgery, which can be very extensive surgeries that require a lot of time off, full-time caregiving. HS patients, on average, often miss up to 30 days of work a year. Getting disease managed early on, early diagnoses and earlier treatment can help us continue to function. A lot of us end up on disability when we don't have that. The day-to-day, those things, [that] early treatment is really important, the systemic treatment for the pain, the permanent damage, and then, of course, the long-term ramifications of all that.

00:14:15

Moderator, RTI International

Okay, yeah, thank you so much. **[Participant 1]**?

00:14:22

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

When my psoriasis started at 33, it started and [ran] like wildfire. I was 80% covered within a matter of a couple of months of plaque psoriasis. Knowing that the heart disease runs in my family, it was very important to get this under control so that it would limit the effects of what it could do to me. And luckily for me, Cosentyx took me down to 20% coverage in a year and a half. It was pretty amazing.

00:15:06

Moderator, RTI International

Thank you so much for sharing that, **[Participant 1]**. **[Participant 8]**?

00:15:10

Participant 8 (registered as a patient)

I don't know if I'm off track here, but when I started Cosentyx, I started on the self-injectables. And the [effects of the] self-injectables only lasted two weeks, and then I was in two weeks of pure spine stiffness, pain in the sacroiliac joints, cannot move. I can't recover from any activities. The stiffness is so bad. Then I went on to the infusions, which, the cost associated with that, astronomical. And if you have only government insurance, you cannot qualify for copay assistance. And that, to me, is a big deal because it's stressful. And on top of everything else, we don't need the stress of that.

00:16:07

Moderator, RTI International

That's really helpful, and I appreciate you sharing. Can you remind us, too, were you taking Cosentyx for a specific condition or a range of conditions at that time, or during this period?

00:16:28

Participant 8 (registered as a patient)

Just ankylosing spondylitis. I have other degenerative diseases, but the ankylosing spondylitis is so progressive. The only other member of my family that has it is my uncle, my maternal uncle, and he had no treatment at all. His spine is completely fused, or it was, from top to bottom. They called it a bamboo spine. And without the Cosentyx, I'm afraid that that's going to happen to me. I'm going to start fusing.

00:17:03

Moderator, RTI International

Understood, yeah. And **[Participant 2]**.

00:17:09

Participant 2 (registered as a patient)

I can speak to ankylosing spondylitis as well, echo a lot of what **[Participant 5]** and **[Participant 8]** both said for Cosentyx. Accessibility and affordability is important. I do the injector pen. I think early diagnosis, as well as treating day-to-day pain, I think that's very important [for] ankylosing spondylitis, just because it is so painful and becomes so limiting that to have something, like a biologic, to effectively mitigate that pain is important just for day-to-day function. And then, along the lines for **[Participant 8]** and **[Participant 5]**, preventing that permanent damage to your spine, the bamboo spine, that **[Participant 8]** speaks to, I have some of that already. So, for me personally, preventing the further progression of the disease where it can affect your lungs and your heart, and things like that.

00:18:12

Participant 8 (registered as a patient)

Your eyes.

00:18:13

Participant 2 (registered as a patient)

And your eyes, yes, I've had that as well.

00:18:18

Moderator, RTI International

[Participant 6].

00:18:20

Participant 6 (registered as a patient)

Hi, thanks. I'm a patient with HS, hidradenitis suppurativa, and to echo what **[Participant 5]** said, I think I have two sides, and so one is now that awareness is finally growing, and just in general, as I think an important part is to slow the progression of the disease as much as possible. But then the other side, for me, my diagnosis took 30 years, and the most debilitating effects for me, actually, are the inflammation and fatigue that come along with the flares, and so anything that can help with that. I feel like I've lived with the pain for so long of the actual flares. It's those other things, the silent parts of the disease, that make it the hardest because it's the things that people don't see or don't know about. Those are the some of the effects for me.

00:19:23

Moderator, RTI International

Yeah, I appreciate you sharing that. **[Participant 4].**

00:19:29

Participant 4 (registered as a patient and representative of a patient advocacy organization)

Thank you. I appreciate what **[Participant 6]** just said, since I'm treating a range of conditions, likely, with Cosentyx, that inflammation and fatigue being treated systemically is incredibly important to me. It allows me to treat multiple conditions with one medication, which is much better than being on multiple medications, which I have done before, and I'm just really grateful for the impact that that has had.

00:19:55

Moderator, RTI International

[Participant 5]?

00:19:56

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

A lot of talking about the earlier treatment, which is important. I know Cosentyx just got its pediatric indication, for HS often onsets in your teenage years. I've had it since I was 13 years old. Granted, when I was 13, we didn't have these options. But the way that it will literally derail your life—we have teenagers who, think about it, they're not going to do sports, they're not going to date, they're going to be [at] much higher risk for mental health issues. HS is a condition I think second to melanoma with completed suicide rates, and so having a systemic medication that's FDA [Food and Drug Administration]-approved for teenagers, and the way that starting these treatments on time to

prevent that permanent damage, you're allowing people, young people, to have their life. Going to college with this condition is mortifying, and there's a lot of dignity that you lose with certain conditions, and HS has the blood, the pus, there's drainage. It can affect your genitals. So, literally everything. You cannot sit, you can't ride a bike, you can't move, it's under your arms. Sometimes people get it on their face or their neck. It's just the breadth of which, it affects every aspect of your life, and especially as a young person, I think that getting these medications covered. And **[Participant 8]** mentioned something that's huge in the community. We have a lot of people [with] lower socioeconomic status in the HS community, and they're on disability. But then they also can't get the Bridge Program [Centers for Disease Control and Prevention's Bridge Access Program], so Novartis does offer these programs, but they don't qualify, and that makes it really difficult. And oftentimes, obviously, then people have to do step therapy, and so they're trying, they're failing all these different treatments before they can even get to what their doctor's prescribing, which is a whole other thing because the long-term antibiotic use, especially with hidradenitis suppurativa, is a major issue in the community as well, antibiotic resistance and stuff. I think having these medications covered will allow people to get better treatment faster, and again, will literally change someone's life.

00:22:00

Moderator, RTI International

I appreciate you sharing all of that, **[Participant 5]**. You all have talked a little bit about things, about how you feel and symptom management, progression, preventing the progression of the disease, the impact on your quality of life, preventing flare-ups, or helping you handle flare-ups, some mental health aspects. Anything else that are aspects of the condition that are important when considering treatment? **[Participant 4]**?

00:22:38

Participant 4 (registered as a patient and representative of a patient advocacy organization)

To comment on what **[Participant 5]** said, I think there's also nonmedical switching, besides the process of step therapy. When Cosentyx is removed from formularies from insurance companies, it becomes really difficult, and nonmedical switching is necessitated by that, which makes it incredibly difficult to have consistency with your care. Loading doses for medications like Cosentyx can take weeks, and you may not have impact for months, and so switching a medication like that could set you back a great deal of time with your actual treatment with your medication. The other thing I will say is, I think we'll probably address this, but I've taken another medication for these conditions, and being able to be on Cosentyx, because it affects a narrower part of my immune system, is really important to me because I had an infection with another medication that landed me in the hospital and almost killed me. So, being on a narrower block of my immune system is really important to me.

00:23:42

Moderator, RTI International

All right, thank you so much for sharing that. Anyone else? **[Participant 2]**?

00:23:49

Participant 2 (registered as a patient)

Yeah, I'm just following up on what **[Participant 4]** said. I was on another medication for ankylosing spondylitis as well, and it had quite a few side effects related to it. It was very hard on me, and so being able to switch to Cosentyx, which has a narrow focus, I think has really been helpful. I've had a much better response to it, just on the day-to-day basis, how it makes me feel, as well as it still being effective. I think that's one of the good things about it.

00:24:20

Moderator, RTI International

Thank you, **[Participant 2]**. I think, **[Participant 4]**, you indicated that we are going to talk about some alternative treatments, too, and how this compares, but, definitely, this is an important point to bring up. **[Participant 8]**.

00:24:31

Participant 8 (registered as a patient)

I don't know if this is coming up now, or this is relevant now, but I just wanted to mention that the copay assistance will pay for the Medicaid, for injectables to be sent to my home, so I can inject myself, full cost, I have zero copay assistance, which is fabulous because it's a very expensive drug. But now that I got put on the infusion, I have to drive an hour and a half to get to the doctor's office, especially if I'm having a really bad day of flare-up and inflammation, and then have to sit in a chair for 30 minutes, which is no big deal, but it cost me \$150 to sit in that chair. I don't understand why they can ship it to your house, but then the infusable, they can't have somebody come in and do it at your home. Because I'm thinking about patients I've seen in wheelchairs who cannot get there to that office visit. It's quite stressful, the whole ordeal revolving around an office visit, when you're inflamed and can't move. And then you're walking into the office, and it's awful. It's an awful experience. That's all.

00:25:59

Moderator, RTI International

Oh, it certainly sounds like that's a lot to manage, for sure. **[Participant 1]**, and then we're going to move on to our next question, which is going to get to some of the things you all have just mentioned.

00:26:14

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

For me, I've been on Medicaid, and I'm currently on the ACA [Affordable Care Act] program as far as getting insurance. And it's super scary when you don't know if you're going to be able to get the medication or not because, like I said, I was 80% covered with plaque psoriasis, and I never, ever want to be back to that point again. Anything that makes it easier to obtain the medication is always a plus. That way, it takes the worry out of, what else is going to happen down the road? Because, as most of us probably can attest, there's always something else that comes up as well, some other kind of problem medically. It makes a huge difference when we can get the medication without having to fight it all the time.

00:27:18

Moderator, RTI International

Yeah, understood, for sure. Thank you, **[Participant 1]**, for sharing that. All right, you all have touched a little bit on this, but we're going to turn our attention to patients' experiences with medications for those conditions that can be treated by Cosentyx, or that are treated by Cosentyx. For the next question, I'm going to ask you to put your responses in the chat as much as you're able to. I know, for a couple of you, you might have some challenges with that—if you need some assistance, we can help. And what we would ask you to do is include, or if you could write, which medications, if any, have you, your loved ones, or patients you advocate for taken, whether currently or in the past, for those conditions that are treated by Cosentyx. I'm going to give you a few minutes to go ahead and do that, and if you don't mind, again, just indicating what the condition is, and then those medications that you've taken. And I know for some of you, the list might be very lengthy, so if you want to go to the most recent, that's okay, too. I think we've had people who've had upward of 10 or 20 or 30 medications, and you don't necessarily have to remember all of those if you just think about the ones that are the most recent. ... I think we've got everybody, okay. Thank you so much for sharing that.

I see a range of some medications and classes of medication for these different conditions. For the next few questions, I want to note that we want to hear about the experiences that you, your loved ones, or patients you advocate for have had with Cosentyx, and with other medications used for the conditions that can be treated or are treated by Cosentyx. Again, if you could specify which medications you're talking about as you share your experiences, and then also which conditions that you're discussing, just to make sure it's captured in our transcript. First, what benefits have you, your loved ones, or patients you advocate for experienced with medications used for the conditions treated by Cosentyx? And as a reminder, let us know which those are. So, what are some of the benefits? We've touched on this a little bit, but any other benefits that you see from those medications. **[Participant 8]**?

00:31:11

Participant 8 (registered as a patient)

My benefits, personally, from ankylosing spondylitis when I started taking Cosentyx, it really reduced the amount of stiffness I had. I was able to move sooner. I can sit down and be able to get up quickly, more quickly than I ever could. I can get up and I can move up and down. I can get up and down out of a chair easily. When the Cosentyx wears off, that stiffness and inflammation's right back. It does work. Works well for me.

00:31:48

Moderator, RTI International

Thanks again. **[Participant 1]**?

00:31:54

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

As I said, Cosentyx took me down to 20% coverage. I've been on Humira, Enbrel, Stelara, Remicade. I think there's one more that I'm forgetting besides the Cosentyx. None of them worked as well, or have or worked at all for me, except for the Cosentyx, which I was very grateful for. And I didn't have any kind of side effects, because I was on methotrexate as well, and the side effects from that were

absolutely horrible, as well as it did nothing to treat the psoriasis. And as far as the psoriatic arthritis, unfortunately for that part of it, I haven't really found anything that's really worked for that. But for me, the most important part is getting the psoriasis under control, because I also know that that causes the psoriatic arthritis to be worse. And also, that's my part of the treatment, is that I want to make sure the plaque psoriasis never gets that bad again.

00:33:10

Moderator, RTI International

Understood. Thanks for sharing that, **[Participant 1]**. **[Participant 6]**.

00:33:15

Participant 6 (registered as a patient)

Hi. In my HS treatment, in step therapy, the first biologic I was on was Humira, and I had about a 50% reduction in my skin flares, and so I was getting them less frequently, and the flares that I had, the severity was reduced, and the most probably significant thing for me is the inflammation in my joints and my body in general was much reduced. However, the effect, particularly in the skin flares, began to taper off after about eight to ten months. Doctor recommended, I agreed, that we switch to Cosentyx, and because the skin flares had returned, had about a 33 percent reduction in skin flares on Cosentyx. Inflammation tapered off. It wasn't as significant a reduction in the inflammation for me on Cosentyx.

00:34:19

Moderator, RTI International

Thank you for sharing that journey. **[Participant 5]**.

00:34:25

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

HS, like a lot of these diseases, they're hard to treat. There's no definitive treatment, and HS is notorious in that. Humira, we have the numbers, about 50% of patients see a 50% reduction in symptoms, which was the best that we had. It was the first one ten years ago, the Bimzelx doesn't have much better numbers, but everybody's different, and obviously they're targeting different inflammatory pathways, which is interesting with these medications. But something that I actually just learned at AAD [American Academy of Dermatology] recently, which a doctor was talking about, I think it's **[Redacted]**, is that they can also stack biologics for, especially for, HS, because oftentimes, we do see that one medication will get you a 40% or a 50% reduction in symptoms, but then that second one will get you to a 70 or 80%. And they're seeing the case studies that presented were oftentimes patients with severe disease who had tried almost everything under the sun, so you're thinking, this is a case of there's just nothing for me, and then they do this, double. Oftentimes they do say that for insurance purposes, it is easier to do an injectable than an infusion. One or the other versus two. But that's something to consider when you have really progressive disease. And at this point, I'm looking at everyone in here, and not to age us, but none of us are spring chickens, so a lot of us, our disease, when we started out, we didn't have options. Now, all of a sudden, we have options. But we're late in the game for treatment, so we might need that more-aggressive approach, and getting that covered is so hard. And you need those doctors who really know how to bob and weave. That's just something to consider because, for **[Participant 6]**'s

experience, sometimes you need that stacking. You get really creative to include a treatment like Cosentyx, and so that has to be part of coverage.

00:36:18

Moderator, RTI International

Thank you, **[Participant 5]**. **[Participant 7]**, other benefits that you've seen from medications used to treat these conditions?

00:36:29

Participant 7 (registered as a patient)

I was on several medications. One of them, like someone else had said, about killed me, put me in the hospital, but Cosentyx has saved my life. I was so depressed, I hated myself, I hated my life, I hated everything, I felt terrible, and all of a sudden, I got my life back. And it was unbelievable. It really saved me, and I think that if it works, it can save your life, it can change your life. Psoriasis and the psoriatic arthritis is what I've been suffering from, and it is so mental, like **[Participant 5]** said earlier, you really do feel at one point, when your face is covered with scabs, and your head, you just don't want to live. I cannot believe that this drug worked for me, and I'm getting ready to become on Medicare. And I'm so scared because I'm on the copay program because there's no way I could afford these drugs. And they helped me, and I know I'm going to have to pay some, but if I don't get it, I'll go back to not wanting to live anymore, and I just wanted to share that because Cosentyx has saved my life.

00:38:04

Moderator, RTI International

Thank you, **[Participant 7]**, for sharing that, and I think I see lots of nods here.

00:38:08

Participant 7 (registered as a patient)

It's true.

00:38:09

Moderator, RTI International

There are people who, seem to appreciate those comments as well.

00:38:14

Participant 7 (registered as a patient)

Thank you.

00:38:16

Moderator, RTI International

[Participant 8]?

00:38:18

Participant 8 (registered as a patient)

I just want to thank **[Participant 7]**, because I agree with everything she said. I've been on Remicade and Enbrel and methotrexate and multiple different medicines, and they all have given me bad side effects. Cosentyx is the only one that I have not received any side effects at all. I feel wonderful. And the mental aspect, **[Participant 7]**, that you brought up, there is hospice for terminally ill patients. There's no hospice for chronically ill suffering people who are going to live with a debilitating disease for the rest of their life. There's no hope, except for Switzerland, where you can go over there and get patient care by your choice. But, **[Participant 7]**, I also have to say, I have two insurances. I have a private insurance we pay out the gazoo for, and I'm on Medicare from a disability, not this disability, something else. And I'm going to lose my insurance when my husband retires this year, so I'm just going to have the Medicare, and I'm not going to be able to afford anything, so right now, I'm working to try to strengthen my body, try to do things naturally, because I'm not going to be able to afford it, Cosentyx is over at the end of the year, unless something changes. Thank you, I just wanted to share all that. Thank you **[Participant 7]**.

00:39:53

Moderator, RTI International

Thank you, **[Participant 8]**, and to all of you for being vulnerable and sharing your experiences with us here, too. **[Participant 2]**.

00:40:05

Participant 2 (registered as a patient)

Speaking to the benefits that I experienced when I started taking this medication, it's pretty dramatic. The reason is that I was pretty much undiagnosed for twenty-plus years, throughout my twenties and thirties, living with the disease and not being able to get a diagnosis, led me down the path to where, ultimately my spine, speaking of what **[Participant 8]** is saying, is fused, for the most part. I experienced that. I went through that without any kind of medication except for ibuprofen, and a lot of stability, mental stability, I guess, from family support, as well as just keeping working at it, moving. I finally got this diagnosis because I'd stop going to the doctors. Because when you don't get that diagnosis, and they tell you it's in your head, you walk away from that, and you think, "I guess I need to work through this." Then it led me down a path where I was like, "I don't know what's going on here, but it's all in my head." When I finally got on the Hyrimoz, the effects were dramatic. By the second shot, I was taking it every two weeks, it just wiped the inflammation out in ways that I couldn't believe. My body felt like rubber, where I was like, "wow," I could not believe I was incredibly stiff. I could finally feel that my spine was fused because the inflammation and fusion are very similar in how they feel. I couldn't move in 15, 20 years ago, but that was because of the inflammation, not because of the fusion. It's really hard to tell, but with taking the medication and then moving on to Cosentyx, which does not have any side effects for me, but still effective. That's been a main benefit as well.

00:42:00

Moderator, RTI International

Thank you so much for sharing that experience, **[Participant 2]**. **[Participant 4]**, we're going to take an answer for you, and then I'm going to ask a follow-up question. **[Participant 4]**?

00:42:13

Participant 4 (registered as a patient and representative of a patient advocacy organization)

You can skip me, that's fine. I was just going to second people.

00:42:16

Moderator, RTI International

Oh, that's fine, I appreciate that. You all have shared some really important experiences related to benefits in in terms of the effectiveness, and symptom management, improved mobility, reduced severity, and some mental health benefits, as well, that were an impact of that, lower side effects, and the ability to stack some of those biologics to amplify the improvement. Were there any other benefits that you wanted to share potentially related to the administration, how the drug is taken or administered, safety or frequency, anything related to those aspects of the drug that you see as benefits? This medication or other medications used to treat those conditions, so it doesn't have to just be Cosentyx. **[Participant 4]**?

00:43:26

Participant 4 (registered as a patient and representative of a patient advocacy organization)

Yeah, thank you. I was previously on Humira, and then I switched to the biosimilar. The biosimilar did not work for me. It is not the exact same thing as Humira, and I had to go back on the name brand, so there was this piece of navigating the process of approvals and everything like that. But the administration was really helpful as far as switching to Cosentyx because I was taking Humira every week, so I was doing an injection every single week. With Cosentyx, I only have to inject once a month, which is really nice. And I also just wanted to say that I'm on two biologics. They are both covered by my ACA health insurance. My doctor's got them covered. My second biologic is for a different condition, not the ones that I'm talking about today, but I have gotten two biologics covered.

00:44:20

Moderator, RTI International

Thank you for sharing that, **[Participant 4]**. Anyone else have thoughts on those administrations? **[Participant 3]**, yes?

00:44:32

Participant 3 (registered as a representative of a patient advocacy organization)

From a holistic, overall patient experience, we've been hearing a lot at the Arthritis Foundation about the intimidation of the self-injectable treatments at first for a lot of people, and this product is really, really helpful because it's a brand drug, you get taught how to use it, but often you still need that level of support to feel confident, especially if you're new to this, or on other products that you might have taken before, the generic has a different actual injectable device that might be completely different than the brand name drug, and might be different by which pharmacy holds which product. If you switch or move, that could be an entire new transition to learning how to use the injectable, and getting on a product that you feel confident using for a longer period of time helps with that care continuity. So, if, I think it was **[Participant 8]**, your husband retires, and you're off your meds, and then what do you do? You might have to learn an entire new product, and how to how to use it. I think it really can make it easier to manage daily life, and make people feel [that]

you're trained, you're confident, you're settled in a routine, you can have familiarity with what really matters, and that can make a huge difference, too, for things like what **[Participant 7]** was sharing, with your mental health. If I understand what I'm doing, and I know what to expect, and how my body responds to that particular treatment, it can make all the difference, especially when I'm stressed and have a lot going on, and you're managing flares and potentially other family dynamics, too. I just wanted to add that in there, too.

00:46:28

Moderator, RTI International

Thank you, **[Participant 3]**, for sharing that and representing some perspectives from other patients as well. **[Participant 8]**?

00:46:36

Participant 8 (registered as a patient)

I just want to quickly say that the self-injectable pens are the easiest there is to use. You take the lid off, you stick it to your leg, you push it down, you hit the button, and it's in and out. Very simple, painless. They couldn't have made it any easier, the Cosentyx injectable. Thank you, that's all.

00:46:57

Moderator, RTI International

No, yeah, that's wonderful. A benefit in the administration, and then we talked a little bit about frequency as well. And then, **[Participant 3]**, thank you for sharing that cascading, I think mental health benefit is what you were suggesting from the administration, so appreciate that.

We're going to shift a little bit. We talked about benefits, and now we're going to talk a little about a little bit about the drawbacks. What drawbacks or challenges have you, your loved ones, or patients you advocate for experienced with medications for the conditions treated by Cosentyx? As a reminder, of course, I'm going to ask you again to let me know which medications you're talking about, if it's Cosentyx or a different medication, and of course, what conditions. So, any drawbacks? **[Participant 1]**.

00:47:50

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

I would say for me, the biggest drawback is always having to fight the insurance company because it's always a fight. It's never just a steady, yes, no, help with moving on, help with getting it. It becomes a total nightmare. You're just on pins and needles, and it stresses you out even more, and it gets to a point that at a lot of times, you're just going, why am I even bothering? Why do I want to even do this fight? Because the insurance is just insane.

00:48:32

Moderator, RTI International

Okay, yeah, thank you for sharing that, **[Participant 1]**. It sounds like some, maybe that's related to access in some way, if you're working with insurance coverage. **[Participant 8]**.

00:48:45

Participant 8 (registered as a patient)

I just was going to say everything **[Participant 1]** just said. Thank you, **[Participant 1]**. But yes, when you're dealing with insurance and you're trying to get approvals, you're dealing with a doctor, you're dealing with a nurse, you're dealing with the infusion nurse, you're dealing with your insurance person, but then you're dealing with a specialty pharmacy. It's mind-boggling. It's like, who am I speaking to? That one already approved it. No, we didn't approve it. You have to call this number, then you have to call this number, and then you just throw all your papers in the air and say, "It's not worth it." And you're just going to live like this. That's the way I feel. The cost is just ridiculous. The paperwork.

00:49:30

Moderator, RTI International

And just to clarify, I guess, **[Participant 8]**, **[Participant 1]**, others, is this, are these challenges things that you're experiencing with Cosentyx and medications that are used to treat those conditions, or is it a broader statement?

00:49:49

Participant 8 (registered as a patient)

For me, it was all the biologics.

00:49:53

Moderator, RTI International

Okay.

00:49:53

Participant 8 (registered as a patient)

I had issues with every biologic. It was the same process. It was the same, if you have Medicare or a government insurance, you can't get copay assistance. Because I have two insurances, you can get it because I have private. Yeah, but it's all biologics.

00:50:16

Moderator, RTI International

Okay, thank you. **[Participant 6]**?

00:50:20

Participant 6 (registered as a patient)

I'll echo what everyone said. For me, it's the cost of time, and especially when you're having flare-ups, it's the fatigue and all that. But if your question also was referring to side effects, for me with Humira, I also suffer from migraines, and instantly, within five minutes, I had a splitting headache. And so, contacted my doctor, my dermatologist for HS, who said, let's reach out to your neurologist, see what they say. So, I started another medication to counteract that side effect, and it worked, but I felt like, okay, here we go with the piling on of meds.

With the Cosentyx, I had an immediate feeling of inflammation, like my knees, my joints were all inflamed, but I, again, reached out to my dermatologist, and she said, "Let's see if you can ride that out, if you need to take some ibuprofen," and that one did subside within two weeks or so, so that was one of those that I just had to sit on a little bit. And those were the main side effects I experienced. I'm a person who took extra precaution, or takes extra precautions, so when I traveled a little bit, I did wear a mask, I will take extra precautions sometimes because I know my immune system's lower, and that's it.

00:51:55

Moderator, RTI International

Thank you for sharing that. **[Participant 4]**?

00:52:01

Participant 4 (registered as a patient and representative of a patient advocacy organization)

For just a second, that extra precaution piece, when I travel, I try to take extra precautions. In group settings, I try to take extra precautions. I also had infection, a serious infection on Humira, I know I mentioned this briefly, but it landed me in the hospital, and then I had to do 21 days of infused antibiotics after that. It was very severe and very scary. And then there's always that fear that that could happen again when being on a medication like this.

I also just want to comment on specialty pharmacies. The biologics, it's very difficult to get your doctor to send them to a local pharmacy. Insurance companies, private insurance companies, really push for the use of their specialty pharmacy, and in my case, I could not get my medications on time or regularly through the specialty pharmacy, so I had to fight to get my doctor to agree to send it to a local pharmacy, and I've had to work with them to make sure they can get it, but at least I get it on time now. The difficulty of dealing with specialty pharmacies, the time suck that **[Participant 6]** was mentioning is unbelievable, being on hold, dealing with that outside of insurance, it is a nightmare.

00:53:13

Moderator, RTI International

Ok, thank you for sharing that as well, **[Participant 4]**. **[Participant 2]**. Drawbacks or challenges?

00:53:20

Participant 2 (registered as a patient)

Yeah, drawbacks and challenges for ankylosing spondylitis. I could talk a little bit about experience with, how the delivery model for two drugs is different. For Hyrimoz, I was able to be approved for [a] three-month supply that could be shipped out to me, but for some reason, with Cosentyx, I only can get one injector pen every single month, and I work with a specialty pharmacy for this. They were sending you just one pen in this very large container, and I had all this waste. I always found that frustrating. Fortunately for me, I was able to get it sent to a local pharmacy, where I don't know if they get the same packaging, but at least I don't have to deal with it. I feel like there are some drawbacks in just how the medicine is delivered, how frequently it's delivered. I do get concerned, is it going to be on time, things like that.

And then just from a side effect perspective, I think going in, someone long-suffering, and then starting a very intimidating kind of medicine that has a list of dozens of side effects and knowing

that my body already feels in such a vulnerable state going into taking it, and trying to figure out, what am I feeling that's a benefit, and what am I feeling that is a side effect? That was really troubling for the first couple months. I did refer to, on Hyrimoz, feeling like rubber, which at first was really great because I was always so stiff, but then you start to realize that maybe something else is happening. I started to suffer a lot of neurological symptoms and contacting back and forth with the doctor, like, "no, that's probably not the Hyrimoz," and after about just getting appointments with other specialists and things like that to sort through, is this a side effect? I felt it immediately after taking the pen, and then eventually just persisted. Sorting through all those side effects, getting to see all the appropriate specialists to finally have the neurologist say, "I think it's worthwhile to get off the Hyrimoz, just to see. I think it's important to change that journey." That was a really challenging, just trying to work through dealing with the disease, and on top of that, trying to sort through the side effects, potential side effects. And that's been a benefit of Cosentyx is that it hasn't had any side effects. It's been a much easier way to deal with it.

But I'll say, that difference between changing drugs, I didn't realize it would be—from the standpoint of injection, the Hyrimoz delivery model is just a quick, quick prick, and it's about five seconds, whereas, the Cosentyx is more about 15. I think that the first one, I wasn't prepared for it to take so long. It took me a couple tries to really realize, okay, this is how long I need to hold it down. That's a lot of medicine to be wasting if you were to do it incorrectly. And the instructional video said it would take a while. I was not expecting it. And then the clicking sounds are different, and things like that, that give you that indication of when it's done, so that also throws you off. I had some concerns initially whether or not I was doing it correctly when I changed.

00:56:44

Moderator, RTI International

That's really interesting, **[Participant 2]**. Thanks for sharing that. We've talked about, I think, some drawbacks or challenges related to access, some of the time that it would take to get these medications for a variety of reasons, some of the side effects, both for Cosentyx and other medications, the delivery model, including how much you could access at a time. And then I think some things also related, **[Participant 2]** just mentioned the learning curve, or switching medications, and how that could be a challenge. Are there any other challenges? I, **[Participant 3]**, I saw you put something in the chat. If you want to share that, we do have time for that, if you if you wanted to share that orally.

00:57:35

Participant 3 (registered as a representative of a patient advocacy organization)

I was mostly just going to reiterate a lot of what **[Participant 2]** said, actually. I just wanted to reaffirm. I think we do hear a lot, especially from newer patients, who don't have a lot of experience, and that intimidation factor, or they just aren't given the training or the time to be taught how to use it. I think one of the things that we hear a lot is, "I wish that I could do this in my doctor's office and have somebody show me exactly what to do for more than one time," especially because something will come up, or say you're in a different state, what do you do when you have something funny happening, or a flare is happening and it's not responding? I think it's just taking the time to make sure that people do feel confident before they're pushed out the door. And when you're switching from a new med, trying to figure out, like, **[Participant 6]**, you were saying, I also have migraine and a spinal fusion. I don't have one of these conditions to speak to, but I do know how difficult it can be in the care coordination when your doctors are not in the same health system,

especially, and we have a lot of patients that tell us, I myself have four different health systems that I'm seeing providers in. A lot have upwards of 34 different doctors, specialists, care providers that they're seeing, and trying to navigate the burden on me, the patient, to figure out every single thing that I could possibly think of that might have an adverse reaction is really challenging. And it's all put on the patient to figure it out for yourself because the doctors don't have access to be able to talk to each other, if they're not in the same health system. I hear a lot of the difficulty of, I think that I have shared everything that I could, but I don't know what I don't know. And we're not medically trained physicians, we've learned a lot as patients, but I think this therapy is really good because it, sorry, Cosentyx specifically, works for some patients better than it works for others. I don't think anyone is saying it's necessarily better than another product, or less impressive, but for a specific patient, it might be night and day between all of their past meds that they've been trying, or balancing the benefits, understanding that there are some downsides, and I'm willing to accept those in order to get the benefits that I really want, which are not necessarily lined up with the clinical data that the doctors want. It might be, I want to go run up the stairs, or I want to pick my kids up from school or carry the groceries in without worrying. I want to be able to sleep overnight and not be waking up 15 times over because I'm in pain, and I'm stiff, and I can't move in the morning because now I'm running late for work, and those are obviously really hard to quantify with clinical data. I think a lot of what I'm hearing, at least from this group, is not every treatment has to work for every person, but it works for them, and it is life-changing, and we should be able to have access to those meds and continue it, if we know that it works, so that we're not progressing our disease even further and backtracking, and time lost, and the opportunity cost that comes with all of that is just grating. It's progressive disease that's not disappearing on its own. I think managing other health conditions can be really an oversight for people that are not involved in managing their chronic conditions themselves and are only viewing it as a clinical risk-benefit analysis. There are always going to be risks and benefits, but the patient wants a life. We want a life.

01:01:33

Moderator, RTI International

Oh, sure.

01:01:34

Participant 8 (registered as a patient)

Quality.

01:01:36

Moderator, RTI International

The quality, [Participant 8]?

01:01:37

Participant 8 (registered as a patient)

We want quality of life. We have a life, but it's a life of worrying about getting treatment, and I'm worried about what's going to happen in September, already it's April. We have no quality of life. It's just survival. We're just surviving.

01:02:01

Moderator, RTI International

Yeah, as **[Secondary Moderator]** said [in the chat], too, thank you for sharing that insight, both of you, and the more holistic picture, as well as these individual aspects of the medication and the conditions that we're talking [about]. It's really helpful for us to hear that broadly, as well. Before we move on to our next topic, I just want to ask one more time: we've talked about a variety of drawbacks and challenges. How about any challenges with the effectiveness, or drawbacks related to effectiveness? We've talked a little bit about administration, anything related to frequency or dosage or safety, is there anything else you wanted to share? **[Participant 1]**?

01:02:53

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

I would say for me, the most disheartening thing is I was on Cosentyx for a year and a half, and it worked great, but then suddenly it just stopped. And then I had to switch to something else. And that gets to a point when it's like that, when you've seen such a major clearance of it and then you're back in the fight of going, "oh God, here I go," having to switch another medication and the fight that's coming with that. If there was a way to improve it to where they don't stop working, where you can go years and years on them, would be so amazing, even for future patients.

01:03:47

Moderator, RTI International

Okay, yeah, thank you. So, you had the experience of a medication working, and then it didn't work anymore, and that is a challenge in terms of knowing what would be effective? Is that right, **[Participant 1]**?

01:04:01

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

Absolutely, yeah. Because you never know, when you first are prescribed the medication. You're going, "I'm hoping, I'm praying it's going to work, and there's going to be a difference." And in the case of Cosentyx, it was a huge difference. Like I said, from 80% to 20% covered with plaque psoriasis, huge difference. And then you go to the next medication, and you're like, "now I have to worry, is it going to work? Is there going to be side effects? Is there going to be other things it might bring on?" And it's like a Ferris wheel that just keeps going around and around, and with every drug, these things come to mind, and it's just a horrible way to have to deal with your condition. It just adds extra factors to it.

01:05:02

Moderator, RTI International

That's a lot to manage, for sure, **[Participant 1]**. **[Participant 2]**.

01:05:10

Participant 2 (registered as a patient)

Yeah, I can speak to dosage requirements for ankylosing spondylitis. When I started Cosentyx, I received my dose. And my employer offered a second opinion service, so I signed up for that, and

the doctor who wrote up the report recommended that I actually go to a double dose, something, I guess, reserved for people of heavier weight, but this doctor said that Cosentyx is more effective at this higher dose. Bringing that information back to my primary rheumatologist and discussing with them, trying to navigate, when do you go up? You started this one dose, is it possible then just to go up? When do you see, when is that worth it? And that's a question, as a patient, I don't really know how to navigate with them. I think that's one of those drawbacks there, so I didn't know that there was a possibility to go up until this second opinion, and then having the conversation with the doctor to really say, "I'm ready, I want to, I need more of this drug," and that's hard because they're resistant, they're like, "it's effective now, let's not go up." That timing around that and figuring that out, I think, is challenging.

01:06:25

Moderator, RTI International

That is a challenge, for sure, yeah. Thanks, **[Participant 2]**. **[Participant 8]**.

01:06:30

Participant 8 (registered as a patient)

I want to mimic what **[Participant 2]** just said about the effectiveness of the self-injection versus the infusion. There's a big difference for me. The self-injection only lasts two weeks of the month, but infusion will last all the way to my next infusion, just about, and it is weight-based because I weigh 93 pounds, I cannot go up on a dose because it would be too much. I'm at that 150 dose, I can't go up anymore. I wish there was a way to go up a little bit more. But the only way to go up is to 300, and I'm not big enough for that. And then the only relief you can get is to get a steroid injection for all over. And then when you already have osteoporosis, that's not good to get the steroids, and that's all I had.

01:07:34

Moderator, RTI International

Thank you for sharing those additional challenges. That's really helpful context. **[Participant 4]**.

01:07:43

Participant 4 (registered as a patient and representative of a patient advocacy organization)

This is a general comment about everything we've talked about, but patients are forced to make really difficult decisions all of the time. Throughout their care with treatment for conditions like these, and considering to go on a biologic, everything from the process of finding a doctor who will take your insurance, actually getting into an appointment, actually doing an intake, dealing with the front desk. Everything. Getting on a medication starts with which insurance you purchase or get from your employer. It starts the entire process, and I think that's being addressed in these conversations, but it's important to point out that patients work incredibly hard to even get to the point where they're able to get on the medication, and then when they are, they are forced to make incredibly difficult decisions about quality of life versus risks versus good things as well. There's just a lot of difficult choices to be made.

01:08:41

Moderator, RTI International

Thank you for highlighting that, **[Participant 4]**, appreciate that. **[Participant 1]**, then we're going to move to our next question.

01:08:50

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

Yeah, I was just going to go with what **[Participant 4]** was saying along the line of the doctors. That's a whole 'nother fight within itself because you go to some of these doctors and they only want to do what they want to do, and not what the patient is saying, and [don't] take the patient's history and what we're telling them into account. And then that becomes a whole 'nother situation of a fight, because then, if they're not listening and all, you've got to switch to another doctor who is, or who does, and it just makes the whole timeline more difficult when you're dealing with something that can potentially cause you grave harm. That's just another side of the coin of the fight that we all have to deal with.

01:09:51

Moderator, RTI International

Thank you for sharing that additional perspective and context as well, **[Participant 1]**, that's so helpful. Moving on, and wrapping this part of the discussion up, overall, when considering a potential medication for these conditions that are treated by Cosentyx, what factors matter to patients the most? For instance, the effectiveness, the safety, side effects, ease of use, dosage, whether it was recommended by your health care provider. What would you say matters the most to patients, just briefly?

01:10:30

Participant 8 (registered as a patient)

Cost.

01:10:30

Moderator, RTI International

Okay, **[Participant 8]** said cost.

01:10:35

Participant 7 (registered as a patient)

Effectiveness.

01:10:37

Moderator, RTI International

Effectiveness.

01:10:38

Participant 7 (registered as a patient)

Yes, effectiveness and, of course, insurance, being able to get it.

01:10:47

Moderator, RTI International

Okay.

01:10:48

Participant 8 (registered as a patient)

If you can't afford it, it doesn't matter if it works or not.

01:10:50

Participant 7 (registered as a patient)

Right, if you can't afford it, then you're not getting it.

01:10:54

Participant 8 (registered as a patient)

Then don't worry about it.

01:10:55

Participant 7 (registered as a patient)

Right? But effectiveness, you want something that's going to work.

01:10:59

Moderator, RTI International

Sure, of course. Cost and effectiveness, the combination there. What else? **[Participant 6]**?

01:11:11

Participant 6 (registered as a patient)

Yeah, insurance coverage, and for me, I worry about black box warnings, so the other side effects, I'm willing to try, but I do fear the black box warnings.

01:11:28

Moderator, RTI International

Okay, those major side effects. I think **[Participant 1]** also said effectiveness, cost and side effects, one of those three?

01:11:43

Participant 2 (registered as a patient)

I would chime in and add frequency, just being able to have a product, medication taken once a month, rather than two to four times a month. I think that's very, very helpful.

01:11:57

Moderator, RTI International

Okay, there's some agreement there, I think, too, and **[Participant 3]**, effectiveness, safety and side effects, and just being able to function. Some things related to, maybe, quality of life. Great. Thank you all for sharing that, and I just want to stop for a second and say the information you provided has been so helpful, and I appreciate your being so open in this conversation. It's giving us a lot of really rich information, and [I] appreciate you sharing your experiences.

We're going to shift a little bit and now talk about how well Cosentyx and other treatments for the condition it treats meets patients' needs. At the beginning of our discussion, we asked you all to reflect on the most important aspects of those conditions treated by Cosentyx to have managed or treated. Aside from the aspects you've already shared, what other medical needs related to these conditions are important to you, your loved ones, or the patients you advocate for? For example, are there important medical needs related to specific symptoms or specific side effects of the available treatments, quality of life, et cetera? **[Participant 1]**?

01:13:19

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

I'd say, for me, part of it is that it not create any other medical conditions. Like I said, I have heart disease that runs in my family. And knowing that psoriasis causes inflammation, but the comorbidity of it is also that it can affect the heart and stuff. To know that a medication, any kind of medication, including Cosentyx, would not exacerbate that or make it potentially worse.

01:13:57

Moderator, RTI International

Yeah, thank you for sharing that, **[Participant 1]**. That's an important factor, for sure. All right, what medical needs were you hoping treatments for these conditions would address? And do you do you feel like that's being met, or are there still additional medical needs that are not being met? **[Participant 8]**?

01:14:32

Participant 8 (registered as a patient)

I expected it to do everything it said, and Cosentyx did that for me. It really has alleviated my inflammation. Therefore, giving me more movement. But the main thing for me was stiffness, and it really has helped out so much. It's done everything that it said it was going to do for me and more. I just wish there was little higher dose.

01:15:02

Moderator, RTI International

Yeah, understood. **[Participant 7]**.

01:15:07

Participant 7 (registered as a patient)

Yes, I was hoping when I started Cosentyx, because it was about my fourth or fifth drug, that I was going to be able to play with my grandchildren, take them swimming, and be able to go in the pool

with them, so I wasn't embarrassed sitting over on a chair with a towel over my legs and a big sun hat so you couldn't see the sores on my face. And be able to play with my grandchildren, and not be intimate with my husband and be embarrassed, and guess what? I can. It worked. I'm swimming. I'm playing with my kids, and I'm so thankful. And if I can't get the medicine, then I guess I'll have to put a towel on and take them to the pool, I don't know. But I thank you for having this today, too.

01:15:55

Moderator, RTI International

Of course, yes. Thank you for being here, **[Participant 7]**. **[Participant 2]**?

01:16:01

Participant 2 (registered as a patient)

Yeah, let me just remember the question. Speaking to expectations?

01:16:08

Moderator, RTI International

Yeah, what medical needs were you hoping [would address]?

01:16:10

Participant 2 (registered as a patient)

For ankylosing spondylitis, given that I had gone so long without treatment, one of those questions really was around, do I need it? And I was going into it thinking, I've made it this far, given all the risk associated with it, is this [treatment] something I need? And then, my rheumatologist really didn't give me a lot of expectations. Basically, it was just, the damage is done. This medicine may or may not relieve your pain. What we're looking to do and accomplish is to prevent it from causing other issues. So, going into it, I didn't have a lot of expectations, but [I'm] very much surprised that it has been very effective, and even with all of the damage, I'm still able to function and work on a daily basis.

01:17:17

Moderator, RTI International

That is great, **[Participant 2]**. **[Participant 1]**?

01:17:23

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

Yeah, I was just going to add, I've talked a lot about the psoriasis, but I have the psoriatic arthritis, too. There was hope that it was going to be a combination medicine for me that would take care of both symptoms, the psoriasis and the psoriatic arthritis. It did wonders and all for the psoriasis part of me, but it really did nothing as far as the psoriatic arthritis part for me. But when it comes down to it, in my opinion, the psoriasis was more of a problem, so I was happy with the result I did get. But as far as the psoriatic arthritis, it didn't do anything, so it was a little bit of a downer on that part, but all in all, it was great, so for me, it was still a success.

01:18:30

Moderator, RTI International

Okay, thanks for sharing that, **[Participant 1]**. So, it treated a part of your conditions, but you didn't see the same kind of result for other aspects, is that—

01:18:45

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

Yeah, absolutely, it was that way. It did nothing for the psoriatic arthritis, but being so widespread, covered with the psoriasis, that was more of a priority to get it under control. And unfortunately, still here I am 22 years later, and I've never seen complete clearance with psoriasis. I still have active patches even to this day, so there'd be a point where I would like to know what it's like to feel clear of the psoriasis being gone from the skin, as far as it goes, but even at a 20%, it's still winning at a point.

01:19:31

Moderator, RTI International

Sure. Thank you for sharing that, **[Participant 1]**. **[Participant 6]**?

01:19:39

Participant 6 (registered as a patient)

Yeah, with the HS, I was hoping for a reduction in the frequency and severity of skin abscesses, reduction in inflammation in the body, the joints, and less fatigue, and that's about it.

01:20:00

Moderator, RTI International

Do you feel like that you have achieved those goals, or are there still some aspects that are unmet?

01:20:11

Participant 6 (registered as a patient)

Definitely haven't achieved all of them to any degree, but lessened. With the Cosentyx, I would say the skin was about 33% improvement. Fatigue probably leveled off, maybe 25%, [and] the inflammation, probably the same about the fatigue.

01:20:37

Moderator, RTI International

Okay, that's helpful. Just a bit of a follow-up. Some of you have mentioned that you were switched to medications when Cosentyx did not work or was not as effective as you had hoped. Could you share which medications you were switched to in those situations? And then tell us a little bit about how effective the switch was to a new medication. **[Participant 6]**?

01:21:13

Participant 6 (registered as a patient)

I have not started my new medication yet. The switch happened, and then life happened. My father went to the hospital, and I often have symptom side effects, and I wanted to delay until I had a chance to assess, so I will be starting that ASAP, but the new one will be Bimzelx. Just because the Cosentyx seemed to taper off and only had reached a minimal level of effectiveness for me.

01:21:49

Moderator, RTI International

Okay. Thanks, **[Participant 6]**. **[Participant 1]**?

01:21:54

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

When the Cosentyx stopped working for me after a year and a half, I got switched to Stelara, and in doing that, it didn't do anything for me. It was the disappointment of that, and then now I'm being switched to Skyrizi, which I haven't started yet. It's just the whole process of having to switch it, it's just draining sometimes.

01:22:32

Moderator, RTI International

Understood, **[Participant 1]**. Is there anyone else who has switched from Cosentyx to another medication? Okay, all right.

For the next couple of questions, I'd like you to reflect on your experiences with treatments for the conditions treated by Cosentyx. These treatments, again, could include Cosentyx or other medications used for those conditions, or other types of available treatments for these conditions. Which important aspects or needs of the condition are being addressed, or at least partially addressed, by the existing treatment options? And we've talked a little bit about this, but they don't necessarily have to just be the needs that we've discussed before, so not necessarily just the clinical needs or, or aspects, and the medications don't just have to be the pharmacologic, or the medications, they could also be therapeutic alternatives as well. **[Participant 8]**?

01:24:00

Participant 8 (registered as a patient)

Are you asking for what we've tried in the past other than that?

01:24:06

Moderator, RTI International

Sure, yeah, absolutely, you can share that. But we're also asking which aspects or needs of the condition are being addressed by any treatment option that's available, holistically.

01:24:22

Participant 8 (registered as a patient)

I get steroid injections that does overall, the whole body inflammation, every now and then because it gets so out of control. Sometimes that can't bring it back down. And I've tried every gel pillow, brace, heating pad, everything on Amazon to try too, and then my swimming pool is the best.

01:24:54

Moderator, RTI International

Okay. And tell me about that, **[Participant 8]**. You said your swimming pool is the best?

01:25:01

Participant 8 (registered as a patient)

Yeah, because you're floating, and I have no pain in the pool because there's no pressure on the joints, there's no inflammation, I feel great in the pool, so aqua therapy works really well for me, except for when the pool is too cold because cold for me just kills my bones. It just hurts. Much worse.

01:25:27

Moderator, RTI International

Okay. That's really helpful. **[Participant 6]**?

01:25:33

Participant 6 (registered as a patient)

I was going to say technically, I know Humira, Cosentyx, Bimzelx all work as inflammation blockers. Technically blocking inflammation, and I know they're all targeting, they're supposed to, in some ways, help with skin, stopping the eruptions, like the abscesses, or slowing down the abscesses in the skin. Also, I can't remember your exact question, but I know one of the things I was thinking about is that all of these medications have programs that have been helpful, like the Cosentyx Connect. The different care programs have been helpful for me in getting started, even helping negotiate sometimes with my pharmacy, or being that contact in that awful process of trying to figure out the insurance, doctor's office, pharmacy, and also making sure I know the difference between the one stick thing, and the 15 seconds here, and the last one that I took. Those have been helpful to me. Those were the two things.

01:26:58

Moderator, RTI International

That's great, yes, and that does answer that, so what you said was responsive to the question I asked. Wonderful. Anyone else? We're talking about the aspects or needs of the condition, just as a whole, that are being addressed, or partially addressed, by any treatment option. And as **[Participant 6]** said that includes some supportive options or a supportive treatment as well. **[Participant 7]**?

01:27:32

Participant 7 (registered as a patient)

Yes, I've forgotten about this because it's gotten almost non-existent, but the itching. Oh my god, that would keep you awake at night, I would have to wear leg wraps, and blood, just from scratching yourself till you bleed. Itching is better in your head, and also with the arthritis, just being able to get up in the morning and not having to take 40 minutes just to get your legs where they can walk down the stairs okay. But I think just not having that incredible itch is a plus.

01:28:22

Moderator, RTI International

Understood, yeah. Okay, that symptom has been helped by the available treatments. **[Participant 2]**?

01:28:37

Participant 2 (registered as a patient)

Yeah, you mentioned holistically looking at your condition and how it's being treated in a variety of ways. Thinking about ankylosing spondylitis, I'm going into the doctor, the rheumatologist, being told what you have, and then being prescribed a medicine, and then a quick demo, and sent on your way. That's a crazy experience, and very intimidating, also, what do I do now? And in a way, the actual disease and the medications themselves become, at least for me, just because the insurance hasn't been such an issue.

I don't think about it as much. And really, it's everything else about navigating the doctors, reading about it, learning from other people, reading patients' stories. Figuring out my mental health and trying to find someone. Because I think, people have chronic conditions, you need to work with people who also have chronic conditions. That's what I found. I've started gravitating because people start to understand, those people understand what you're going through on a day-to-day basis, and they can provide a lot more insight into what you're experiencing and then how to deal with it. But I think the management day-to-day is less about the actual condition and the state of the condition and the drug, and more about figuring out how to have a quality life, as we talked about before, as well as anticipating what's going to change in the future and making sure you have everything in place.

01:30:27

Moderator, RTI International

Great, thank you, **[Participant 2]**. All right, switching that up a little bit, what important aspects or needs of the condition, broadly, including the medical needs and other needs as well, are not being addressed by the existing treatment options? **[Participant 1]**?

01:30:47

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

I'd say it's the mental health aspect of it that's not being talked about, asked about. Along that line are being offered as maybe counseling or something along that line because when I was 80% covered, I had been married for a year at that point. And I told my husband, if he wanted out of the marriage, I'd let him out because I didn't know how bad it was going to get for me. There's a lot of the

whole mental aspect of it. That's just not addressed. It's not talked about. How you're functioning with the medicine, none of the mental aspect is being addressed.

01:31:43

Moderator, RTI International

Thank you for sharing that, **[Participant 1]**. I think some of you also talked about the mental health impact of some of this, so I appreciate you sharing that. **[Participant 2]**?

01:32:04

Participant 2 (registered as a patient)

Yeah, I think something not addressed in that experience directly is a way of dealing with and understanding the side effects of taking these medications, because that was a big part of my experience in the last year and a half. It's just trying to figure and sort that out. When you're handed a very large booklet with a million side effects listed, your doctor doesn't—it's like, "yeah, these things won't happen." But then as you start to experience things, you want to be able to reach out to someone who maybe can more directly speak to the side effects of the medication, who can help you, counsel you through that, whereas your doctor, at least my doctor, was not able to do that effectively, or in a timely manner. I think having that support network there available as the drug is first given to you would be beneficial.

Cosentyx, coming into that second, it seemed like, Cosentyx Connect, there's more of a network around it. But at that point, I was somewhat comfortable with managing the medicine when I started that one, so I hadn't really taken advantage of it, but that's what I felt was missing.

01:33:28

Moderator, RTI International

I appreciate that. That's, really helpful. Thank you. Anyone else? Any major gaps or in treatment or concerns that remain despite the treatment options that are available? All right.

We are wrapping up, but before we leave, I want to give you an opportunity to summarize your thoughts on the importance of Cosentyx for patients and to raise any topics that you feel were not adequately covered by our discussion today. Do you have any final thoughts about Cosentyx, conditions treated by Cosentyx, or other medications that treat the same conditions that you feel are important to share with CMS? **[Participant 8]**?

01:34:33

Participant 8 (registered as a patient)

I only have the issues of the cost factor. If people are going to be on Social Security, how are they going to afford this medication? You can't get copay assistance if you're on government insurance. I would like an answer for that. What are we going to do? I don't even know if Medicare pays any of it. I have no idea. That's my main concern, is making it more affordable for everyone, and making it not so difficult to have to go and get it, if you have to get an infusion, because the infusion works better than the injectables, for me, anyway. I don't get the same benefit from both. That's all I have to say is the cost.

01:35:29

Moderator, RTI International

Thank you for sharing that, **[Participant 8]**. **[Participant 4]**?

01:35:34

Participant 4 (registered as a patient and representative of a patient advocacy organization)

Thank you. I am very concerned about access to the medication outside of affordability. I live in a state where there are efforts to possibly set upper payment limits on medications. And I'm concerned if upper payment limits are set, that patients may not have access to medications, due to either drug companies pulling out of states or pharmacies not being able to stock it due to the cost incurred by the pharmacies. I'm very concerned about upper payment limits when it comes to actual state issues.

01:36:14

Moderator, RTI International

Okay, yeah, that's great. And I see, **[Participant 8]**, you added something in the chat, too. Thank you for sharing that.

01:36:22

Participant 8 (registered as a patient)

I was just wondering, I've been on these medications for so many years, what's going to happen to my body when I stop cold turkey because I can't afford it anymore? I've just now had that thought. I've never thought about that before until now. I'm curious about that. If anybody has any thoughts about that, I'd like to know.

01:36:46

Moderator, RTI International

Thank you for sharing that, **[Participant 8]**. **[Participant 3]**?

01:36:51

Participant 3 (registered as a representative of a patient advocacy organization)

Thank you. I think from my vantage point, just to summarize, working with a variety of patients all over the country with the Arthritis Foundation, what stands out to me is just how important it is to find an effective treatment as early as possible in the disease course, before symptoms worsen, before it leads to greater loss of function, before disease progression, because as soon as all of those happen, everything gets more expensive, you utilize a lot more health care, there's a lot fewer options when you get to the more severe stages of your disease, and it's not necessarily reversible. Then you have to figure out how to manage it. And I think treatments like Cosentyx can be really meaningful for some patients in helping to control those symptoms, like the pain and stiffness and fatigue, and supporting day-to-day functioning and mobility. And what we consistently are hearing is that when patients can find that treatment that works for them, it can give them that independence, **[they]** can stay engaged at work, they can be able to participate in family life, like **[Participant 7]** was saying, going to the pool and taking your kids out and enjoying life. And over your entire lifetime, not just at a point of, "I saw my doctor, and I get a 90-day follow-up." That's

insufficient. We're talking over the entire lifetime of someone's disease and avoiding further disease progression. And at the same time, there is still variability in response, and not all patients experience the same level of benefit, which is why having those options remains really important.

From a broader patient perspective, managing disease effectively earlier on can help reduce the overall burden of everything with their conditions over time, not just individually, but for the entire health care system as well, and outcomes and the need for more-intensive care later, I think is a really important thing to note, too. It is major, me, the individual, having to pay a lot more out of pocket, but it is also a lot higher cost to the health care system if we're not treating effectively early on. Ultimately, I think it's most important to share that patients are just looking for treatments that work for them. They want to continue their life, they usually want to work, they want to be able to be engaged in society, and I think we should do everything we can to help maintain quality of life and function and help people age respectfully and with dignity. And thank you all, I really appreciate hearing all of your sharing and experiences, and thank you for hosting this, **[Moderator]** and **[Secondary Moderator]** [for] moderating this.

01:39:40

Moderator, RTI International

Yes, thank you all so much for coming, for sure. **[Participant 6]**.

01:39:45

Participant 6 (registered as a patient)

I'd echo what everyone says, and I would say that, I really support the idea of Cosentyx as an accessible medication available for everyone in the community, and keeping in mind that listening to my stories as a patient with HS, I didn't start any biologics until I was diagnosed as a Level 3, early Stage 3 person with HS. As hidradenitis suppurativa is gaining more awareness, and if we're able to reach patients earlier in their disease, if they're able to reach Cosentyx, have an accessible medication at an earlier stage, it can do so much more. And this may not have been the medication for me for the long term, but this may be the right medication for them if they're Stage 1, even Stage 2, and this could really slow the progression for other people. Just having an accessible medication can mean the world, so thanks.

01:40:58

Moderator, RTI International

Thanks so much, **[Participant 6]**, for sharing that. Yeah, **[Participant 2]**?

01:41:05

Participant 2 (registered as a patient)

Yeah, I would add this idea of dependency. We're all dependent on these drugs for the quality of our life. But there's also this insecurity around using them, that they may go away. What am I going to be like if they're not here? Because there really isn't a cure for any of these things, even if you get started early on, it's still working within your body. And people that I've talked to, I haven't really met anybody that has, say, lived their life on a biologic. They all come to it later in the game, further progression in the disease. For me, I'm curious about information, studies, things for people who've actually started biologics when they're younger, and what that progression looks like, and how they actually live their life long-term. Because that's something I can only speculate about, wondering if

there was something there, because these drugs haven't been around that long, right? We don't really know. And that's an area of concern, something I think about regularly. What's it going to look like in 10, 20 years? Especially if my access to these drugs goes away because I become dependent on them, and maybe I don't do the other things that I need to do in terms of diet, exercise, and things like that to manage my condition because I have a drug to do it for me. And just trying to remember that and keep that in mind as I move forward. When I think about the medication, I think about my life, that's where I usually tend to go and spend a lot of time speculating and wondering.

Closing Remarks

01:42:54

Moderator, RTI International

Sure. These are just great, thoughtful, insightful comments, and I really appreciate, again, you all sharing all of that with us, and including these summary perspectives.

I'm going to ask our CMS colleagues to come back on video. And I want to thank you for participating in today's event. We appreciate you taking the time to talk with us. As I said, your experiences and input were extremely valuable and will help inform CMS' negotiation for Medicare pricing for Cosentyx. And these colleagues that we have here have been listening to the roundtable and will be able to bring your perspectives back to the team. I'm going to turn it over to **[CMS Staff]** again for a closing statement.

01:43:46

CMS Staff

Yep, I would just like to thank you guys all again for sharing your experience. It was very impactful, and we loved listening in the background, so just thank you, and we're grateful for all you guys coming here today.

01:43:58

Participant 8 (registered as a patient)

Thank you.

01:43:59

Moderator, RTI International

Wonderful. If you have any questions following today's session, you can submit them to the mailbox at IRARebateAndNegotiation@cms.hhs.gov, with the subject line "Public Engagement Events." Thank you again, everyone, for your time today.

===== END OF TRANSCRIPT =====

For a list of the drugs selected for the current 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-2028.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 selected drug or the conditions treated by the selected drug; 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 health care 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 conditions treated by 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
No	Direct assistance preparing your remarks from someone who is NOT a family member, caregiver, friend, or your health care 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 3: Registered as 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 health care 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
Yes	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 4: Registered as a patient who has experience with the selected drug, the conditions treated by the selected drug, or other treatment(s) or drug(s) similar to the selected drug for those conditions; 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 health care 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
Yes	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 5: Registered as 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 health care 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 6: Registered as a patient who has experience with the selected drug, the conditions treated by the selected drug, or other treatment(s) or drug(s) similar to the selected drug for those conditions

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 health care 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 7: Registered as a patient who has experience with the selected drug, the conditions treated by the selected drug, or other treatment(s) or drug(s) similar to the selected drug for those conditions

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 health care 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 8: Registered as a patient who has experience with the selected drug, the conditions treated by the selected drug, or other treatment(s) or drug(s) similar to the selected drug for those conditions

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 health care 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

