Transcript: Pomalyst Roundtable Event, April 24, 2025, Medicare Drug Price Negotiation Program Public Engagement Events

This transcript was lightly edited for readability.

Introductory Remarks

Moderator, RTI International

All right. Hi, everyone. Thank you so much for joining today. I'm so happy to have you all here. My name is **[MODERATOR]**. like **[REDACTED]** and excited to be here with you today. I work for a company called RTI International, and I also am joined by my colleague, **[SECONDARY MODERATOR]**, RTI International. You can see they're waving in the camera. Hey, **[SECONDARY MODERATOR]**. You may hear from **[SECONDARY MODERATOR]** a few times during today's discussion as we go through our discussion guide.

The Centers for Medicare & Medicaid Services is convening this patient-focused roundtable event and others as part of the Medicare Drug Price Negotiation Program. And, the purpose of today's event is to hear from you all, a group that includes patients, caregivers, and patient advocates, about your experiences with the conditions and diseases treated by Pomalyst, with Pomalyst and other medications for the same conditions.

Today's focus is more patient-focused about the experiences of patients and what their lives are like. If you have more policy-related discussions, or if you want to share input on other topics related to the Drug Negotiation Program, we have a mailbox that you can send comments to, that is, and you don't have to remember this because I'll show you a slide later, but it's IRARebateAndNegotiation@cms.hhs.gov. Again, today is mostly focused on the patient experiences.

The information shared during the events will help CMS understand patient experiences with the conditions and diseases treated by Pomalyst, patient experiences with the selected drugs themselves, and patients' experiences with other drugs used to treat the same conditions as Pomalyst.

CMS may use this information in negotiating Medicare, pricing with the manufacturers of selected drugs. Your experiences and perspectives are very important to us, and we genuinely appreciate your time today.

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

CMS Remarks

00:02:27

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

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

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

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

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

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

00:04:03

Moderator, RTI International

I also want to make you aware that staff from CMS will be sitting in to this event, so they can hear from your experiences and opinions directly from you. Let me hand it over to **[CMS STAFF]** for a moment so they can speak. Hey, **[CMS STAFF]**.

00:04:17

CMS Staff

Hi, **[MODERATOR]**, thank you. I want to welcome everyone on behalf of CMS. On the call today, we have staff from the Medicare Drug Price Negotiation Group, which manages the Negotiation Program. We want to thank you for participating, and we're looking forward to hearing about your experiences during this roundtable discussion. We're going to go off camera now, so you can focus on the discussion. But we will be here in the background and listening to the conversation. Thanks.

Housekeeping

00:04:43

Moderator, RTI International

Great. Thank you, **[CMS STAFF]**. Before we begin, I want to go over a couple of housekeeping items and ground rules so that everyone knows what to expect today. First, for participation, we hope that you all will contribute your perspectives throughout the session. However, if a question arises that you don't want to answer, that is totally okay. Please minimize background noise and silence your cell phones. Also, mute yourself when you're not speaking.

This discussion is not open to the press or the public. We will use first names only today to protect your privacy. Please do not share any unnecessary personally identifying information or personal health information during the discussion.

We are audio and video recording today. But these transcripts will not be shared publicly. Following the event, CMS will prepare transcripts that have participant names and identifying information removed, and these will be available to the public, the transcripts as well. I also want to highlight a few things to keep in mind for discussion. Video, thanks in advance for having your video on. Please keep it on throughout our discussion. This session will last about an hour and a half.

We also have a lot to discuss, and I have a guide of questions that I want to ask you all today. It's possible I may have to move the conversation on if we're running short on time. That's not me being rude. That's me trying to get to all of our questions today in our time.

If you get disconnected, please attempt to rejoin. And, if you have trouble rejoining, there is an email address on your screen here. That's IRADAPtechsupport@telligen.com. If you get disconnected, someone at that email address can help you reconnect. If you need to take a step away briefly during discussion, that is totally okay. Just turn off your microphone and camera, and then rejoin when you're able to. You don't need to ask for permission to leave. You can leave at any time that you need to.

Please try to speak one at a time. It's possible that at times, there may be more than one person speaking at a time, and I may play traffic cop. But as much as possible, try to keep it one at a time. If you want to, you can also use the raise hand feature in Zoom, to use that, and then that will let me know that you're also ready to speak.

Finally, most importantly, your opinions and experiences will differ. And, that's totally okay. We want to know what each of you thinks and be honest about the topics we're going to discuss today.

All right, that was a lot of me talking. I want to pause for a moment and see what questions you all have before we begin.

Okay, all right. So, let's take a moment to get to know each other, and do some quick introductions, and take about 30 seconds to do a quick introduction, and let me know your first name, and then the condition or conditions that Pomalyst treats that you have experience with, that's multiple myeloma or Kaposi sarcoma.

And, then also let me know whether you're going to be sharing your personal experience with the drug or conditions, you're going to be sharing the experiences of loved one or someone, or if you're sharing the experiences as a patient advocate, and some of you may be wearing multiple hats. And, that's totally okay, too. And, let me start on my screen. I see **[Participant 1]** first. Hey, **[Participant 1]**?

Discussion

00:08:01

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

Good morning. How are you?

00:08:03

Moderator, RTI International

I'm good.

00:08:04

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

Good. I am **[Participant 1],** Cancer Support Community **[REDACTED]**. Cancer Support Community is the largest professionally led nonprofit offering 100% free psychosocial support services to both cancer patients and their loved ones. We have 196 network partner locations in about 50 markets across the U.S. Also, a couple in Canada, and some internationally, as well. I'll be speaking on behalf of patients and also their loved ones as a patient advocate.

00:08:35

Moderator, RTI International

Well, thanks, **[Participant 1]**. And then **[Participant 2]**, you're next on my screen.

00:08:42

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

Thanks. My name's **[Participant 2]** and I'm here representing the American Cancer Society Cancer Action Network. We, as an organization, advocate on behalf of cancer patients, their families and caregivers, and survivors. Not just patients, but those who have survived cancer. And, I'm here on behalf of the organization today to share the views of a subset of cancer patients. We, as an organization in advance of these meetings, did a survey of cancer patients who are on Medicare who are taking this particular drug, Pomalyst in this instance, and asked them their views, their experience, and tried to pull this information together for the purposes of these meetings, and I very much look forward to the conversation and hearing about the lived experience and the experience of others in the patient advocacy community.

00:09:40

Moderator, RTI International

Wonderful, thanks, **[Participant 2]**. And then, **[Participant 3]**, you're my final person.

00:09:45

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

Yeah. Hi, **[Participant 3]**, I'm **[REDACTED]** of Patients Rising. First, I want to say, thank you to CMS for hosting these. I've heard from others outstanding feedback about this round of roundtables compared to last year. And, I just think credit should be given where credit's due. So, I just want to call that out first. Patients Rising, we're in the business of patient empowerment. We do a lot of work on educating and helping develop people into patient advocates, whether that's in the medical system or in the halls of Congress, for example.

We focus a lot on patient storytelling, as well as what I like to say, patient-inspired health policy. We typically do not focus on disease-specific roundtables like this, since we do focus broadly on the chronic disease population. But we do have a unique relationship with the International Myeloma Foundation, where we have a customized masterclass program. And, so as a result, I've been able to interact with a lot of people in the multiple myeloma community, I have a number of their stories, and I'd like to share those stories where appropriate as the questions come up.

00:10:56

Moderator, RTI International

That'd be great. Thank you, **[Participant 3]**.

So, just so I have an understanding of peoples' perspectives today, we're going to use the chat window for a quick moment, and then this is the only question we're going to use it, and you can just put yes or no in the chat window, and that is, have you personally, or do you have a loved one who's taken Pomalyst, either currently or in the past? Again, have you or loved one taken Pomalyst, either currently or in the past?

Let's see, two no's, and then not personally. Okay. Great. Thank you, everyone. That gives me a sense. All right.

So, first before we even talk about the medications to treat multiple myeloma and also Kaposi sarcoma. I want to actually focus on the conditions themselves and how they affect patients' day-to-day lives. And, I want to first start with multiple myeloma, because I've already heard that come up in the chat. In general, how does multiple myeloma affect you, your loved ones' or patients' day-to-day lives? Again, how does multiple myeloma affect people's day-to-day lives?

00:12:11

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

Sure, I'm happy to share. So, Cancer Support Community actually has our own RTI, our Research and Training Institute. And, with that we have a longitudinal cancer experience registry. So, this is a survey both for patients and caregivers. We can follow them didactically over time.

But our cancer experience registry report in 2020 for multiple myeloma patients includes data from 442 patients and, as **[Participant 2]** noted, survivors at various stages of multiple myeloma diagnosis and recurrence.

And, so what we learned from that qualitatively and also quantitatively, long-term nature of multiple myeloma treatment can make patients feel like they have very little control over the disease. It can also lead to high levels of anxiety, depression, and fatigue. In terms of impact on quality of life, that same 2020 cancer experience registry report on multiple myeloma highlighted many concerns with day-to-day experience of the disease. And so I'll get into some of the quantitative now.

Sixty-one percent of patients were concerned about eating and nutrition, 58% of patients were concerned about mobility and physical activity, and 55% of patients were concerned about their ability to complete daily tasks or activities of daily living, such as brushing your teeth, showering, etc. In addition to that, 52% of patients were concerned about pain and discomfort, 47% of patients concerned about sleep problems, 46% of patients were concerned about cognitive difficulties, 45% of patients were concerned about financial and insurance issues, 43% of patients were concerned about uncertainty about the future. And, I'm at the last one, 42% of patients were concerned about disruption to work or home life as well.

00:14:03

Moderator, RTI International

So, **[Participant 1]**, I want to say that was interesting quantitative data. I want to talk about it more contextually. So, they mentioned, for instance, a lack of control. Can you talk a little bit more about what that means for a multiple myeloma patient?

00:14:18

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

Sure. Depending on where the patient is located geographically, depending on other sociodemographic factors affecting the patient, they recognize that this is a long-term disease. There is no cure for multiple myeloma. There are multiple treatment options, and unfortunately, a lot of effort and money can be spent on exploring these treatment options. And, when one fails, going on to another, but that causes that sense of not being able to control your outcome. You're not really sure if this next line of treatment that you've already invested in, not only in terms of money but also time, is going to work. And, so there's that increased anxiety.

I'm a clinician by background. So, having this sense of not knowing causes this anxiety, this lack of control, with your outcome, regardless of how much you're willing to explore different lines of treatment and going to multiple myeloma specialists,

00:15:22

Moderator, RTI International

Thanks, **[Participant 1]**.

So, others, how does multiple myeloma affect people's day-to-day lives?

Yeah, go ahead, **[Participant 2]**.

00:15:38

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

I think **[Participant 1]** referenced this, but I just want to point out, any cancer patient but multiple myeloma patients, maybe in particular, there's a cost factor to treatment, even if you're on Medicare. People find that there are up to thousands of dollars that they're having to spend, and I don't know about other people, but most people's bank accounts are not accounting for that kind of cost in any given year. And, multiple myeloma is one of those diseases where you could have treatment over multiple years. So, that is one thing I think we hear all the time from cancer patients is first sort of, to hear you have cancer is very upsetting, because you just don't know what that means, and it is good that we have many more treatments than we used to have. But the second thing I often hear from cancer patients is, oh, my God. Can I afford this? And, I think that is particularly true of this community. And, I think it's something that is true, not just for Medicare, but it's true for the patients as well. I just want to make that point because I don't know that people from a policy perspective consider that enough.

00:17:05

Moderator, RTI International

And then, yeah, **[Participant 3]**, go ahead.

00:17:07

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

Yeah, I think most has already been said, and I particularly agree with the costs not necessarily directly associated with the health care system, typically are not factored into value assessments. But I think one aspect that's also important to talk about, I think everybody has acknowledged getting a cancer diagnosis period is pretty devastating for most people, same speaking true for multiple myeloma. And, I think because of the symptoms people experience, what I have heard a lot from people is, when you think about daily life, it is pretty altering. Some people, it means early retirement. Other people, it may mean that you have to be a little bit more choosy, if you will, as it relates to working hours. So, there's definitely an economic impact, disregard the cost of treatment, things like that, there's an economic impact that's definitely associated with it. That treatment can help support.

And then, I think, also because of some of the fatigue, some of the pain, some of the other issues associated with it, daily activities just as simple as exercise, getting a walk can be difficult for people, which can also have additional downstream health effects.

00:18:18

Moderator, RTI International

And, **[Participant 3]**, you and **[Participant 2]** and others have touched on cost. And, I want to delve into that a little bit more. When you're talking cost, are you talking about the cost of treatment? Are there external costs, like travel or so forth, or caretakers? Tell me what kind of cost multiple myeloma patients incur.

Again, **[Participant 2]**.

00:18:45

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

Sure. There is the above and beyond cost of treatment, right? Even on Medicare, studies have shown, and including studies by the American Cancer Society Cancer Action Network, that people are spending $5 to $7,000 more to be treated for cancer. Just take that in. Some of that is treatment. Some of that is copays, I don't even know all the different things people are paying for, but recognize that.

And, then I think the other thing we didn't talk about in terms of cost, is time. I think **[Participant 3]** referenced it when he talked about the choices people have to make about their time, but also how you get treatment affects how much time you have. Like, whether you're going once a month and then taking a drug like Pomalyst on a daily basis or in a pill form as opposed to going somewhere to get treatment. That's a big issue for cancer patients and multiple myeloma patients. So, I think there are a lot of aspects to it. And, anytime you're going through a process like this, a treatment process, you also have to think about all the other things in your life that you also have to do or have to be done. And, if you're not doing them, how are you making them happen? And, there's a cost factor affiliated with that.

00:20:13

Moderator, RTI International

Yeah, **[Participant 1]**?

00:20:15

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

Thank you, **[Participant 2]**, and I just wanted to add to that, and this is based on conversations that we've had with multiple myeloma specialists across the country, something that they noted was, unlike thalidomide, which is more often used in first line myeloma treatment, Pomalyst is used in relapsed myeloma, and typically in first or second relapses. So, there is that additional distress factor that Pomalyst patients have in terms of cost. They've already spent, as **[Participant 2]** noted, a lot of time and effort, in addition to that money, with just induction and maintenance therapy only to relapse. And, now, spend more effort, time, money to stay alive.

Pomalyst is also preferred over Revlimid for myeloma patients with kidney problems. So, again, when we're talking about cost, not just the financial cost of then addressing these other symptoms and side effects, but the cost in terms of your health and in terms of your daily living.

I did also just want to highlight again, rurality plays a role here. Transportation to and from treatments, labs, etc. People living in rural and frontier areas have the additional burden when it comes to accessing treatment and maintenance on the therapy.

00:21:31

Moderator, RTI International

Yeah. **[Participant 3]**?

00:21:33

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

I was going to mention the transportation, as well. I think that's a great point. And, I think also, when you think about costs outside the system, it might be a little bit difficult to be definitive, because I think it depends a bit on your stage of life and the time of treatment. But I do think you can categorize things such as home health aids, mobility support as one category of things. Depending on your time of life, you could be dealing with certain childcare situations that would be costs outside of the health system, as an example. Again, I think the transportation is another good example. But, there's a lot of cost sometimes when you're managing a chronic illness. I don't know if home modification is a great example in this case, but that's often the case for many diseases, especially as you get older in life, that just are not being captured by the health system overall.

00:22:26

Moderator, RTI International

Okay.

Now, when it comes to multiple myeloma, whether it's Pomalyst or any other treatment that's out there, what aspects of multiple myeloma are most important to patients to be managed or treated? So, again, for multiple myeloma, what's most important to patients to be treated or managed in the treatment? And it could be things like how people feel, how long they live, their functions and daily life, like, what are the most important things for treatment?

Yeah, **[Participant 3]**?

00:23:05

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

All right, so I'll try to share a couple of my stories here. So, I think we have to start at baseline for these particular patients. And, so for them, I think that increase in quality of life for them is significant. I have several stories where I'll use one individual. This is an exact quote when you talk about quality of life, and she's talking about Pomalyst specifically.

"I think it's awesome. You can get your therapy in a pill form and just take it home, and it gets you out of a situation where you have weeks lined up, in and out of chemotherapy, and just taking a pill is just much easier."

That's a direct quote from somebody. I have several stories where people talk about, while they still may experience some symptoms of fatigue or nausea, relative to some of the other pain and some of the other muscle fatigue issues that they experience, they're able to push through in many cases. I have several stories of people who are doing, CrossFit exercises for example and things like that, that they believe they wouldn't be able to do otherwise. So, I think there's a substantial quality of life impact that probably is not fully measured in a clinical trial.

00:24:23

Moderator, RTI International

So, people are looking for increases in quality of life. Yeah, **[Participant 1]**, go ahead.

00:24:28

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

Sorry, also want to add some of the research that I referenced earlier. More than half of patients who were on Pomalyst surveyed said that the common side effects, such as the fatigue and nausea, were really problematic for them in terms of their quality of life, and how the medication impacted it, and that managing these side effects required a multimodal approach. But most patients, that we surveyed at least, did not have access to evidence-based approaches to manage this due to cost and also limited insurance coverage.

I also just wanted to note in terms of what is important to patients, they really have lauded the shared decision-making model, being able to have conversations with their doctor, with their care team about what is important to them in their lifestyle. Is the goal to make it to their daughter's high school graduation? Or is the goal to be able to run another marathon? And how that plays a role, in what medication they will be prescribed, and how to manage side effects.

I mentioned earlier that there is currently no cure for multiple myeloma. And so, our patients really do want to have multiple accessible and affordable treatment options, especially because we know with Pomalyst, as was mentioned earlier as well, this is after some other lines of therapy have failed them. This is not the first line treatment so wanting to have options and affordability is really important in terms of increasing access, and also just if side effects become unmanageable or if the treatment starts to fail them, having that reassurance, when we talk about anxiety, that there are other treatments that they can access that are potential lifesaving treatments for them, life-extending treatments for them.

00:26:18

Moderator, RTI International

We've talked about myeloma. Are there folks also who can speak from the perspective of Kaposi sarcoma today, can share patient experiences of Kaposi sarcoma?

If not, okay. I see heads shaking no. Okay, all right. So, we'll continue. Then we'll just discuss multiple myeloma for today.

So, next I want to talk about, so there's different medications that are available for treating multiple myeloma. Those have been brought up today. When considering the potential medications for multiple myeloma, what matters most to patients in these treatments? Again, when considering all the different medications that are available for multiple myeloma, what matters most to patients?

Yeah, **[Participant 2]**.

00:27:23

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

Sure, I think the framing of these questions can be a little bit challenging, for me at least. For cancer patients, I mean, first of all, everybody's a little bit different. I think what **[Participant 1]** said about being able to have that real lived conversation, right? Because it's different. Somebody does want to get to a graduation or a wedding or extend their life. But fundamentally, we're talking about people want to extend their lives, honestly, as much as possible, as long as their quality of life remains good from their perspective. I don't think you can say one thing about the experience of people with this disease, multiple myeloma. I think you have to recognize there are different people who have this, and they have different goals. And in their experience, there are some things that are the same, there's some things that are going to be different for all of them. But, in the work we've done, I think I'd say one, I think it's important to note that patients are talking to their clinician, they're talking to their doctor, and they want to be able to have a real conversation and seek the treatment that makes the most sense, for their bodies, is what I'm going to say, because I'm not a clinician. I don't understand all the science, but I know there's information inside our bodies that demonstrates how we will best respond to treatment, and that should be a conversation between a patient and their doctor.

And then, I think there are a lot of considerations. I mean, money. I mean, I get why CMS is concerned about the cost of all this care. I also get why patients are concerned by the cost of care, and that is a consideration that I think people take into account, and probably it's a difficult consideration, is I guess what I'd say.

And, I do think something that we saw a lot when we surveyed people on this, was utilization management services and the challenge of having to go through a drug that doesn't work to get to a drug that does work. And, that's just something I've raised in this context, because I can't imagine in some ways how difficult that would be to be told, well this is what your doctor says you should use, but the insurance company says you should use this, and you have to use this for a while until we know it's not working. And, you're a cancer patient. This isn't allergies. This is your life. And, we hear that a lot from cancer patients. And, I believe utilization management is on the rise because of how frequently we hear it from the lived experience of patients. So, I'm going to throw all that into the mix, because I think that's a big piece, particularly for this community.

00:30:34

Moderator, RTI International

And, one thing that, **[Participant 3]**, you may be able to answer this. But one thing I heard also that matters most to patients and treatment, I think maybe, **[Participant 3]**, you had mentioned it that patients like having a pill option as opposed to having go to an infusion clinic. That's one example, something that matters in the treatment. But **[Participant 3]**, go ahead.

00:30:54

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

Yeah. Well, **[Participant 2]** did great. I echo everything **[Participant 2]** said. But, the theme that I continue to take away, similar to what she said, is obviously extension of life, quality of life. But the other one is being able or having the feeling that you're able to contribute to your family or to your community. And I think that's an aspect that's under-recognized quite a bit. Also, I think, to **[Participant 2]**'s point, I don't know a soul who doesn't want affordable and accessible medicines. Everybody wants that. And, I do think that there's legitimate challenges. I assume we will get into some of the insurance barriers. I assume there's questions associated with that. But I mean, that's obviously a major concern for a lot of people.

00:31:45

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

Okay. Let me just throw back in. I'll put something in the chat. But I mean, the other thing we heard was about side effects. With Pomalyst, I think we can say that people do have some side effects, but it is markedly better for a lot of people than other medications they've been on. And then I think the other thing I'd say there is that, yeah, the oral treatment improves people's quality of life. If you don't have to go somewhere to get infused, it's a whole different experience, and it makes, I think, to **[Participant 1]**'s point earlier, the uncertainty, right? It gives you a little measure of control in a very uncertain world, and I think that it's hard to put a price on, but it's very important for patients.

00:32:33

Moderator, RTI International

In terms of what matters in medication, does how frequently it needs to be taken matter? Once a day versus four times a day, does that matter, or is it not an issue? What do you all think?

00:32:45

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

Honestly, I mean, I think we've already underscored the point that no group is a monolith, right? But I think it's patient-dependent. It's case-by-case dependent. Most of my conversations, if I were to do an informal survey right now, probably once a day is the easiest for patients versus having to set timers or making sure that their medication is with them, or making sure they have enough if they're going to be traveling, so on and so forth. But I don't have a definitive answer in terms of what patients would actually prefer. That's just my [inaudible].

00:33:18

Moderator, RTI International

So, we've been talking, although all different therapies are available for multiple myeloma, and I want us now to drill down and think specifically now about Pomalyst and patient experience with Pomalyst.

First, what are some of the main benefits that you've heard from patients who have taken Pomalyst, and what do they like about Pomalyst?

And, we'll talk about the drawbacks later. But first like, what are some of the benefits? **[Participant 2]**?

00:33:50

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

Yeah, I think it's some of the same things we've talked about from the flip side, which is, it manages their cancer and sometimes manages their cancer after other therapies didn't work. It has easier side effects than some of the alternatives that people have been on. And, as we talked about, the oral treatment method improves our quality of life.

00:34:17

Moderator, RTI International

Yeah, **[Participant 3]**?

00:34:18

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

So, I will say, I think convenience is definitely a factor here. Obviously, fewer treatments is typically viewed as better from patients for any particular disease, not specific to this, but I will say on the flip side, people do care about extension of life, quality of life. And, so if people have to take more than one treatment, I think they're typically willing to do that.

I think in Pomalyst's case, it is a fairly convenient treatment for patients, and I do think that that is highly valued. And, as I've mentioned before, I know you want to get into side effects a little bit later, but the sentiment I get from people is that the side effects tend to be more manageable, not non-existent, but more manageable, where they're able to kind of continue with their daily activities and daily lives, whether it's physical activities, work activities, things like that. And, those are things that are very important to patients.

00:35:25

Moderator, RTI International

Others on benefits? And also, **[Participant 3]**, I think I know what you mean, but when patients were talking about convenience, I think you mean a pill versus an infusion. But is that the only dimension of convenience?

00:35:36

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

Well, yeah. So, I would say, that's a good example. But I would also say and not necessarily been speaking in this particular space, but I think in other disease areas, there's some treatments that are once a day, and then the competitor will be twice a day. But once a day is always preferable. But you may actually get a more of a benefit from twice a day. And, so that's a value judgment that you have to make. But if all things are treated equal, I think convenience is always, yeah, but once a day is always preferred. And, yeah, pills always preferred.

00:36:08

Moderator, RTI International

Okay, so let's talk about the flip side.

What are some of the drawbacks and challenges that you've heard from patients that they have faced with Pomalyst?

Yeah, **[Participant 2]**.

00:36:29

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

I do think it has side effects. I mean, it does have side effects for patients. I think that is something we've heard, and it is also true it has fewer side effects than other medications they've taken. So, I think it's one of those things you have to balance out, but I don't think it's not to be considered. And, then the other thing we heard was around cost and utilization management that it is one of the drugs that you can't always get to directly.

00:37:06

Moderator, RTI International

So, side effects, costs. What are some of the other drawbacks that you've heard from patients specifically about Pomalyst?

00:37:21

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

Yeah, one specific example I've been given is someone says, on their third treatment of every month when the toxicity builds, they tend to feel nauseous, occasional vomiting. And, as it relates to their daily life, that's sort of something they have to carve out in their lives, and then they try to live their best life on the good days. But I think, to **[Participant 2]**'s point, most of the challenges that I hear for folks are really insurance-related barriers.

00:37:57

Moderator, RTI International

Let's kind of talk about those specific insurance barriers you've heard. Is it being on the formulary? Is it the copay? Tell me specifically what it is about insurance, **[Participant 3]**.

00:38:13

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

Well, it's formulary. It is prior authorization. It is having to go through multiple prior authorizations. So, I'll give you a couple of examples. There's a principal, who was diagnosed and was recommended Pomalyst. And her biggest challenge was facing, what she described as, the exhausting battle with her insurance company over prior authorization process, and despite her doctor's clear documentation of medical necessity, she spent weeks navigating paperwork and appeals process while her disease progressed.

I know someone who's a construction worker who also was responding well to Pomalyst. I think there was a change in an insurance company, and it required him to do the fail first for less expensive medicines, even though the doctor knew that those drugs were not going to work for him.

That's a pretty consistent theme that people spend a lot of time arguing with insurance companies. I'm not even talking about the affordability aspect at this point. I'm just talking about the ability to access the medicine.

00:39:26

Moderator, RTI International

That's helpful.

Any other parts about challenges or drawbacks of Pomalyst?

[SECONDARY MODERATOR], I think you also had a question. Go ahead, **[SECONDARY MODERATOR]**.

00:39:38

Secondary Moderator, RTI International

Thank you. Before we move on to the other question. So, it's our understanding that Pomalyst is taken in combination with other drugs, and those drugs require patients to go to the clinic. Have you heard from patients that using Pomalyst reduces those trips to the clinic? And, how does that affect their life?

00:40:08

Moderator, RTI International

Yeah, **[Participant 2]**?

00:40:09

Secondary Moderator, RTI International

Thanks, **[Participant 2]**.

00:40:10

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

Yeah, we've definitely heard that it requires less of going to the clinic. I think probably treatment differs for different people. I'm trying to find the quote from one of the patients speaking specifically to this question. And, it talks about how much better it was when they didn't have to go to the clinic as frequently. So, that's what I would say.

It's not easy being a cancer patient. There's a lot that you have to attend to. And, I think **[Participant 3]** spoke to, the issue of, you have to deal with the insurance company, and that is a whole thing, and you have to deal with all the things. So, yeah, the more we can give people access to drugs where they have some control, as I said before, I think it's really important.

00:41:10

Secondary Moderator, RTI International

That one less trip to the clinic makes a difference.

00:41:14

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

Well, it's probably not just one less, but yeah, it makes a huge difference. It's probably not just one less, but it is a huge difference.

It's not just the trip. It's that you have to figure out how to get there. Like, I'm a single woman. I live alone. Should I have something happen to me, and I can't drive myself to something like that, I have to go figure out a whole system for transportation. I happen to live in a suburban area where I could probably get a taxi or a Lyft or some kind of thing. But if you live in a rural area, that doesn't actually happen.

The lived experience of anyone with one of these diseases is different, depending on all this range of factors. But the reality is, it's one of those things that happens to you, that you have to then go figure out completely. And, you don't go to school to learn the cancer 101, like how to live with cancer. That is something that is thrusted upon you, and you have to figure it out, and it's everything from insurance to what is this disease I have? How do I live with it? What does any of this mean?

And, you're sitting there trying to read things from groups like the American Cancer Society, and you don't necessarily understand the science, and you don't necessarily understand everything you're being told. And, as you're hearing this information from your clinician, your emotions can cloud how much you can take in that information. So, just to give you some of that feel of it.

There's so many pieces involved with this, no matter what kind of patient you are, but with something like multiple myeloma, where, as **[Participant 1]** spoke to, it's not curable in that sense. So, there's treatment. But you're going to live with it. And, what does that look like, and how long are you going to live? And, all of those issues. I throw that into the mix because I think that's all an important piece of the puzzle.

00:43:14

Secondary Moderator, RTI International

And, I think what struck me is like every little thing that seems apparently easy requires significant planning.

00:43:24

Moderator, RTI International

Thanks, **[Participant 2]**. Thanks, **[SECONDARY MODERATOR]**.

We've touched on this a little bit today, but I want to dive in a little bit more about, aside from Pomalyst, what medications have you heard from patients that they've taken for multiple myeloma?

This might be a perfect question for **[Participant 1]** as a clinician. But again, what medications other than Pomalyst have people taken for multiple myeloma?

00:43:49

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

And just to clarify, not a medical doctor. Thalidomide, which is usually used in first line multiple myeloma treatment. As I mentioned earlier, Pomalyst can be first or second relapse.

And, then there's also been some note of Pomalyst for patients who are refractory to Revlimid, as well. So, those are the two most common that we've heard of. I could check in with our multiple myeloma specialists. They know much more than I do in that area. But thalidomide and Revlimid.

00:44:32

Moderator, RTI International

So, those drugs are what I'm going to call the therapeutic alternatives. So, drugs that also treat multiple myeloma. And, I want to compare, for our next part, Pomalyst versus the therapeutic alternatives and kind of compare and contrast them for a moment.

First, how do the benefits of these therapeutic alternatives differ from Pomalyst? Again, how did the benefits differ of these alternatives compared to Pomalyst? Yeah, **[Participant 2]**.

00:45:14

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

So, I'm going to pop some quotes from patients in the chat. But one reads, after Darzalex stopped working, I was put on Scarlisa and Revlimid. Revlimid made me very sick and affected my kidneys, so I switched to Empliciti and Pomalyst. Side effects have been minimal and numbers are going down. Another quote, Revlimid, a similar medication, caused a lot of GI [gastrointestinal] side effects. I was worried that Pomalyst would do the same thing, and it didn't.

00:45:43

Moderator, RTI International

Okay. So, Pomalyst had less side effects from the alternatives. So, that was the benefit of Pomalyst? Okay.

And, we can combine them. We could say, how is Pomalyst better than alternatives? And, maybe also, how Pomalyst is worse than the alternatives. We can do both together here.

00:46:03

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

I think this is a challenging question, because Pomalyst, and please anybody, correct me if I'm wrong on this one, but I believe Pomalyst tends to be a third line treatment. And, so usually you're going to Pomalyst after you can no longer get benefit from first, second line treatment. So, that's inherently a benefit to Pomalyst.

00:46:23

Moderator, RTI International

That's true.

Okay. So you all have provided a lot of helpful information so far. One thing I want to talk about is, what it would be like if there were no treatments available for multiple myeloma?

So, what would it be like for someone who has multiple myeloma if Pomalyst or other medications for this condition were not available? What would their lives be like?

00:47:01

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

So, no treatment for multiple myeloma at all is the context? I mean, shorter or with poor quality of life, shorter, depending on certain sociodemographic factors, even higher differences in mortality rates. And, I mean not good.

00:47:24

Moderator, RTI International

So would be a higher mortality rate? And more quickly, people would pass away from it.

What else? How else would it affect people if there was no treatment available for multiple myeloma?

How would they cope with it? How would they cope and manage the symptoms if there were no treatments?

00:47:59

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

So, I guess I can share a story from one of our patients who had a significant delay time to diagnosis. He was misdiagnosed for a couple of years, and maybe I guess my assumption would be then, if there were no treatments for multiple myeloma, patients would be receiving other medications that don’t necessarily treat multiple myeloma, but treat some of the symptoms inadvertently.

Yeah, they would be incorrectly dosed with other treatments.

00:48:36

Moderator, RTI International

Now, when it comes to multiple myeloma, what aspects of multiple myeloma, if any, are Pomalyst and other drugs not able to address? So, what do they not help patients with?

So, what aspects of multiple myeloma do these drugs, Pomalyst and others not address for patients?

00:49:07

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

I want to make sure I understand the question, is this singular to multiple myeloma symptoms or other symptoms and experiences that you have as a result of being multiple myeloma patients?

00:49:21

Moderator, RTI International

Great question, I would say a bit of both actually, so maybe more the latter.

00:49:26

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

Okay, if we go down that road, then we talked earlier about the emotional distress. Pomalyst is not an anxiolytic, it's not an antidepressant. And, so, while it's designed to treat some of the physical symptoms, the physical health aspects of multiple myeloma, it will not help with some of the mood disorders, and other mental illness that might arise as a result of being multiple myeloma patients.

It may exacerbate it actually, if you're having these other side effects and wondering whether you're going to need another treatment after all, or what your next step is going to be, whether you'll have to go back to the infusion center clinic, and you no longer can be on this oral route. That's just my theory.

00:50:08

Moderator, RTI International

So, can't help with the emotional part. What else can these therapies not help multiple myeloma patients with?

00:50:24

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

[Participant 1] you actually kind of tugged at a heartstring for me a little bit there. I do think the mental health aspect of illness, in general, is so underappreciated. And, it's certainly not the fault of any, well, generally speaking, it's not the fault of any drug. But yeah, there's certainly depression, anxiety, all sorts of issues, obviously, when you're facing a life and death situation that it's difficult to treat those situations, period, but I think generally, like I said, the things that I've heard. [T]hese are sort of just like the continuing things, a lot of times, pain's gone. But you still have some of the fatigue. You still have some of the muscle weakness. You have some of the nausea, things like that, but generally people feel like quality of life is better despite those side effects.

00:51:38

Moderator, RTI International

So, we're actually about to wrap up. We're getting moving pretty quickly here.

I want to talk a little bit about the importance of Pomalyst to patients. So, thinking about the topics we've discussed today, how would you summarize the importance of Pomalyst for people with multiple myeloma?

Yeah, **[Participant 2]**.

00:52:15

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

I think it's lifesaving. It is very critical to people's quality of life and their ability to live their life. When you think about what it is to be a cancer patient, I think **[Participant 1]** spoke to and **[Participant 3]** as well spoke to, how important it is to have some goals and things you're looking forward to, and I think Pomalyst enables patients to have that ability to see their future. One patient I was speaking with recently talked about hope, that this kind of drug is a hope, because it gives people the ability to look forward and think about what they can be doing.

00:53:07

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

Just to very briefly add to that, an increased sense of agency and autonomy. We talked about the importance of being able to make your own choices and decisions. So, this is another option in your toolbox or toolkit that you can choose from, and if it works for you, having also that increased flexibility to travel, to do other things that you enjoy because it is in the world.

00:53:35

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

Yeah, I mean, it's life, and that's especially for people dealing with a devastating diagnosis, that's invaluable. [H]aving time, being able to see a child graduate from college that you may have not otherwise seen is incredibly meaningful, being able to play a role in a grandchild's life is incredibly valuable to that individual, but also the grandchild itself.

And, I do think, too, I think it's important to note that oftentimes a lot of the reasons why we see the issues with utilization management has to do with the fact that a lot of times of how certain diseases, many deadly diseases, are sort of viewed from a value perspective, is that they're not doing enough to sort of restore people back to full and healthy life. And, that incentive is wrong.

The reality is that those that are the sickest, and particularly those who, from no fault of their own, are dealing with a devastating illness, are the people that should be invested in the most, in my opinion, and unfortunately, the way that some of the health economic measures work, it sort of flips that incentive. And, so, when they're setting formularies, they're trying to avoid this because from their perspective, they're not seeing the value because they're looking at it simply from systemic costs as opposed to the full value of life.

And, I think fundamentally, not to get overly philosophical, but to get overly philosophical, the fundamental challenge and why we're here is because the incentive structure is not set up to invest in people's long-term health and well-being. It is to manage costs over the short-term, calendar year by calendar year. And, that's the fundamental issue here. And, I think if we can liberate people from that calendar year dynamic, the cost equation starts to change quite a bit.

00:55:41

Moderator, RTI International

So, we've talked a lot about Pomalyst and so forth, and I wanted to see before I move on, **[SECONDARY MODERATOR]**, any other follow-up questions that you think are important to address? I put you on the spot, **[SECONDARY MODERATOR]**.

00:56:02

Secondary Moderator, RTI International

Yes, thank you. One just came up in the chat. If anyone could provide context on a patient's journey about relapse, when there's a relapse in multiple myeloma. What's that experience like?

00:56:22

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

Yeah, I have one story from a lady who was diagnosed with high-risk multiple myeloma. She received Pomalyst alongside with daratumumab, I think, and dexamethasone, and she initially responded, but she started progressing after a few cycles. And, the story here is really about that emotional toll, from having a relapse and having that hit really hard. And, I think her message was, it's really important to have more options, more points of view. And, ultimately, encouraging that effort to continuously improve, that constant kind of iteration, innovation cycle through advancements of clinical trials, so that we continue to have ongoing advances in science and innovation to help those people who, unfortunately, may be beyond the point of some of these drugs.

00:57:20

Secondary Moderator, RTI International

Thank you, **[Participant 3]**, and just wanted to kind of piggyback. Have you all heard, how many relapses are common, and how much like seeking of new treatments is necessary among the individuals you work with?

00:57:35

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

Sure, from speaking with some of our multiple myeloma specialists at high-volume institutions, high-volume institutions as in cancer centers that see a high volume of multiple myeloma patients, they said that it's not uncommon for patients to need six or more different lines of therapy throughout their lives.

And, so, yeah, the number increases. And, so again, when we talk about options and choices, Pomalyst in the toolbox, maybe for a time for some patients, short-term, long-term, but it's not uncommon to have six or more different lines of [inaudible].

00:58:15

Secondary Moderator, RTI International

And, I want to follow on. What are the challenges in getting to that right treatment, have you heard?

00:58:24

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

So, honestly, and this is more anecdotal and qualitative. But part of it can be just being able to get in to see your specialist, getting to a specialist. We know that not all multiple myeloma patients have access to a multiple myeloma specialist at a high-volume institution. The research also supports that those who can see a specialist at a high-volume institution have lower mortality rates, improved quality of life, etc.

But there's not only the logistics of getting into a specialist and getting that right treatment identified because you're at a specialist office. There's also just cost. We've talked so much about cost already, but the cost of getting there, the time involved with troubleshooting and doing that differential diagnosis and figuring out what works and what doesn't work.

And, then I just want to underscore again, depending on certain factors, rurality, for example, whether you're in an urban health care desert, whether you are someone who looks like me versus someone who doesn't look like me, difficulty with accessing the right treatment, and also medical mistrust, and having your symptoms believed, and being able to identify the right treatment as a result of that. The stories I know about delays to diagnosis and delays to correct treatment often involve biases in health care and issues that have come up between the patient and the care team.

00:59:54

Moderator, RTI International

That's helpful. Thanks, **[Participant 1]**.

00:59:57

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

I don't love this term, but I'm going to use it because I hear a lot from the patient community, is "medical gaslighting" where, and, I think this goes a bit to what **[Participant 1]** was saying, I choose to assume the best intent, so, I don't think there's bad intentions, but maybe education of doctors to some extent, experience with certain diseases to some extent. But there's a lot of people that go misdiagnosed, or are told that it couldn't be this, maybe you should try this instead. There's definitely stories out there of physicians being what patients interpret as dismissive of their disease, and obviously that leads to delays, which can be very significant for people in terms of their health.

But then I think the other thing that we've hit on quite a bit is, we've had multiple examples of people who struggle to get treatment simply because their insurance company is second-guessing their physician. And, I don't think that that can be taken lightly, because fundamentally, that is the role of insurance is to help shield those people from those devastating financial impacts. And, most patients, many patients feel like the insurance companies aren't kind of holding up their end of the contract.

01:01:26

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

Just one last thing I also wanted to add. We know that the average age of a multiple myeloma patient tends to be higher. And, so when I'm also talking about biases, I'm not just talking about race and ethnicity. I'm also talking about ageism. **[Participant 3]**, you alluded so well to the fact that patients often aren't believed. And, when I say, depending on what a patient looks like, or how they present, or what their educational attainment level is, etc. All of that plays a role in not only delayed time to diagnosis, but often being able to get to the right treatment.

01:02:01

Moderator, RTI International

Can you speak more about ageism, do you mean someone younger, is not treated seriously, or tell me what you mean by ageism?

01:02:08

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

So, yeah, I mean, when we're talking about different biases in health care, like confirmation bias and others that I'll get into in another point, it just depends. Someone younger, because they are not the age of someone who typically presents with multiple myeloma, depending on their background. They may be not believed or misdiagnosed. Someone older also might be seen as malingering or attention-seeking or needing companionship or needing some sort of interaction when really they're actually complaining about symptoms that are happening because they happen to have multiple myeloma. And, the treatment that they have isn't working anymore. So, I think it can go both ways, younger or older, depending on the doctor and the care team that they're in front of. And, this isn't always right. I want to highlight that many, many doctors are doing a phenomenal job. They're aware of how to engage different patients and look for symptoms, etc. But it can play a role.

01:03:02

Moderator, RTI International

That was very helpful. Thank you.

So, those are all the questions I have for you all today. And, I want to say, I didn't mention this, but my best friend has multiple myeloma, which is one reason why I wanted to do this. I've been on a five-year, sorry, I'm getting a little teary. I've been on the five-year journey with her through this, and I knew a lot about it going in, but I learned more listening to you all. And, so I really appreciate it. And, **[Participant 1]**, she's actually in her forties, so, she's experienced a lot of ageism. And, that's why I asked that question. She's a unique patient for her age. Sorry, **[Participant 2]**.

01:03:36

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

Thanks for sharing that.

01:03:37

Moderator, RTI International

Yeah, no problem. Sorry, I'm a little teary right now, just thinking about it.

01:03:42

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

If, when you do this work, I get a little teary, and that's part of it. So, I just encourage you to lean in. We all have to, so, please lean in.

01:03:53

Moderator, RTI International

Thank you. I appreciate that.

So, we talked a lot today. Anything else that you all want to discuss, that you feel is important to share with CMS that we haven't talked about? I'm going to open the floor to you all to talk about what you feel is important to talk about.

Yeah, **[Participant 2]**?

01:04:13

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

Yeah, I just wanted to say, earlier this week, I noted that CMS put out some new guidance about looking at drug formularies. I just wanted to say how positive I thought that was. I think we've talked a lot in this panel about utilization management practices, and we've always been concerned that, we're just concerned that cancer patients have access to drugs, and looking at the formulary and making sure that drugs are available. And, they're not moved to second tier, and that there's some sort of rationalization for why, is something that we see as really critical for cancer patients. So, I just wanted to note that because I mean, it's not specific to Pomalyst. But I think it's specific to this issue. And, these issues around sort of the cost of oncology drugs. So, I wanted to note that in addition. And, **[Participant 3]** said it at the beginning. But these panels are a good opportunity to kind of plumb the information we have about the patient experience, and really appreciate the opportunity to share and hope to continue to be part of the thinking, as you guys pursue what you need to pursue in order to contain costs, but also provide treatment.

01:05:38

Moderator, RTI International

Thanks,**[Participant 2]**. Any other final thoughts? Yeah, **[Participant 1]**.

01:05:41

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

Wanted to thank you for your time and, **[MODERATOR]**, thank you for sharing as well. Underscoring a lot of what we talked about because Cancer Support Community focuses on the non-physical aspect. The psychosocial support, the mental health and well-being of patients and their loved ones, wanted to underscore that we really do need to be talking, not only about controlling costs, but care that is integrative. I think better, improving access to palliative care, having folks have the understanding that palliative care is not necessarily end-of-life care. It really is about improving your quality of life where you currently are, and of course, enhancing the social and emotional support that we offer alongside medications and treatments.

01:06:29

Moderator, RTI International

Thanks, **[Participant 1]**. Yeah, **[Participant 3]**.

01:06:31

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

Yeah, I'll wrap up and I'll say, again, like everybody, thank you for hosting these. I appreciate the questions. And, I think we're all here because we recognize not just Medicare, but the American health system in general is, it has a lot of challenges. No doubt. I will say, though, I do believe, not blindly and naively, because I think there's some faults in them, too. But I do think two aspects of the American health system that work really well is how well we're able to advance science, medicine, and technology into new treatments, which is critical for that. And, I think that maintaining that incentive structure is critical for future advances in science, medicine, technology. But the other aspect that I think works pretty well, generally speaking, is the process of developing a multi-source generic environment, which is the most effective way of lowering cost for medicines, bar none.

And, I think Pomalyst in particular, is an interesting case. Where before any negotiated price would go into effect, there should be generic competition for Pomalyst entering the market in, I believe, April next year, roughly a year from now. And, I think that that is a really important factor when thinking about this, because I understand once generic competition comes in place, you can remove the MFP [Maximum Fair Price]. But I think when once the MFP's out there, you can't pull it back in reality. I think the PBMs [Pharmacy Benefit Manager] will quickly tie to that, and you may say that that's not a big deal, because that's going to be driving costs down, but I would disagree.

Because I think one of two things, or I think I can envision two scenarios as a result of this. The first scenario is, it drives a rapid race to the bottom on price, which for these generics companies, that early stage of post-launch, that's when they're making the money, and that's when they're able to reinvest in their plants, make plans for future generics. That is the lifeblood of the generics industry. And, so I think, undermining that is a bit, it makes me a little nervous.

But on the other side, too, is, I think, when you put an MFP out there, when a generics process is taking place, you may actually see generic competitors choose not to launch, which may actually sort of keep the price of the generics kind of maybe just a little bit below the MFP for a longer than necessary period of time.

And, so I would just ask CMS to really consider that, certainly for Pomalyst, or whenever these circumstances comes, because the generics market in general and there should be my understanding is six approved generics already, we should see dramatic drops in prices next year, and certainly once the negotiations would go in effect for this particular drug in 2027. And, so I don't think that there's necessarily a strong case for a rationale for intervention at this point. I think the generic market dynamics will take care of themselves and lower the price for patients, which we all want at the end of the day.

01:10:01

Moderator, RTI International

Thanks for that, **[Participant 3]**.

Thank you all again for participating in today's group. It was very enjoyable. I loved hearing from you all. We appreciate the time you spent with us today. Your experiences and input were extremely valuable. It will help CMS' negotiations for these drugs. As I mentioned, CMS staff have been listening to roundtable, and will be able to bring your perspectives back to the team. And, **[CMS STAFF]**, I just want to see if you want to add anything else before we adjourn.

01:10:27

CMS Staff

Yes, thank you. I just want to thank you all for joining us today on behalf of CMS and my colleagues. We really appreciate you sharing your experiences and the experiences of the communities that you support. We greatly appreciate your time and your openness, and we will take the information you shared and consider it. Thank you.

01:10:51

Moderator, RTI International

Thanks, **[CMS STAFF]**. And if you have any questions following today's session, I mentioned that there will be a slide at the end with an email address. You can submit any additional questions you have to this mailbox, IRARebateAndNegotiation@cms.hhs.gov. Again, IRARebateAndNegotiation@cms.hhs.gov, with the subject line, public engagement event.

That's all I have. Thank you, everyone. You have a good rest of your day.

01:11:21

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

Thank you for your time.

=== END OF TRANSCRIPT ===

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

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

Appendix

Participant 1: Registered as a representative of a patient advocacy organization

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

Participant 2: Registered as a representative of a patient advocacy organization

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

Participant 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 healthcare provider
Yes	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