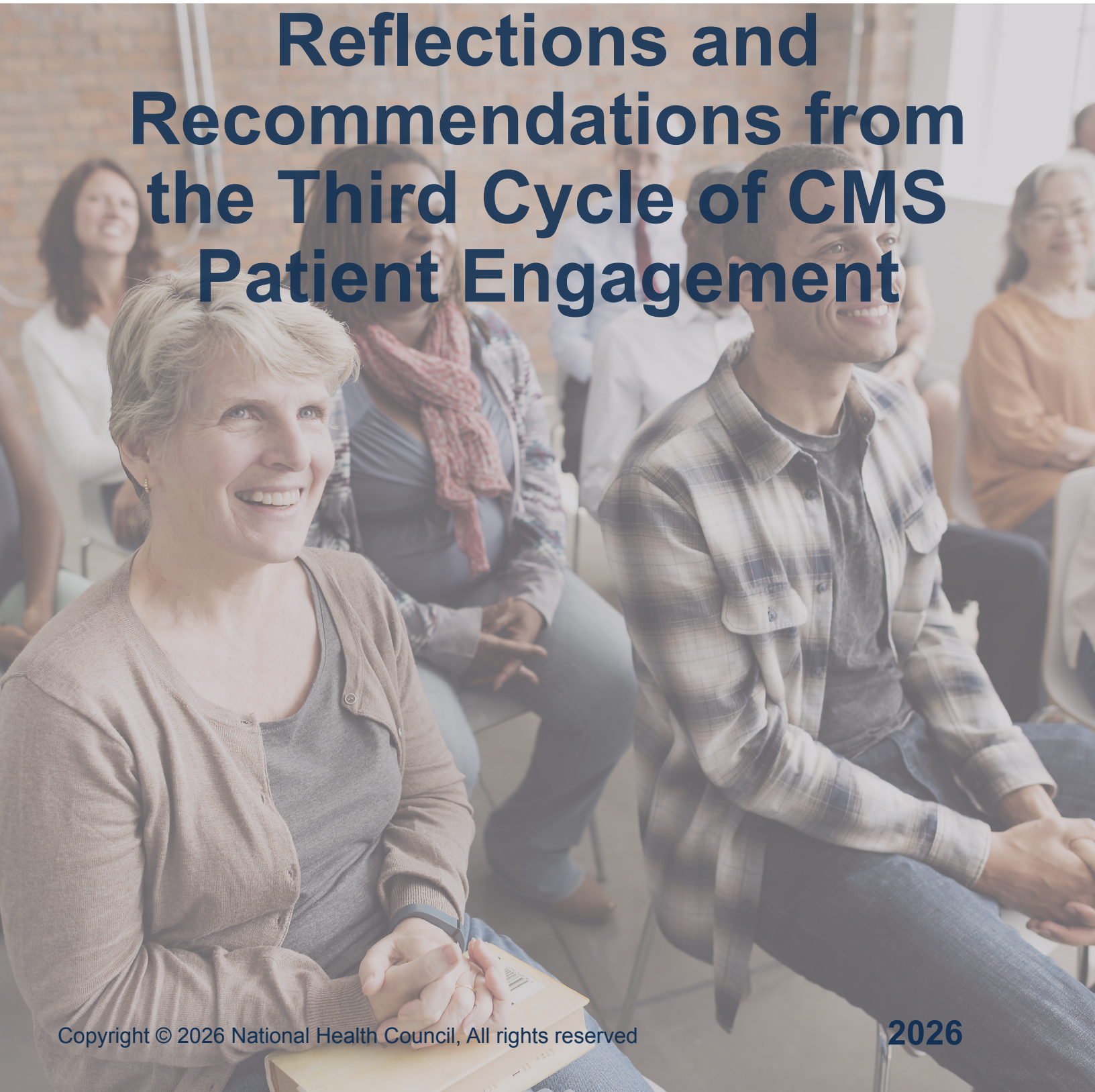
NATIONAL HEALTH COUNCIL

Amplifying the Patient Voice:

Reflections and Recommendations from the Third Cycle of CMS Patient Engagement



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2026

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Introduction

In early 2026, the Centers for Medicare and Medicaid Services (CMS) held a series of public engagement opportunities under the Medicare Drug Price Negotiation Program (MDPNP). These opportunities included patient-focused roundtables, town hall sessions for clinicians and researchers, and a written request for public input through an Information Collection Request (ICR). The Inflation Reduction Act of 2022 (IRA) established the MDPNP, which authorizes CMS to negotiate with manufacturers on the process of selected drugs covered under Medicare Part B or Part D. For this third cycle, 15 drugs were selected for negotiation, and CMS held 16 patient roundtables, one for each selected drug and one for a drug from a previous cycle selected for renegotiation. This cycle corresponds to initial price applicability year (IPAY) 2028, when the negotiated and renegotiated prices will take effect.

On July 8, 2026, the National Health Council (NHC) held a roundtable discussion with representatives from groups in patient advocacy community who participated in one or more of these CMS engagement opportunities. The aim was to review patient engagement during this third MDPNP cycle and develop recommendations for continued improvements to future cycles. This roundtable built on the reflections and recommendations gathered by the NHC after the first and second MDPNP cycles, captured in two reports: Amplifying the Patient Voice: Roundtable and Recommendations on CMS Patient Engagement and Amplifying the Patient Voice: Reflections and Recommendations from the Second Cycle of CMS Patient Engagement.

With three cycles of experience now available, the NHC and the patient community are increasingly able to assess whether the existing patient engagement opportunities are accessible, meaningful, and connected to decision making. Now that negotiated prices from the first MDPNP cycle are in effect, understanding how patient input informs the program and how implementation affects patient affordability and access will become increasingly important.

Changes in Process from Cycle 2 to Cycle 3

The public engagement process has evolved across the three MDPNP cycles, with CMS introducing more discussion-based engagement formats and revising how it selects

speakers and gathers input. Several changes made from cycle 1 to cycle 2 stemmed from the work of the NHC and our report on patient experience with the first cycle. In Final IPAY 2027 Guidance, CMS acknowledged NHC's feedback (see pg. 112) and indicated plans to make changes in response to the report and the comments made on the draft guidance, specifically the shift from livestream to private meetings and the addition of the town hall. The NHC's report on the second cycle details the changes implemented after the first cycle, which includes those identified in the first report.

The third cycle largely retained the expanded opportunities for input introduced in the second, with changes to the town hall schedule and the addition of a roundtable for a drug selected for renegotiation.

Session Format

The second cycle replaced the first cycle's livestreamed listening sessions with private, discussion-based patient roundtables. CMS retained this format in the third cycle. Also like in the second cycle, CMS held one patient-focused roundtable for each drug selected for negotiation. In the third cycle, CMS also held a roundtable for the first re-negotiated drug.

In the second cycle, CMS added a live-streamed town hall for clinicians and researchers, held in two sessions covering different selected drugs. In the third, CMS split the townhall into four sessions with a set of drugs listed for each session. In both cycles, the patient roundtables were private, while the town hall remained livestreamed. CMS published de-identified transcripts of both types of events on its website.

Participant Selection and Facilitation

In the first cycle, CMS randomly selected speakers, which was replaced in the second cycle with an "intentional process" to select speakers. CMS retained this process in the third cycle, with the goal of ensuring a diverse representation of viewpoints (see Final IPAY 2028 Guidance, pg. 101).

In the second and third cycles, CMS used a contractor rather than CMS staff to facilitate discussions. According to CMS, this approach is intended to "mitigate the risk of bias" (see Final IPAY 2028 Guidance, pg. 101).

Written Input

In all three cycles, all members of the public had the opportunity to submit written comments via the Negotiation Data Elements and Drug Price Negotiation ICR. For the third cycle, CMS stated that it had streamlined the ICR's content and question structure, including tailoring questions to patient populations (see final guidance for the third cycle (IPAY 2028), p. 102).

CMS also reiterated throughout the third cycle guidance that it welcomes input from interested parties at all times at IRARebateandNegotiation@cms.hhs.gov.

Reactions to the Third Cycle

Improvements

Participants in the NHC's roundtable brought experience from one, two, or all three MDPNP cycles. Their feedback highlighted improvements in the written ICR, roundtable registration, and interaction with CMS during the third cycle.

Several changes to the written ICR addressed concerns raised during the previous cycle. Specifically, participants welcomed clear identification of patient- or caregiver-focused questions at the beginning of the form. They also appreciated the ability to view all questions without first providing an email address or answering questions sequentially. This helped participants decide if they wanted to respond and prepare responses before submitting them. Finally, the 30-day response window, compared with two weeks in the second cycle, made gathering patient input easier, although they noted that additional time could further improve the quality of responses provided.

Participants reported easier registration for the roundtables. They also appreciated increased discussion and dialogue with CMS compared with cycle 1, and having more CMS staff on camera than in cycle 2.

The shift to four town hall sessions drew mixed reactions. Some participants appreciated the shorter sessions, noting that clinicians may have limited time to wait for their turn to speak during long sessions. However, others were concerned that clinicians wishing to comment on more than one drug might need to attend multiple sessions.

Areas for Continued Improvement

Despite these improvements, participants continued to report challenges. A recurring concern continues to be whether CMS' timelines allow enough time to gather patient input

and prepare for engagement. Most groups reported using patient surveys—both pre-existing and newly created—to gather information to inform their engagement in the process. Gathering and synthesizing patient experience data, reviewing clinical information, preparing written responses, and identifying and preparing patients and caregivers for the sessions required substantial staff time and resources.

Written Input:

Even professional advocates continue to find the written ICR confusing. Its format differs significantly from other requests for written feedback issued by the federal government, such as requests for information published in the Federal Register for which patient advocacy groups could prepare a single document and submit it though Regulations.gov.

Patient groups also reposted difficulties responding to the ICR when it is organized drug. Patient groups are often reluctant to frame their input around specific drugs, instead advocating for patients to have access to whichever drug works best for them.

Despite the longer period that the ICR was open for comments, participants still felt they had too little time to gather meaningful input from their patient communities. In addition, the ICR deadline was before the date when participants learned whether they had been selected for roundtables or town halls making it difficult to prioritize their work across these opportunities.

Roundtables:

Experiences with roundtable moderation varied. Some participants reported that their moderator seemed knowledgeable of the disease state and were able to engage in conversation with participants. Others reported the opposite: that moderators appeared to be covering a set of prescribed questions with no conversation or ability to deviate from the questions.

Communication about selection was also inconsistent. Some participants reported that they never heard back from CMS if they weren't chosen for a roundtable, while others stated that they did receive notice that they had not been selected. Some participants were disappointed that the deadline for the ICR passed before they received notice, leaving them feeling like they had no opportunity to provide input.

Differences in roundtable size added to recurring confusion about participant selection. One participant said her roundtable had only one other patient representative, even though she knew of another group that had been turned down. Others reported groups of six to eight patient representatives. Although CMS has stated in its final guidance for the third cycle (IPAY 2028) that it would use an "intentional" process to try to promote diversity

among participants—a goal supported by NHC roundtable attendees—the selection criteria remained unclear.

As in previous years, scheduling flexibility remains a concern. Participants would like more options for attending roundtables, including evenings and weekends. In its final guidance for the third cycle (IPAY 2028), CMS said it would further vary roundtable times if feasible (p. 102). However, in practice, attendees said the available options remained limited to weekday mornings and afternoons in the Eastern time zone. They felt that greater flexibility and a range of different days and times would improve the accessibility of sessions and the diversity of participants.

Another recurring concern participants shared is that they do not feel comfortable being asked to compare therapeutic alternatives. Patients who had used multiple treatments could describe their experiences, but not everyone had a basis for comparison. Participants continued to want to talk about broader experiences and barriers to accessing prescription medications, especially utilization management.

Finally, one group noted that for patients with certain conditions, it was difficult to participate in the entire roundtable without a break.

Questions of Impact

As with the previous two cycles, participants wanted a better understanding of how CMS used their input in negotiations. They appreciated that CMS publishes transcripts, but they also expressed wanting to see summaries explaining what CMS learned from patient engagement activities and how patient input informed its decisions, even at a high level. They asked for these summaries to be included in CMS' published price explanations and shared directly with participants. This feedback would help participants understand the value of their contributions.

Participants would also like more specific guidance about what information CMS is seeking to help them prepare relevant input. The NHC has supported this preparation through resources such as the IPAY 2028 Patient and Provider Toolkit, which helped patient and provider organizations engage in the MDPNP during the third cycle. Further clarity from CMS on the role of patient input in negotiations would improve the effectiveness of this preparation.

Recent research has shown the stand-alone Part D and Medicare Advantage drug plans studied are covering all 10 drugs from the first negotiation cycle in 2026, when their negotiated prices took effect. However, some patient groups are concerned about negative changes in formulary tier placement or more restrictive utilization management if, as a

result of the lower price, pharmacy benefit managers steer patients to other, higher-priced drugs.

Patient groups are not alone in these concerns. In its response to the public comments in the Final IPAY 2028 Guidance ([. 130), CMS writes that it "shares concerns that Part D sponsors may be incentivized in certain circumstances to disadvantage selected drugs by placing selected drugs on less favorable tiers compared to non-selected drugs, or by applying utilization management that is not based on medical appropriateness to steer Part D beneficiaries away from selected drugs in favor of non-selected drugs."

Further, the health research publication *Health Affairs* has launched an Eye on the IRA project. In a 2024 editorial report the author notes that, in addition to plan coverage, "access also depends on affordability, benefit design, and Part D plans' use of utilization management tools" and highlights the need to monitor formulary tier placement and utilization management.

Recommendations

Participants continued to express gratitude that opportunities for input existed, especially as these engagement sessions are not required by law. They also had recommendations for improvement.

Participation in the Sessions

Flexibility in session times. CMS should allow for flexibility in scheduling that accounts for sickness, personal responsibilities, and work that may prevent participation. Sessions should be available outside of standard business hours in the Eastern time zone. Such flexibility will promote broader and more diverse participation. Offering town hall sessions outside business hours would also help clinicians participate without conflicting with scheduled patient appointments.

Take health conditions into account. CMS should take into account the health conditions of patients participating. For example, patients with arthritis may struggle to sit for extended periods without a break, so roundtables discussing arthritis should have a break built into the session. Other examples of accessibility improvements include considering session length, breaks, disability accommodations, and caregiver needs.

Consider organizing sessions by condition. As the number of drugs being negotiated has increased, CMS may wish to consider grouping sessions by the conditions that selected drugs commonly treat. This would provide patients with an avenue to discuss their

experiences with a disease and available treatments without having to focus on a specific drug.

Improve consistency of communication. All applicants not selected for the roundtables should be informed of the decision in a timely manner and reminded that they can still provide input via email.

Improve consistency of moderators. CMS should ensure that all that each roundtable includes a moderator familiar with the relevant condition and treatments who can ask follow-up questions and engage participants in discussion. If possible, having one consistent moderator to facilitate all sessions, alongside the moderator with specialized knowledge, could help ensure a consistent approach across roundtables.

Clarity on CMS staff participating. CMS staff participating in the roundtable sessions should explain their roles beyond listing their titles and continue to be on camera if possible. Understanding who they are speaking to will help participants feel more comfortable and appreciate that they are being heard.

More directly communicate the information CMS is seeking. CMS should share clear guidance on the information it is seeking with participants promptly after registration, with enough time for them to prepare.

Consider patient experience with alternatives. Questions about therapeutic alternatives should be focused on the patient's personal experience, and patients should not be expected to function as comparative effectiveness experts. CMS should frame questions around treatment burden, side effects, quality of life, adherence, preferences, access barriers, and personal experience with alternative therapies and treatments.

Continue to work with FDA. CMS noted in its guidance that it worked with FDA to learn and build from the Patient-Focused Drug Development process. CMS should continue that collaboration to learn how FDA has improved its processes.

Written Responses

Separate information collection requests by respondent type. CMS should develop separate information collection requests for patients, clinicians, and manufacturers. Separate forms would CMS to use a more user-friendly form for patients and clinicians, while still relying on the Health Plan Management Site (HPMS) for manufacturers,

Provide more time for patient responses. If CMS separates out the written responses that are applicable to patients and clinicians, CMS should leave the patient and clinician responses open until the roundtables are over. More time for written responses would

improve the quality and breadth of information that can be collected. It would also provide those who are not selected for the roundtables with another means to participate.

Impact of the Sessions

Show impact of the input. CMS should, to the extent allowed by law, summarize the information gained in the roundtables and how it impacted the negotiation process. Even when confidentiality requirements limit what CMS can disclose, participants should receive high-level information about the themes raised, how those themes were considered, and where patient experience informed the agency's approach. CMS should also consider best practice4s in qualitative research methods, such as sharing a summary of information with roundtable participants to ensure that participants' information was accurately collected.

Share information in price justifications. CMS should include information about how patient input was incorporated into the outcome of the negotiation for each drug as part of the justifications released at the end of the negotiation. This will encourage continued involvement in future cycles.

Ensure patient priorities inform negotiation. CMS should use information gathered in the roundtables, town hall, and ICR to ensure patient priorities inform negotiation. This includes identifying the outcomes and access issues that matter most to patients and clearly articulating how these priorities are considered in the negotiation process.

Future of the MDPNP

Track outcomes. To the extent allowed by law, CMS should publish data on coverage, cost sharing, formulary placement, and utilization management so that CMS and advocates can monitor the program's effects on affordability and access, including potential steering of patients away from negotiated drugs.

Expand avenues to discuss access. Currently, MPDNP patient engagement sessions are one of the only ways that patients and advocates can interact directly with CMS. CMS should offer additional opportunities for patients and advocates to discuss broader access concerns. These opportunities could help keep MDPNP engagement focused on issues directly relevant to the program.

Conclusion

CMS has made meaningful improvements to its patient engagement process over the first three cycles of the Medicare Drug Price Negotiation Program (MDPNP), and the NHC

appreciates the agency's continued willingness to listen and respond to feedback from patients, providers, and caregivers. Participants in this year's roundtable recognized several improvements, including a more accessible written submission process, additional time to provide input, easier registration, and greater opportunities for dialogue with CMS.

As the program continues to improve, however, meaningful patient engagement must extend beyond providing opportunities to participate. Patients, providers, and caregivers should understand how their experiences and perspectives inform CMS decision making and should be able to assess whether negotiated prices ultimately translate into improved affordability and access. Closing this feedback loop will be essential to maintaining trust and encouraging continued participation.

The NHC looks forward to continuing to work with CMS and the patient community to strengthen this process and to apply lessons learned through the Medicare Drug Price Negotiation Program to patient engagement across the agency. Patients should not only have a seat at the table. Their experiences, priorities, and needs should meaningfully inform the decisions that affect their health and access to care.

Appendix A

The organizations that participated in the NHC Roundtable were:

- Alliance for Aging Research
- American Cancer Society Cancer Action Network
- American Lung Association
- Arthritis Foundation
- Association of Cancer Care Centers
- Asthma and Allergy Foundation of America
- Cancer Support Community
- Community Liver Alliance
- Eisai
- Eli Lilly & Co.
- FORCE: Facing Our Risk of Cancer Empowered
- Genentech
- HIV+Hepatitis Policy Institute
- Lupus Foundation of America
- Merck
- National Psoriasis Foundation

- Neurocrine Biosciences
- Patient-Centered Outcomes Research Institute (PCORI)
- Pfizer
- Susan G. Komen

Appendix B

Table of Evolving Public Engagement Activities

Cycle	Drug-Specific Engagement	Town Hall	Written Comments
1	One listening session for each of the 10 selected drugs for patients and clinicians	None	Through formal ICR and anytime by email
2	One roundtable for each of the 15 selected drugs for patients	Two town halls for clinicians in one day	Through formal ICR and anytime by email
3	One roundtable for each of the 15 selected drugs for patients plus one drug selected for renegotiation	Four town halls for clinicians in two days	Through formal ICR and anytime by email

Cycle 2 Town Halls

Four sessions over two days

Drug	Indication
Breo Ellipta	Asthma, Chronic obstructive pulmonary disease
Trelegy Ellipta	Asthma, Chronic obstructive pulmonary disease
Austedo; Austedo XR	Chorea in Huntington's disease, Tardive dyskinesia
Calquence	Chronic lymphocytic leukemia/small lymphocytic lymphoma, Mantle cell lymphoma

Drug	Indication
Ozempic; Rybelsus; Wegovy	Type 2 diabetes, Type 2 diabetes and cardiovascular disease, Obesity/overweight and cardiovascular disease
Janumet; Janumet XR	Type 2 diabetes
Tradjenta	Type 2 diabetes
Pomalyst	Kaposi sarcoma, Multiple myeloma

Ibrance	Breast cancer
Linzess	Chronic idiopathic constipation, irritable bowel syndrome with constipation
Ofev	Idiopathic pulmonary fibrosis
Otezla	Oral ulcers in Behçet's disease, Plaque psoriasis, Psoriatic arthritis

Xifaxan	Hepatic encephalopathy, irritable bowel syndrome with diarrhea
Xtandi	Prostate cancer
Vraylar	Bipolar I disorder, Major depressive disorder, Schizophrenia

Cycle 3 Town Halls

Four sessions over two days

Drug	**Indication**
Anoro Ellipta	Chronic obstructive pulmonary disease
Biktarvy	Human immunodeficiency virus type 1 infection
Botox; Botox Cosmetic	Chronic migraine; Overactive bladder; Spasticity; Other movement disorders
Rexulti	Major depressive disorder; Schizophrenia; Agitation associated with dementia due to Alzheimer's disease

Drug	**Indication**
Kisqali	Breast cancer
Verzenio	Breast cancer
Erleada	Prostate cancer
Lenvima	Thyroid cancer; Endometrial cancer; Liver cancer; Kidney cancer

Drug	**Indication**
Xolair	Asthma; Chronic spontaneous urticaria
Cosentyx	Plaque psoriasis; Psoriatic arthritis
Orencia	Psoriatic arthritis; Rheumatoid arthritis

Drug	**Indication**
Cimzia	Crohn's disease; Plaque psoriasis; Psoriatic arthritis; Rheumatoid arthritis
Entyvio	Crohn's disease; Ulcerative colitis
Trulicity	Type 2 diabetes; Type 2 diabetes and cardiovascular disease or multiple cardiovascular risk factors

Xeljanz; Xeljanz XR	Psoriatic arthritis; Rheumatoid arthritis; Ulcerative colitis

Tradjenta (renegotiation)	Type 2 diabetes

Appendix C

Drugs included in the Third Cycle of Negotiations

Drug name	Commonly Treated Conditions	Manufacturer
Anoro Ellipta	Chronic obstructive pulmonary disease	GlaxoSmithKline Intellectual Property Development Ltd. England
Biktarvy	Human immunodeficiency virus type 1 infection	Gilead Sciences, Inc.
Botox; Botox Cosmetic	Chronic migraine; Overactive bladder; Spasticity; Other movement disorders	AbbVie Inc.
Cimzia	Crohn's disease; Plaque psoriasis; Psoriatic arthritis; Rheumatoid arthritis	UCB, Inc.
Cosentyx	Plaque psoriasis; Psoriatic arthritis	Novartis Pharmaceuticals Corporation
Entyvio	Crohn's disease; Ulcerative colitis	Takeda Pharmaceuticals U.S.A., Inc.
Erleada	Prostate cancer	Janssen Biotech, Inc.
Kisqali	Breast cancer	Novartis Pharmaceuticals Corporation
Lenvima	Thyroid cancer; Endometrial cancer; Liver cancer; Kidney cancer	Eisai Inc.
Orencia	Psoriatic arthritis; Rheumatoid arthritis	Bristol-Myers Squibb Company
Rexulti	Major depressive disorder; Schizophrenia; Agitation associated with dementia due to Alzheimer's disease	Otsuka Pharmaceutical Company, Ltd.
Tradjenta*	Type 2 diabetes	Boehringer Ingelheim Pharmaceuticals, Inc.
Trulicity	Type 2 diabetes; Type 2 diabetes and cardiovascular	Eli Lilly and Company

	disease or multiple cardiovascular risk factors	
Verzenio	Breast cancer	Eli Lilly and Company
Xeljanz; Xeljanz XR	Psoriatic arthritis; Rheumatoid arthritis; Ulcerative colitis	PF PRISM CV
Xolair	Asthma; Chronic spontaneous urticaria	Genentech, Inc.

*Renegotiation