



ONCOLOGY STATE SOCIETIES AT ACCC

ADVOCACY ENGAGEMENT REPORT

Findings from the Oncology State Societies

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LETTER OF INTRODUCTION

Hello,

On behalf of the Oncology State Societies team at the Association of Community Cancer Centers (ACCC), I am proud to introduce the Oncology State Societies Advocacy Engagement Report. The report summarizes insights from states who participated in the Oncology State Society Policy Pilot funded by Johnson & Johnson Healthcare Systems, Inc. The Policy Pilot supported a policy communication and learning infrastructure in nine, participating states to address legislation and regulations impacting patient care, provider access, health equity, and disparities.

Each of the state societies participating in the Pilot formed a Policy Engagement Committee that served as the focal point for the initiative. Participants in the policy committees included ACCC staff, a Janssen Health Policy and Advocacy Director (HPAD), state society board leaders and members, and representatives from external advocacy organizations. The HPADs do not lobby, direct advocacy partners or third parties to influence policies, engage in promotional product discussions, or provide external consulting.

The case studies included in the report outline issues that galvanized state societies to act and document the actions taken by the Policy Committees to affect change.

The states who participated in the Policy Pilot demonstrate that when members of the healthcare community work together to address policy issues, they can affect change that improves the quality of life for all patients and those who care for them.

Sincerely,

Stephanie Van Winkle
Executive Director, Oncology State Societies
Association of Community Cancer Centers

ADVOCACY AIMED AT REDUCING HEALTH DISPARITIES IN CANCER CARE

Action on many of today's most pressing public policy issues in oncology are happening at the state and local level. Some of this is because of legislative gridlock at the federal level, although much is due to the enduring notion that healthcare—and particularly cancer care—is best regulated locally.

Although state legislative agendas vary, the desire to combat policies and practices that create or exacerbate inequities in patient care unite the cancer care community. In 2022, nine oncology state societies participated in a pilot program examining policy priorities and member engagement and communication.

The participating state societies had similar priority advocacy issues, including:

“White Bagging”

“White bagging” refers to the practice of pharmacy benefit managers (PBMs) requiring certain high-cost drugs to be shipped from specialty pharmacies directly to the cancer practices, where clinicians administer the drugs to patients.¹

For more information on white bagging, see ACCC’s resource titled, [“Principles to Preserve Provider and Patient Choice in Cancer Treatment.”](#)

“Brown Bagging”

“Brown bagging” refers to medications that are shipped directly to patients’ homes. Under this model, patients are required to bring the drug to the infusion center, clinic, or practice for administration. Alternatively, brown bagging policies might require patients to self-administer the drug or have help from a home health aide. This prac-

tice is concerning for multiple reasons including, but not limited to, needed adjustments to medication, delivery and storage of the drug, and whether the drug was properly mixed, labeled with an expiration date, and has been properly handled.²

Prior Authorization

Prior authorization is a utilization management mechanism used by health insurers that requires patients or their providers to secure pre-approval as a condition of coverage or payment for a specific medication or service. The biggest concern with such requirements—aside from the administrative burden on providers—is that they can act as a barrier to patients accessing necessary services

and treatments, potentially leading to delays in care and harm to the patient. When combined with a lack of transparency in the approval process and determinations made by personnel with limited knowledge of oncology, prior authorization requirements have become a top concern of cancer care providers and their patients.



Step Therapy

Step therapy is a managed care approach that some health insurers use to cut costs. Often referred to as “fail first,” step therapy requires that beneficiaries try lower-cost medications before insurers will allow or authorize more expensive treatments—despite recommendations from the patients’ healthcare providers. Patients with

cancer require complex treatment care plans that can change as medical and scientific advancements are made and new therapies are developed. The use of step therapy for patients with cancer creates unnecessary barriers to appropriate and timely care.

Non-Medical Switching

Non-medical switching is a strategy that health insurers use to control costs and maximize profits. It is done by requiring patients to switch from their current, effective medications to drugs that may not be as effective, for reasons unrelated to

health.³ In other words, insurers force patients to change medications for non-medical reasons, disregarding physician recommendation and patients’ individual needs.

Copay Accumulators

A copay accumulator is a strategy used by health insurers and Pharmacy Benefit Managers (PBMs) that prevents copay assistance coupons from counting towards deductibles and maximum out-of-pocket spending. As drug companies

create programs to subsidize patients’ out-of-pocket costs, health insurers require patients to pay deductibles and co-insurance up to their out-of-pocket costs, undermining the value of these programs.

Patient Steerage

Patient steerage refers to the practice employed by PBMs or health insurers that directs patients to

preferred specialty pharmacies typically owned by the PBM or health insurer.

Limited Access to Biomarker Testing

Biomarker testing evaluates a cancer patient’s unique genetic make-up to determine which targeted therapies will lead to improved survivorship and better quality of life. Targeted therapies also have fewer adverse side effects

and symptoms than chemotherapy and radiation. Biomarker tests are considered a key element of precision medicine, but may not be covered for all diseases, by all health insurers.

Keys To Successful Grassroots Advocacy

ACCC and its member Oncology State Societies identified six keys to successful grassroots advocacy.

They include:

- 1 GOALS:** Clearly defined advocacy goals vetted by the society's policy committee, communicated clearly to members, and reported upon at least annually.
- 2 LEADERSHIP:** A diverse, multidisciplinary policy committee that meets regularly to drive priorities forward.
- 3 COMMUNICATION AND EDUCATION:** Clear and consistent messaging, templates, and educational tools that support advocacy at all levels of the membership.
- 4 POLICY GUIDANCE:** The presence of at least one policy expert who can provide strategic support; can be either a hired consultant, lobbying firm, policy staff, or volunteers with relevant experience.
- 5 COLLABORATION:** Representatives from other state-based patient advocacy groups, professional associations, and/or coalitions who participate on the policy committee to help identify shared priorities.
- 6 MEMBER ENGAGEMENT:** Membership involvement in policy activities is measured and encouraged; members see their society as advocacy leaders.

ADVOCACY CASE STUDIES

The Power of Membership Engagement: A National Case Study

Goals

Communication/Education

Policy Guidance

Member Engagement

In the past two decades, PBMs have dramatically grown in scale, as has their power to direct revenue flows across much of healthcare. Their enormous purchasing power allows them to negotiate steep discounts and rebates with drug manufacturers. In theory, these savings should be passed along to patients, however a lack of transparency surrounding these negotiations, combined with practices such as white bagging,

patient steerage, copay accumulators, among others, is believed to be tied to the increasing amount of financial toxicity among patients.

Similarly, PBMs apply what is called a "spread pricing model," where health insurers are charged more for medications by the PBMs than they reimburse the pharmacy.

Early in 2022, in response to growing public pressure, the Federal Trade Commission (FTC) voted whether to investigate PBM business practices. After deadlocking in a two to two vote, the FTC did not open a formal inquiry, but did open a comment period for the public, especially

patients, physicians, employers, independent and chain pharmacies, and other affected stakeholders, to gather more information before once again voting whether to investigate.

The ACCC and its member societies quickly mobilized to demonstrate to the FTC how great the demand for a formal investigation into PBMs was nationally.

The ACCC drafted a template letter calling for review of their PBM business practices, including contract terms, spread pricing, formulary exclusions, among others.

ACCC recently implemented a **digital grassroots advocacy** tool to enable members to share their experience and provide information on patient impact. ACCC then created a multi-media campaign including email blasts and podcasts, to inform all member organizations of the tools created to help submit comments to the FTC. The member state societies followed suit by creating similar educational campaigns, encouraging individual members to use software to upload their own letters. ACCC and oncology state society members submitted comment letters, and overall, the FTC received well over 24,000 comments, resulting in their ultimate unanimous decision to open a formal investigation into PBMs.

The extraordinary number of comments also captured the bipartisan attention of Congress, prompting the introduction of the Pharmacy Benefit Manager Transparency Act of 2022. If passed, it would prohibit PBMs from engaging in a range of anticompetitive practices and would require PBMs to report to the FTC how much they earn specifically through spread pricing and pharmacy fees.

Lessons Learned:

Grassroots advocacy tools such as software and template letters that include clearly stated goals and calls-to-action can quickly engage membership when disseminated across an organized, multi-channel route of communication. This engagement has the power to create immediate change.

“In many cases, the states [not federal government] are leading on the PBM reform efforts. ACCC works with 21 different state oncology societies, and every single one of them has an eye on PBM reform at the moment... States are moving quickly on this and are having more success than at the federal level.”

Matt Devino, MPH
Director, Cancer Care Delivery and Health Policy, ACCC

STATE BY STATE

ROCKY MOUNTAIN ONCOLOGY SOCIETY

Colorado

Goals

Policy Guidance

Membership Engagement

Communication/Education

Collaboration

The Rocky Mountain Oncology Society (RMOS) created its policy committee in 2021, placing PBM reform at the top of the list for advocacy priorities. Because RMOS currently does not have the resources to hire a government affairs consultant, they instead leveraged the policy and advocacy expertise of others on their committee, including a Healthcare Policy and Advocacy Director (HPAD), and their State Government Affairs (SGA) personnel.

The Health Policy and Advocacy Director informed RMOS's policy committee of a relevant bill, the Dependable Health Care Coverage bill, making its way through the statehouse. Crafted by a broad coalition, the bill also had strong support from the state's governor. In anticipation of mobilizing a large grassroots effort to call upon legislators to support the bill, RMOS monitored the bill to see if it would advance. Instead, when RMOS evaluated the bill and realized that the robust patient protections in the bill had been stripped down, RMOS called off supporting passage of the bill entirely due to fears they would be undercutting patients with their endorsement. The committee plans to advocate for a revised version of the bill next session.

When a new state law mandated a multidisciplinary board be formed to review and regulate drug pricing within state lines, the HPAD educated RMOS policy committee members on the

novel law's potential to impact oncology patients. RMOS President Alan Miller, MD, PhD, petitioned for a chance to personally inform the board of the oncology community's concerns and how their work would directly impact cancer patients.

Lessons Learned

There is high value in forming a policy committee comprised of engaged stakeholders from multiple organizations who can guide coalition building, provide legislative updates, and spot the obstacles and opportunities that impact a society's ability to deliver on its advocacy mission. This in turn can help the society's leaders translate stated policy goals into strategic action plans, help the membership track important changes to pending or existing legislation, and identify when and where membership engagement would be most effective.

“The role of state societies taking a lead in state and federal advocacy is crucial. Practicing physicians have multiple responsibilities and may not have the resources to track and react to pending legislation that has a major impact on their ability to provide optimal treatment to their patients. By providing advocacy on behalf of their members, state societies fill an important function.”

Alan Miller, MD, PhD

President, Rocky Mountain Oncology Society

LOUISIANA ONCOLOGY SOCIETY

Louisiana

Collaboration

Communication/Education

Goals

Membership Engagement

The goal of the Louisiana Oncology Society (LOS) advocacy efforts is to better equip members to successfully advocate for accessible, affordable cancer care. In 2021, LOS signed on to a coalition of cancer patient advocacy groups in a successful bid to pass legislation banning white bagging in Louisiana, the first in the nation to do so. After the law passed, LOS sent members an email announcing the law's passage, demonstrating the power of collaborative advocacy to help patients. Based on the success of their policy efforts, LOS explored the opportunity to hire a lobbyist to help define the future direction of the Society's involvement in advocacy efforts.

Lessons Learned:

It is important to educate members about the basics of policymaking and why advocacy matters. Taking for granted that members understand the connection between advocacy and patient care can undermine progress toward decreasing disparities in care. Clearly and consistently communicating the impact of advocacy efforts also reinforces the importance of member engagement.

See more about Louisiana's work [here](#).

MISSOURI ONCOLOGY SOCIETY

Missouri

Goals

Leadership

Communication/Education

Member Engagement

Increasing access to affordable care and avoiding financial toxicity are core to Missouri Oncology Society (MOS) policy goals. To educate the membership about on the unnecessary financial barriers to care and to help focus the membership on how to become financial advocates for patients, MOS dedicated its Fall 2021 virtual meeting to financial advocacy strategies for patients with cancer. In addition, Joseph J. Muscato, MD, FACP, President, MOS, has been educating membership about PBM-adjunct vendors who deny coverage of specialty medications without documentation of a failed attempt to receive free or steeply discounted from drug manufacturers or patient assistance foundations.

Dr. Muscato suspected the companies were skirting legal and regulatory guidelines, creating financial toxicity for patients. A well-known champion of patient rights in Missouri who regularly testifies to state lawmakers on how they are directly impacting cancer care, Dr. Muscato is now spearheading a movement to stop this predatory practice.

Lessons Learned:

Having a policy leader who monitors healthcare trends that impact stated policy goals can help alert the membership and lawmakers to emerging threats to patient care. Focusing on these emerging threats with educational tools can engage membership to learn how they can

become effective patient advocates.

NEW MEXICO SOCIETY OF CLINICAL ONCOLOGY

New Mexico

Goals

Leadership

Policy Guidance

Collaboration

Communication/Education

Membership Engagement

The New Mexico Society of Clinical Oncology (NMSCO) has prioritized PBM reform in their policy efforts. However, because it is a relatively new organization, NMSCO leadership began first with educating its membership on why patient advocacy matters.

NMSCO's president, Barbara McAneny, MD, FASCO, MACP, a recent past president of the American Medical Association and a nationally recognized healthcare innovator who has hosted a webinar in collaboration with Janssen to address policy issues in New Mexico, Nevada, and Arizona. NMSCO invited the membership from The Arizona Clinical Oncology Society (TACOS) and the Nevada Oncology Society (NOS) to attend the webinars, setting a precedent for peer-to-peer networking among these states.

All three societies signed on to letters drafted by the American Society of Clinical Oncology (ASCO) to their respective state legislators in support of PBM reforms. Dr. McAneny remains in constant contact with legislators at both the state and federal level and makes regular visits to Capitol Hill in Washington, D.C.

Lessons Learned:

Established policy goals may be met by focusing on building coalitions, peer-to-peer education, meeting with lawmakers, and consistently communicating messaging about the importance of advocacy.

“All doctors start out taking care of one patient at a time. Then you realize that several of your patients are facing the same issues when they try to access care, get care paid for, and try to manage the rest of their lives. That is when you understand the impact that local state and national governments have on our patients and on our ability to care for them. When you decide that you want to do something about that, you are an advocate! Our patients are busy being sick, they need us to fix the system for them.”

Barbara L. McAneny MD, FASCO, MACP
President, New Mexico Society of Clinical Oncology

EMPIRE STATE HEMATOLOGY & ONCOLOGY SOCIETY

New York

Goals

Leadership

Policy Guidance

Collaboration

Communication/Education

Member Engagement

Led by its president, Rahul Seth, DO, Assistant Professor of Medicine at the State University of New York Upstate Medical University, a self-described “fighter” and passionate advocate for his patients, the Empire State Hematology & Oncology Society (ESHOS) has made expanding access to precision medicine testing, reforming prior authorization, and ending copay accumulators its top priorities.

In collaboration with several cancer advocacy organizations, ESHOS initiated a letter writing campaign, in-person appointments with legislators, educational presentations, and appearances of patients who publicly shared their personal stories, in support of the passage of bills that would expand access to biomarker testing in cancer care, and make all copays count toward deductibles. Both bills passed the state legislative bodies and now await the governor’s signature.

Another bill, which would exempt doctors from having to seek prior authorization for a period if they demonstrated a greater than 90 percent track record of authorization, the so-called, “gold card” bill (SB299), has stalled in committee. However, the campaign has brought attention to the high administrative burden placed on doctors by third party payers and has inspired several other state societies to attempt passage of similar legislation, including Texas, which did pass a “gold card” law.

Dr. Seth drives member engagement through regular email blasts outlining advocacy and legislative concerns. As a guest on ACCC’s CANCER-BUZZ podcast, he detailed the barriers to care PBMs and other third parties create for patients and emphasized that providers can have a dramatic impact on relieving disparities in health-care. He also urged providers to encourage their patients to speak out about their own experiences, which he said is very effective at changing hearts and minds.

Lessons Learned:

Having a vocal champion who can clearly articulate policy goals using multiple channels of communication to engage members and others can lead to big policy wins and can help create momentum for change in other states.

“The more you [advocate for patients], the more you meet people who want to help you, who want to help you fight for your cause and to change things.”

Rahul Seth, DO
Assistant Professor of Medicine,
State University of New York Upstate
Medical University

SOUTH CAROLINA ONCOLOGY SOCIETY

South Carolina

Goals

Policy Guidance

Communication/Education

Membership Engagement

After setting PBM reform as its top priority, the South Carolina Oncology Society (SCOS) policy committee studied the lessons learned by other state societies like those in Louisiana, New York, and Texas where attempts to legislate curbs on PBM abuses were succeeding. The SCOS decided to seek creative strategic policy guidance.

The SCOS hired policy consultants that suggested using the Freedom of Information Act (FOIA), to determine how widespread the effects of PBMs on pharmacies, patients, and care plan sponsors had become statewide. By filing several FOIA requests with the state insurance commissioner's office, the SCOS learned that PBMs operating in the state routinely under-reimbursed beneficiaries and plan sponsors.

The SCOS policy committee is tracking its ongoing findings for membership through regular email updates and is working on legislative proposals they will present to state lawmakers in collaboration with other patients' rights organizations, to reign in PBMs in the state.

Lessons Learned:

Clearly defined goal and expert guidance can result in novel strategies that engage members to track and expose gaps in patient protections and clarify the need for reform.

TEXAS SOCIETY OF CLINICAL ONCOLOGY

Texas

Goals

Leadership

Communication/Education

Policy Guidance

Member Engagement

Because the Texas Society of Clinical Oncology (TxSCO) has a long history of helping to pass pro-patient legislation, they are often looked to as a model for best practice in advocacy. TxSCO is highly engaged in a range of policy goals aimed at improving access to care, but chief among their priorities is eliminating third party restrictions on how doctors care for patients through prior authorization policies.

With help from their lobbying firm, TxSCO mobilized to educate state lawmakers on the harms third party payers create by demanding prior authorization for nearly every clinical treatment decision made in cancer care. The campaign was successful, resulting in a law exempting providers who have a 90 percent prior authorization approval rate on certain services over a six-month period, from having to obtain further prior authorization to provide patients with those services.

Lessons Learned:

Policy goals that are shaped by expert guidance and clearly communicated to all stakeholders, help to engage membership in educating lawmakers on the importance of legislation and managed care reform to support high-quality, affordable cancer care. This can be accomplished by regularly educating members on policy goals and how they can advocate for policy change.

“Prior authorization used to be an infrequent tool, and now it is a ubiquitous tool to manage utilization...Ultimately, they all get approved, so the fact that I have to spend 15 hours a week dealing with this is crazy.”

Debra Patt, MD, PhD, MBA, FASCO
President, *Texas Society of Clinical Oncology*

WEST VIRGINIA ONCOLOGY SOCIETY

West Virginia

Collaboration

Communication

Education

Membership Engagement

The West Virginia Oncology Society (WVOS) prioritizes medication access, medication waste, telehealth, screening, and incentive payments for survivorship as key policy priorities.

WVOS has also been monitoring SB559, or the Oral Health and Cancer Rights Act, which will require health insurers to cover medically necessary dental procedures that result from cancer treatment. The bill was introduced in the 2022 Regular Session, however the bill stalled in committee. WVOS hopes to work to move the bill forward in the next season.

WVOS also worked with Dr. Steven Blankenship, an epidemiologist with the West Virginia Department of Health and Human Services who oversees the state’s tumor registry, to understand regulations that restrict access and use of the registry for research purposes. The Society plans to invite Dr. Blankenship to speak at their next

meeting to educate members on tumor registry regulations and will explore opportunities to advocate for legislative changes to improve access in the future.

Lesson Learned:

WVOS is engaging with other coalitions who are working on similar advocacy issues, as well as continuing to highlight state policy issues through multiple modalities including the ACCCBuzz Blog. It is important for societies to share resources with organizations in the state who have similar interests and collaborate to be an active voice for change.

WISCONSIN ASSOCIATION OF HEMATOLOGY AND ONCOLOGY

Wisconsin

Goals

Communication/Education

Member Engagement

The Wisconsin Association of Hematology and Oncology (WAHO) policy committee focuses on advocating for increased regulation of PBMs and representing the voice of the cancer community in the state of Wisconsin.

With the overall goal of ensuring leadership has a multidisciplinary perspective on cancer care, WAHO regularly reports on member activity through email blasts and podcasts that share tips on what members can do to help patients, while also tracking legislation, and promoting the use of educational tools members can use in their advocacy.

This approach has helped make engaging with and educating lawmakers about PBM abuses more effective. Shared frustrations over the lack of any arbitration process in disputes with PBMs, expressed through member communication channels and members testifying to state lawmakers, has led to strong membership engagement and collaboration with other affected advocacy groups in support of the passage of a law establishing state oversight of PBMs.

Lessons Learned:

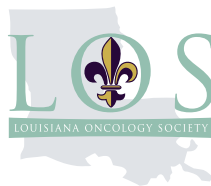
Membership engagement can sometimes come from the ground up, with members directing the policy committee to provide them with information and inspiration. Listening and then responding to all stakeholders, strengthens membership engagement, which in turn strengthens advocacy education efforts, leading to positive change on behalf of patients.

At the end of the day, I think what's good for the patient is good for healthcare."

Dean Gruber, RPh
Member-at-Large, Wisconsin Association
of Hematology and Oncology

Acknowledgment

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The Oncology State Societies at ACCC is a network of 22 State Chapters that are managed by—and collaborate with—the Association of Community Cancer Centers (ACCC) and are members of the American Society of Clinical Oncology State/Regional Affiliate Program. State Society members receive select benefits from ACCC and valuable state-specific resources to help them stay ahead of the shifting healthcare landscape and the challenges that directly impact the high-quality care their patients deserve. For more information, visit acc-cancer.org/state-societies or call 301.984.9496. Follow us on Twitter @OSSatACCC.

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