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Remote Patient Monitoring: The New Frontier in Telemedicine
Remote patient monitoring involves transmission of health data, such as vital signs, from the patient’s home to healthcare providers via a wearable device, mobile app, and/or home hub. Studies have shown promising results for this technology, including improvements in health equity and reductions in hospitalizations. This quality improvement project evaluated the Current Health platform to remotely monitor patients with cancer.

by Ksenia Gorbenko, Alaina Kessler, Mark Liu, Melanie Besculides, Carol Kisswany, Madhu Mazumdar, and Cardinale B. Smith
Cardio-Oncology: A Component of Comprehensive Cancer Care

BY SIBEL BLAU, MD

Technology advances in cancer research and treatment have converted an increasing number of cancers to chronic diseases. With the development of new treatment modalities, which are typically used in combination with other therapies, oncology providers must effectively manage an increasing number of anticipated—and unanticipated—side effects. We constantly collaborate with our colleagues, seek help from molecular and traditional tumor boards, create multidisciplinary teams, and use digital tools to learn, communicate, and perform.

Cardio-oncology is a field born of necessity. Cardioxicity, once a result of only a few drugs, is a condition that can now result from chemotherapy, radiotherapy, molecular-targeted agents, and immune-modulating agents. Though treatment focuses on eradicating the cancer, many patients develop cardiac disorders, and these can result in high morbidity and mortality.

Although oncologists have some idea of which drugs can cause cardiotoxicities, understanding these types of issues—from arrhythmias and cardiomyopathy to heart failure—is complex, and oncologists do not have the know-how to treat these conditions. From the cardiology perspective, oncology is a specialized condition and not every cardiologist has the full understanding of how to best treat these patients. Add to this complexity the fact that uninterrupted anti-cancer treatment is critically important for patient outcomes, and you can see why the interdisciplinary field of cardio-oncology is necessary.

As an oncologist at a community practice, I have historically worked with cardiologists when my patients had heart-related comorbidities or experienced cardiotoxicity. And then a cardio-oncologist came to town.

I was immediately struck by how much he knew about our drugs, the different types of heart issues patients may have, and the tests each condition required. As this cardio-oncologist developed his care team, our providers came to understand that this was more than a service to be used when patients develop problems—it was an integral part of comprehensive cancer care.

Now our providers preemptively ask for help for patients with comorbidities and anytime we use drugs that can lead to unusual or severe side effects or with several drug interactions. Our cardio-oncologist has protocols on what studies should be done and how often they need to be performed. Since the introduction of cardio-oncology in our community and practice, we now diagnose and treat heart conditions before patients even start their anti-cancer treatment. A few patients had preventive treatments prior to the initiation of their chemotherapy regimen to treat conditions that were unknown to them before their cancer diagnosis that may have helped avert serious life-threatening cardiac events.

Cardio-oncology also became a part of our survivorship program. Patients with underlying heart issues or cardiac conditions caused by anti-cancer treatments are followed by the cardi-oncology team during their cancer journey. Many times, patients are asked to change their lifestyle based on discussions with their survivorship and cardio-oncology teams. With more people surviving their cancers, we are treating their comorbidities, especially heart-related issues, not just with drugs but with rehabilitation and by resolving issues with smoking, sedentary lifestyle, alcohol consumption, poor diet, and obesity.

The field of oncology continues to evolve, and we will likely see other specialties join the cancer care team. To learn more about this interdisciplinary specialty, I encourage you to read “Best Processes for Developing a Successful Cardio-Oncology Program in a Community Hospital” on page 36.
Technology Solutions to Mitigate Workforce Shortages

BY DAVID R. PENBERTHY, MD, MBA

On Aug. 19, more than 40 ACCC members came together for the second in a series of four “Tech Talks” exploring my ACCC presidential theme, “Leveraging Technology to Transform Cancer Care Delivery and the Patient Experience.”

Discussion focused on select artificial intelligence- and business intelligence-enabled platforms in use at three ACCC member programs: Michiana Hematology Oncology, Northwest Medical Specialties, and St. Elizabeth Healthcare.

A pharmacist shortage—coupled with the costs of adding full-time equivalents to an already lean clinical team—resulted in Northwest Medical Specialties choosing the HouseRX technology platform to manage its medically integrated dispensing program. With HouseRX taking over resource-intensive tasks like prior authorizations, the benefit to staff was immediate, alleviating hours spent on the phone with payers and reducing stress and burnout. Northwest Medical Specialties also uses a care management tool, Canopy, to improve staffing and operational efficiencies. In addition to service ticketing, a centralized worklist with smart routing and filtering capabilities, the platform offers triage pathways and ePROs (electronic patient-reported outcomes). Though the practice found many benefits to an artificial intelligence-enabled technology to help identify patients at risk for burnout, Northwest Medical Specialties made the difficult decision to drop the Jvion technology to help identify patients at risk for mortality, Northwest Medical Specialties chose the HouseRX technology platform to manage its medically integrated dispensing program. With HouseRX taking over resource-intensive tasks like prior authorizations, the benefit to staff was immediate, alleviating hours spent on the phone with payers and reducing stress and burnout. Northwest Medical Specialties also uses a care management tool, Canopy, to improve staffing and operational efficiencies. In addition to service ticketing, a centralized worklist with smart routing and filtering capabilities, the platform offers triage pathways and ePROs (electronic patient-reported outcomes). Though the practice found many benefits to an artificial intelligence-enabled technology to help identify patients at risk for burnout, Northwest Medical Specialties made the difficult decision to drop the Jvion technology platform when its MEOS (monthly enhanced oncology services) payments from the Oncology Care Model ended in June.

Michiana Hematology Oncology took another approach and focused on “back of the house” technology solutions to stay operationally and fiscally sound. Outsourcing revenue cycle management to the AC3 platform helps the practice realize every dollar owed from payers. For Michiana Hematology Oncology, this technology investment increased net collections by 2 percent, reduced cost per claim by 31 percent, and increased cash collection efficiency by 22 percent. The technology continues to evolve with the addition of a retro-auditing feature that helped the practice recover $2.8 million in payer-related underpayments and missed drug-related billing.

To help mitigate its workforce shortages and improve operational efficiency, St. Elizabeth Healthcare adopted a real-time location system with color-based, way-finding technology. Every patient, staff member, and room are tagged, so the healthcare system can track cancer center activities in real time and develop an “air traffic control-like response” when issues arise. Bottlenecks are immediately visible, allowing for real-time solutions like freeing up exam room space or re-assigning staff. Faced with a shortage of front desk staff, this technology allowed the healthcare system to do away with both in-person check-ins and waiting rooms—a major patient satisfier.

Though technology tools are certainly streamlining processes and improving the patient experience, decisions about technology investments are complex—especially for cancer programs and practices operating on lean margins—so a return on investment analysis is critical. And then there’s the volatility in the technology industry. Since June 1, at least 16 digital health companies have undergone layoffs.1 But ACCC has resources to support the adoption of new technology, including ACCCeXchange, where members regularly post and describe their real-life experiences with technology-driven solutions. Such an exciting time to be in oncology! ☛

Reference

Oncology Issues 2022

A Comprehensive Oncology Program for Elders (COPE)

Establishing Best Practice Care Coordination for Breast Screening, Cancer Detection, and Diagnosis

Digital Reasoning: An Innovative Lung Nodule Program

Reimagining Healthcare for Lung Nodules

Simulate and Educate: A Nurse-Led Pilot to Enhance Patient Education and Experience

Genetic Navigation: Improving Patient Outcomes and Identification for Hereditary Cancers

Population Health Navigation: An Innovative Approach for Addressing Cancer Health Disparities

Addressing Social Determinants of Health Through a Medical-Legal Partnership

Chemotherapy Care Companion: A Remote Patient Monitoring Program

Expediting Cancer Treatment Through a Rapid Access APP-Led Diagnostic Clinic

Deploying Technology Across an Interdisciplinary Team to Improve Oral Oncolytic Compliance

Acupuncture for Cancer Patients at St. Elizabeth Cancer Center

The Expanding Role for AI in Cancer Prevention, Detection, Diagnosis, and Treatment

Integrating ePRO into Clinical Practice: The Highlands Oncology Group Experience
Hospitals

- Attracting talent: 26%
- Retaining talent: 21%
- Avoiding burnout: 15%
- Scheduling providers: 19%
- Location proximity or convenience: 19%
- Ability to work with care team of choice: 15%
- Quality of care: 15%
- Improving the patient experience: 15%
- Preventing patient adherence: 15%
- Controlling costs: 9%
- Other: 8%

More online @ accc-cancer.org

Malnutrition in Cancer Care
Kelay Trentham, registered dietitian and nutritionist, and Christie Mangir, patient advocate and breast cancer survivor, share how malnutrition affects people with cancer in different ways, even impacting their anti-cancer treatment plans. Watch the first episode in a three-part series on malnutrition in cancer care: accc-cancer.org/malnutrition-podcast.

ACCC Legislative Action Center
Engage with elected officials by customizing a pre-drafted letter that will be sent directly to members of Congress on legislative issues that ACCC members have identified as top concerns, like reducing administrative burden in step therapy protocols, encouraging prior authorization reform, permanently extending telehealth access, and ensuring equitable access to clinical trials. accc-cancer.org/LAC2022.

Remote Symptom Monitoring Using PROs
An MD Anderson study about the impact of telehealth on patient adherence with remote symptom monitoring before and during the pandemic. Watch today at: accc-cancer.org/telehealth-success-stories.

ACCC Submits Comments on CY 2023 Physician Fee Schedule Proposed Rule
The proposed rule would significantly expand Medicare beneficiary access to telehealth services and colorectal cancer screening, among other provisions relevant to oncology care providers, including changes to the Quality Payment Program. Read the ACCC comment letter here: accc-cancer.org/CY2023PFS.

Biomarker Testing Conversation Guide
Use this set of questions to guide patient-provider conversations related to biomarker testing. Type answers in a fillable PDF or print blank copies for patients to take their own notes. Access online at: accc-cancer.org/biomarker-patient-guide.

Physicians may not be as opposed to rural practice as once believed; new survey reveals 90% would consider it.


Our Unpaid Caregivers at Risk
About 20% of U.S. adults (more than 50 million people) now serve as unpaid caregivers—an increase of 10 million caregivers since 2015. A 2021 study found that COVID-19 increased mental health symptoms and suicidal thoughts of these unpaid caregivers:

- 70% of caregivers reported at least one adverse mental health symptom during the pandemic.
- 85% of “sandwich” caregivers (those caring for individuals in two age groups, for example, both children and parents) experienced adverse mental health symptoms, with 52% reporting suicidal thoughts.
- 54% of caregivers who scored as “high intensity” on the Caregiver Intensity Index seriously considered suicide in the previous 30 days.

The 411 on Locum Tenens

LocumTenens.com surveyed healthcare leaders from across the country, asking:

How long has your facility used outsourced physician staffing?
- More than 5 years: 52%
- 3 to 5 years: 25%
- Less than 3 years: 23%

What types of locum tenens clinicians does your facility use?
- Only physicians: 57%
- Both physicians and APPs: 26%
- Only APPs: 9%
- Other: 8%


Analysis of 2 million Medicare beneficiaries establishes the cost of cancer by stage and time since diagnosis for 17 common cancers. Diagnosis at a later stage is up to 7 times more expensive than diagnosis at an earlier stage, and that cost remains higher for at least 5 years after diagnosis.


Biggest Concerns for Today's Hospitals

- Attracting talent: 26%
- Retaining talent: 21%
- Avoiding burnout: 19%
- Controlling costs: 15%
- Improving the patient experience: 9%
- Scheduling providers: 9%


What Americans Are Willing to Pay More for in Healthcare

- Quality of care: 57%
- Ability to work with care team of choice: 47%
- Ability to work with hospitals of choice: 41%
- Location proximity or convenience: 41%
- Ability to get an appointment quickly: 40%


Our Unpaid Caregivers at Risk

About 20% of U.S. adults (more than 50 million people) now serve as unpaid caregivers—an increase of 10 million caregivers since 2015. A 2021 study found that COVID-19 increased mental health symptoms and suicidal thoughts of these unpaid caregivers:
- 54% of caregivers reported at least one adverse mental health symptom, with 52% of caregivers who scored as "high intensity" on the Caregiver Intensity Index seriously considered suicide in the previous 30 days.
- 85% of caregivers experience adverse mental health symptoms, with 78% of caregivers reporting suicidal thoughts.


BY MATT DEVINO, MPH

On Tuesday, Aug. 16, President Joe Biden signed the $740 billion Inflation Reduction Act of 2022 into law, delivering on several key aspects of his “Build Back Better” social and environmental agenda. Notably, the legislation includes some significant prescription drug reform and healthcare affordability provisions set to take effect over the next six years.

The sweeping budget reconciliation package was originally introduced in the House of Representatives as the Build Back Better Act (H.R. 5376) in September 2021 and passed the House on Nov. 19, 2021. Senate negotiations on a counterpart to the House-passed legislation fizzled out in December, when moderate Democratic Senator Joe Manchin (D-WV) balked at the $2.2 trillion price tag. Still, the Senate Finance Committee continued working on the prescription drug pricing reform elements of the legislation in the spring, and Manchin suggested in private meetings with the White House that he would support a slimmed-down version of the Build Back Better Act, addressing only energy and climate, prescription drug prices, tax reform, and deficit reduction.

These negotiations took a backburner (at least publicly) as Congress focused on passing other bipartisan pieces of legislation through much of its 2022 session. As the summer wore on, passage of a broad Democrat-only package seemed more and more unlikely in a 50-50 Senate. However, in a move that took many on Capitol Hill by surprise, Manchin and Senate Majority Leader Chuck Schumer (D-NY) jointly announced they had reached a deal on a budget reconciliation bill on July 27. The Inflation Reduction Act was passed by a 51 to 50 vote in the Senate on Aug. 7, and a 220 to 207 vote in the House on Aug. 12; it was signed into law on Aug. 16.

Healthcare Affordability and Prescription Drug Costs

First, on the side of health insurance affordability, the Inflation Reduction Act extends the enhanced Affordable Care Act (ACA) premium tax credits for three years through the end of 2025. The subsidies for purchasing ACA marketplace health plans were originally expanded beyond 400 percent of the federal poverty level by the American Rescue Plan Act of 2021, but they were set to expire at the end of this year. The White House estimates that the passage of the Inflation Reduction Act will allow 3 million Americans to maintain health insurance in 2023 and that Americans will save $800 per year, on average, on health insurance premiums.1 The passage of this law was especially timely, because a July analysis by the Kaiser Family Foundation found that premiums for marketplace plans are expected to rise by 10 percent in 2023, on average, on health insurance premiums.1 The passage of this law was especially timely, because a July analysis by the Kaiser Family Foundation found that premiums for marketplace plans are expected to rise by 10 percent in 2023, and these subsidies will help to shield most Americans from these significant price increases.

Another set of provisions of the law are meant to address increasing out-of-pocket drug costs by redesigning Medicare Part D, the Medicare prescription drug benefit. The law will eliminate the current 5 percent coinsurance requirement above the catastrophic threshold in 2024 and implement a $2,000 cap on out-of-pocket drug spending in 2025, with the ability to spread one’s annual out-of-pocket amount into monthly payments. This means that once a beneficiary has reached their $2,000 annual spending cap, they would have no further financial obligation for the cost of their covered prescriptions. This provision is seen as a major win for patients with cancer because the high out-of-pocket cost of prescription drugs at the pharmacy counter is often a barrier to medication adherence and the completion of treatment.

The final healthcare piece of the Inflation Reduction Act is a set of provisions that will allow the Department of Health and Human Services (HHS) to negotiate the price of prescription drugs covered by Medicare Parts B and D for the first time. Beginning in 2026, the drugs eligible for negotiation will include brand-name drugs or biologics without generic or biosimilar equivalents that are 9 or more years (small-molecule drugs) or 13 or more years (biologics) from approval by the U.S. Food and Drug Administration. For a negotiation-eligible drug, a “maximum fair price” would be negotiated between the Medicare program and drug manufacturers, impacting both patient cost sharing and provider reimbursement. The federal government can impose a financial penalty in the form of an excise tax on drug manufacturers that do not negotiate with HHS. The law also institutes a provision
requiring drug manufacturers to pay a rebate if drug prices increase faster than the rate of inflation. These inflation caps are expected to help reduce prescription drug price growth over time.

**Concerns Around Medicare Drug Price Negotiation**

Of all of the reforms included in the law, ACCC is most concerned about the impact of drug price negotiation on Medicare Part B reimbursement. Specifically, basing provider reimbursement on the proposed “maximum fair price” would negatively impact reimbursement for providers who administer oncology drugs covered under Medicare Part B. These cuts could significantly reduce beneficiary access to crucial medications and treatments and threaten the financial viability of cancer programs and practices across the country. Over the past year, ACCC has communicated this concern to congressional leadership in the form of letters and formal testimony for the record, all of which can be found at: accc-cancer.org. ACCC also had the opportunity to engage directly with Senate Finance Committee members on potential solutions that would hold providers harmless.

Ultimately, the gradual implementation of the Part D redesign and prescription drug price negotiation provisions of the law over the next six years leaves the potential for future legislative delays or alterations to this reform at the federal level prior to implementation. Advocacy efforts will remain important during this time, as ACCC and other stakeholder groups continue to educate members of Congress about the downstream impacts of drug price negotiation and prioritize continued access to high-quality, equitable cancer care for all.

**References**


**Matt Devino, MPH, is the director of Cancer Care Delivery and Health Policy at ACCC.**

**Implementation Timeline of the Inflation Reduction Act**

**2023:** Drug companies are required to provide rebates if their drug prices increase faster than the rate of inflation. The cost sharing for adult vaccines covered under Part D is eliminated.

**2024:** The 5 percent coinsurance requirement above the Part D catastrophic threshold is eliminated. Income eligibility expands for Part D Low-Income Subsidy full benefits up to 150 percent of the federal poverty level.

**2025:** Part D out-of-pocket spending is capped at $2,000 annually and other Part D benefit changes are implemented.

**2026:** HHS is required to negotiate the price for 10 Part D drugs.

**2027:** HHS is required to negotiate prices for 15 Part D drugs. (The implementation of the Trump administration Rebate Rule will be delayed to 2032.)

**2028:** Price negotiation expanded to include 15 Part D and Part B drugs.

**2029:** Price negotiation expanded to include 20 Part B and Part D drugs.
Jumping Through the Hoops of Prior Authorizations and Denials to Deliver Comprehensive Cancer Care

By Teri Bedard, BA, RT(R)(T), CPC

Comprehensive cancer care is not just a tag line, it is a mindset and practice afforded to patients with cancer no matter where or by whom they are treated. With a focus on comprehensive cancer care comes the requirement by health plans and payers to support and justify what may be viewed as costly, experimental, and outside-the-standard care. To do so, health plans and payers often require providers to “jump through hoops” like prior authorizations and potential denials of payment to show why the selected modality or regimen is necessary for the patient. The better equipped providers are about how to handle and plan for the various “hoops,” the better the chance of avoiding unnecessary treatment delays and excessive administrative burdens.

Prior Authorization Burdens

A prior authorization (also referred to as prior approval, predetermination, or precertification) is an approval from a health plan or its intermediary, such as a benefit management company, for coverage of a service before any services are administered or delivered to the patient. The word “prior authorization” invokes negative connotations for most providers. Although not all services require a prior authorization, if providers do not obtain a prior authorization for a service that requires one, the services will be denied coverage. Additionally, a prior authorization for coverage does not guarantee payment(s) will be made. The provider must still support the services provided and bill with appropriate documentation.

To highlight just how difficult and egregious the prior authorization process has become, the American Medical Association (AMA) conducted a 2021 survey (an update to a previous survey), and the results did not paint a pretty picture for health plans and providers. Survey results highlight that providers and their staff spend approximately 2 full business days (13 hours) per week completing 41 prior authorizations on average. Other data show that most providers do not have dedicated staff for prior authorizations; 41 percent indicate they do. This means the other 60 percent of prior authorizations are done by physicians or other staff, piling these tasks on top of direct patient care responsibilities and other work assignments.

Survey results show that various health plans and benefit management companies have different processes to submit and approve prior authorizations, which also impacts patient care. Of those responding to the survey, 93 percent of physicians report that care was delayed and 82 percent indicate that the resultant delays could lead to abandonment of treatment. One of the most alarming survey results: 34 percent of physicians report that prior authorizations have led to a serious adverse event for a patient in their care.

Legal Changes to Prior Authorizations

As with most aspects of healthcare, progress of regulations and reimbursement moves slowly, but the prior authorization issue is on the radar of many, including Congress. This past year, legislation was introduced at different times by both the House of Representatives and the Senate. In late July, the House of Representatives’ Ways and Means Committee unanimously voted to advance this legislation, Improving Seniors’ Timely Access to Care Act of 2022 (HR 8487). This bill would require Medicare Advantage health plans to provide real-time decisions for routinely approved services, release annual information on the number of prior authorizations approved and average response times, and meet other standards set by the Centers for Medicare & Medicaid Services related to quality and timeliness.

The push for legislation was in response to a report released by the Office of Inspector General (OIG) due to concerns with Medicare Advantage health plans inappropriately denying coverage for services to increase profits. The OIG found that from 2014 to 2016, Medicare Advantage organizations overturned 75 percent of its prior authorization denials when appealed. Approximately 216,000 denials were overturned, but only 1 percent of providers appealed denials to the first level.

Building an Offense

To help ease the burden created by the prior authorization and denial processes, providers should consider taking these actions:

- Create a health plan workbook for staff tasked with obtaining prior authorizations and appealing denials. Every payer and/or benefit management company should have their own page with links to forms, contact information, clinical and billing guidelines, and timelines for

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Building a Defense

A mentor of mine instilled the motto, “prior planning prevents poor performance;” however, there are times when being on the offense does not make a difference. Some modalities, treatment regimens, and/or health plans or payers may not require prior authorization. Some payers may give prior authorization for coverage but when billed they deny the claim or charges. This is a big problem because the services have already been provided and now time must be spent backtracking in an attempt to obtain payment. Prior planning using the steps outlined below can help providers respond to payers when payment is denied:

- **Identify an individual(s) to receive denial notifications.** Designate a backup if this individual(s) is out of office.

- **Know the deadlines for appeals and make sure that deadlines are not missed.**

- **Know if the payer has a policy or if your specialty society has information or a stance to help support medical applying and appealing denials, which are outlined and accessible.

- **Organize a clinical process workbook** created by physicians and clinical staff to outline various treatment modalities and regimens and the common codes and quantities related to each. This tool can be an interactive form or some other way to communicate what information should be applied for authorization based on the patient and planned therapy.

- **Dedicate space in the health record** where all communications and applications for prior authorization and appeal of denials are documented. Ensure that all documentation has a date, time, the individual contacted, and details of the communication.

- **Appeal all denials.** Health plans must have a process for providers to appeal prior authorization denials. Familiarize yourself with the appeals process. With the volume of denials found in previous reporting for prior authorizations, it is best to adopt the philosophy of appeal, appeal, appeal.

- **Review your state laws.** Understand what additional support you may have at the state level. The AMA has dedicated a section of its website to the 2021 Prior Authorization State Law Chart, which outlines each state’s legal requirements for health plans. This information may give the added support you need to identify what legally is expected of health plans, but information does vary greatly by state.

- **Compile a list of patient resources.** Review and update (as necessary) resources for patients when care is denied coverage. Does your organization have or provide resources to assist patients when their insurance will not cover their treatment and/or when patients cannot afford their treatment? Does your organization have a financial navigator or billing representative to review with patients their options for payment or financial responsibility? What other treatment options that are covered by the health plan would still be medically and clinically appropriate for treating the patient?

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**Table 1. Medicare Parts A and B Appeals Process**

<table>
<thead>
<tr>
<th>DESCRIPTION</th>
<th>TIMING</th>
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<tbody>
<tr>
<td>1 Redetermination by a Medicare Administrative Contractor</td>
<td>Submitted within 120 days of receipt of denial</td>
</tr>
<tr>
<td>2 Reconsideration by a qualified independent contractor</td>
<td>Submitted within 180 days of receipt of notice of redetermination</td>
</tr>
<tr>
<td>3 Disposition of Office of Medicare Hearings and Appeals (OMHA)</td>
<td>Filed within 60 days of receipt of reconsideration letter</td>
</tr>
<tr>
<td>4 Review by the Medicare Appeals Council</td>
<td>Filed within 60 calendar days of OMHA decision</td>
</tr>
<tr>
<td>5 Judicial review in U.S. District Court</td>
<td>Filed within 60 days of Council’s decision or after Council decision time frame expires</td>
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Table 1. Medicare Parts A and B Appeals Process

1. **Redetermination by a Medicare Administrative Contractor**
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   - Submission: within 180 days of receipt of notice of redetermination
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   - Submission: within 60 days of receipt of reconsideration letter
4. **Review by the Medicare Appeals Council**
   - Submission: within 60 calendar days of OMHA decision
5. **Judicial review in U.S. District Court**
   - Submission: within 60 days of Council’s decision or after Council decision time frame expires
necessity documentation for a patient’s denied treatment. Providing this information, along with any studies or other information supporting the selected modality, can assist in the appeals process.

- **Identify an individual(s) to collect this documentation and ensure they know what this information looks like or where to find it.** The biggest reason denials are not overturned is because incorrect documentation is submitted for appeal. Not all documentation is a narrative note; most documentation for radiation oncology services is not a narrative. Ensure that staff who are dealing with denials and appeals know who to reach out to and/or where to find documentation.

- **Annotate documents.** Sometimes it helps to annotate PDFs that will be sent to payers. Highlight and use arrows or other annotations to identify and point out supporting components or statements for the treatment.

- **Provide adequate documentation.** Typically, the procedure note or specific document for the code is not enough. Providing documentation on the patient’s initial or most recent visit, treatment order(s), and other information to tell the story of the patient will assist in the appeals process.

- **Know the appeals process.** Medicare has five levels of appeals (Table 1, page 9). Providers should use all of them as needed. Providers can learn about the Medicare Parts A and B appeals process through MedLearn Matters. Medicare also has a website section for patients who need help filing an appeal. Do not stop at the first level of appeal if treatment is denied. Use the other levels if you have the support and medical necessity documented for the regimen or treatment course.

- **Remember that arguing for change starts at the patient level.** You may not be successful in getting a policy changed, but you may be successful for an individual patient. Start there and the potential for a bigger change is more likely.

Continuous reimbursement cuts and restrictive and burdensome payer provisions against comprehensive cancer care are challenging for providers. Having processes in place may not guarantee 100 percent success, but they create a game plan that can help decrease the stress and uncertainty of the overall prior authorization and denials process. Healthcare technology is always evolving—unlike the regulatory aspect. Teri Bedard, BA, RT(R)(T), CPC, is executive director, Client & Corporate Resources at Revenue Cycle Coding Strategies in Des Moines, Iowa.

**References**


Recognizing the burden prior authorizations pose to its provider membership, ACCC developed a Prior Authorization Clinic to address key issues surrounding prior authorizations, to streamline efficiencies, and to minimize access challenges and treatment delays. As part of this education project, ACCC held three focus groups in August and September 2022 to:

- Better understand the administrative burden of prior authorization processes by sharing best practices
- Address key areas of prior authorization, including new technologies or areas where there are high errors in billing and coding resulting high denials
- Provide examples of standardized criteria for ordering and prescribing services that align with evidence-based guidelines
- Gather case-based prior authorization scenarios that cancer programs and practices can use to advocate for change, locally and nationally
- Discover successful methods and processes to track prior authorizations.

Learn more and read recommendations and key takeaways at: accc-cancer.org/projects/prior-authorization-clinic/overview.
Geriatric Oncology Gap Assessment
Assess your program’s performance against validated measures and best practices related to older adult care.

Nine domains offer four levels to help identify current practices of care. A personalized report provides a score and recommendations for improvement.

How-To Guide
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Online Resource Library
Explore validated assessment tools, offering solutions in all care delivery settings.

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- Functional Status
- Nutrition
- Pharmacy/Medication Management
- Psychological Health

COGNITION
How does your program assess cognitive function?

- LEVEL 1: Not sure/not performing.
- LEVEL 2: Ask simple questions of the patient or caregiver during the interview.
- LEVEL 3: Perform a validated screening tool that includes one of the following: Mini Cog, clock drawing test, 3-item recall.
- LEVEL 4: Perform one of the following validated screening tools: BOMC, MOCA, or MMSE.

ACCC-CANCER.ORG/GERIATRIC

In partnership with:

The Association of Community Cancer Centers (ACCC) is the leading education and advocacy organization for the cancer care community. Founded in 1974, ACCC is a powerful network of 28,000 multidisciplinary practitioners from 2,100 hospitals and practices nationwide. As advances in cancer screening and diagnosis, treatment options, and care delivery models continue to evolve—so has ACCC—adapting its resources to meet the changing needs of the entire oncology care team. For more information, visit accc-cancer.org or call 301.984.9496. Follow us on Facebook, Twitter, and LinkedIn; read our blog, ACCCBuzz; and tune in to our podcast, CANCER BUZZ.

Thank you to Pfizer Oncology for their collaboration and support in developing these resources.
Northwest Montana is home to one of the fastest growing “small towns” in the state—Kalispell. Within the borders of this mountainous city sits Logan Health, Logan Health Cancer Program. Though healthcare delivery is complex in any setting, this cancer program must meet the needs of a continuous influx of new patients. Montana’s unique population density is another hurdle Logan Health Cancer Program must navigate. The state has approximately 1.2 million inhabitants across 147,040 square miles—making it the fourth largest landmass in the United States. Therefore, developing a dynamic cancer program to deliver high-quality care to a diverse and rural population is vital.

For the last 13 years, Melissa Kaptanian, MD, FACS, has been a breast surgical oncologist at Logan Health Cancer Program. While describing its patient population, Dr. Kaptanian said, “We have a very diverse rural population, so we are really trying to focus on taking healthcare to people.” The cancer program embodies the American small-town spirit to meet patient’s needs. “It is kind of wonderful small-town America. It is listening, deep roots, and meeting people where they are at,” she explained. “That is how we try to do things.”

Logan Health added its cancer service line in 2020, with Dr. Kaptanian serving as its physician executive. The service line brings together medical and radiation oncology, palliative care, research, genetics, and a breast center. Implementation has helped streamline the health system’s strategic planning and budgeting, as well as unify patients’ experience during their cancer journey. Dr. Kaptanian wagers that care delivery and the patient experience are optimized when there is open and effective communication between all service providers. “It has only been two years,” she said, “but I do not think we would have actually survived COVID-19 without being able to focus on patients’ journey throughout the health system in the way the cancer service line has allowed us to.” Logan Health Cancer Program is accredited by the Commission on Cancer and National Accreditation Program for Breast Centers.

Multidisciplinary Care in Rural America
Logan Health Cancer Program has small offices closely located to each other on one medical campus. There is a dedicated infusion suite for hematology/oncology treatments that is located near its hematology/oncology offices. It also has an infusion suite for patients to receive non-oncology/hematology treatments in its main hospital—Logan Health Medical Center. This infusion suite serves as an overflow area for hematology/oncology on weekends, during holidays, and in the evenings. Medical oncology is co-located with palliative care and pediatric oncology in one office. Radiation oncology is just across the street, where patients receive treatment from two Varian TrueBeam® 5423s, which operate virtually nonstop throughout the day. Lastly, the breast center, which neighbors a mammography center and surgery suite, is adjacent to the main hospital that houses its main surgery suite.

Oncology infusions are provided to patients at Logan Health Medical Center, as well as in two other partner hospitals—Cabinet Peaks Medical Center in Libby and St. Luke Community Healthcare in Ronan, Mont. These hospitals administer patients their chemotherapy treatments in conjunction with Logan Health physicians to meet patients where they are at. “Both of these programs are an hour away from us,” Dr. Kaptanian said. “It has been exciting for me to watch our cancer program expand and tell people that they do not have to drive an hour away for their treatment.”
navigation program. “In a bid to improve patients’ access to healthcare, the cancer program launched a mobile mammography unit. “We put a mammographer, sonography technologist, and DEXA [bone density] scanning onto a mobile coach and go to small towns,” Dr. Kaptanian explained. “Women in those towns can have their scans come to them, instead of patients coming to us.” This practice has had positive effects on the cancer program’s early detection rate and patient satisfaction. “When a patient’s needs are conveniently met, it helps them understand that Logan Health is here for them,” Dr. Kaptanian said. “It keeps patients in our system, so we can take care of them from diagnosis to survivorship.”

For patients traveling longer distances to reach the cancer program, a network of oncology and non-oncology nurse navigators works together to ensure that each patient visit is maximized. “We want to make sure that these patients have multiple specialists and tests on the same day,” Dr. Kaptanian said. This focus on patient-centered care and a dedication to being sociologically imaginative has served the cancer program well, especially when delivering care to distinctive segments of its diverse patient population.

Alternative Medicine in Cancer Care
The Pacific Northwest is also a unique area of the country when looking at healthcare philosophy. “Patients here have a different take on traditional medicine sometimes,” Dr Kaptanian said, adding that patients “seem to be more interested in herbal medicine, naturopathy, and homeopathy.” Due to the prevalence of this worldview in the community, coupled with the possibility of patients seeking alternative medicine providers without informing their care team, a naturopathic oncologist was hired. “Dr. Lynn Troy has been working with us for some years, and she sees patients who have questions about herbalism, homeopathy, or alternative medicine,” Dr. Kaptanian said. “I think it is the most innovative thing we do.”

The cancer program also offers massage, acupuncture, and guided imagery services to patients to support them in their cancer journey. In recognition of the importance of mental health in a patients’ life, an increased emphasis has been placed in providing mental healthcare to patients.

Fueled by the ethos of small-town America, patient relationships are an important part of Logan Health Cancer Program’s mission. “Every provider in the program will always speak up for their patients,” Dr. Kaptanian said. “We are big enough to have the things you need and small enough to care.”

Reference
**Approved Drugs**

- On Sept. 16, the U.S. Food and Drug Administration (FDA) approved Aponvive™ (aprepitant) (heron Therapeutics, herontx.com) for the prevention of postoperative nausea and vomiting in adults.

- On Aug. 11, the FDA granted accelerated approval to Enheru™ (fam-trastuzumab deruxtecan-nxki) (Daiichi Sankyo, Inc., daiichisankyo.com) for adult patients with unresectable or metastatic non-small cell lung cancer (NSCLC) whose tumors have activating human epidermal growth factor receptor 2 (HER2) mutations, as detected by an FDA-approved test, and who have received a prior systemic therapy.

- On Aug. 24, the FDA approved Imbruvica® (ibrutinib) (Pharmacyclics LLC, pharmacyclics.com) for pediatric patients one year and older with chronic graft-versus-host disease after failure of one or more lines of systemic therapy.

- On Sept. 2, the FDA approved Imfinzi® (durvalumab) (AstraZeneca, astrazeneca.com) in combination with gemcitabine and cisplatin for adult patients with locally advanced or metastatic biliary tract cancer.

- On Sept. 30, the FDA granted accelerated approval to Lygobri® (futibatinib) (Taiho Oncology, Inc., taihooncology.com) for adult patients with previously treated, unresectable, locally advanced, or metastatic intrahepatic cholangiocarcinoma harboring fibroblast growth factor receptor 2 gene fusions or other rearrangements.

- On Aug. 26, the FDA approved Pemazyre® (pemigatinib) (Incyte Corporation, incyte.com) for adults with relapsed or refractory myeloid/lymphoid neoplasms with fibroblast growth factor receptor 1 rearrangement.

- On Sept. 21, the FDA granted accelerated approval to Retevmo® (selpercatinib) (Eli Lilly and Company, lilly.com) for adult patients with locally advanced or metastatic solid tumors with a rearranged during transfection gene fusion who have progressed on or following prior systemic treatment or who have no satisfactory alternative treatment options. The FDA also approved Retevmo for adult patients with locally advanced or metastatic NSCLC with a rearranged during transfection gene fusion, as detected by an FDA-approved test.

- On Sept. 9, the FDA approved Rolvedon™ (eflaprostagastin-xnst) (Spectrum Pharmaceuticals, sppirx.com/index.html) to decrease the incidence of infection, as manifested by febrile neutropenia, in adult patients with non-myeloid malignancies receiving myelosuppressive anti-cancer drugs associated with clinically significant incidence of febrile neutropenia.

- On Sept. 6, the FDA approved Stimufend® (pegfilgrastim-fpgk) (Fresenius Kabi, fresenius-kabi.com), a biosimilar of Neulasta® (pegfilgrastim) (Amgen, amgen.com), which is indicated to decrease the incidence of infection, as manifested by febrile neutropenia, in patients with non-myeloid malignancies receiving myelosuppressive anti-cancer drugs associated with a clinically significant incidence of febrile neutropenia.

- On Aug. 10, the FDA approved Tabrecta® (capmatinib) (Novartis Pharmaceutical Corporation, novartis.com) for adult patients with metastatic NSCLC whose tumors have a mutation leading to mesenchymal epithelial transition exon 14 skipping, as detected by an FDA-approved test.

- On Sept. 28, the FDA approved Vegzelma® (bevacizumab-adcd), a biosimilar to Avastin® (bevacizumab) (Genentech, gene.com), for the treatment of metastatic colorectal cancer; recurrent or metastatic non-squamous NSCLC; recurrent glioblastoma; metastatic renal cell carcinoma; persistent, recurrent, or metastatic cervical cancer; and epithelial ovarian, fallopian tube, or primary peritoneal cancer.

**Drugs in the News**

- Clovis Oncology, Inc. (clovisoncology.com) announced the submission of a supplemental new drug application to the FDA for approval of Rubraca® (rucaparib) as a first-line maintenance treatment for women with advanced ovarian cancer regardless of biomarker status who have responded to first-line platinum-based chemotherapy.

- Seagen (seagen.com) announced that the FDA accepted for priority review the supplemental new drug application seeking accelerated approval for Tukysa® (tucatinib) in combination with trastuzumab for adult patients with HER2+ colorectal cancer who have received at least one prior treatment regimen for unresectable or metastatic disease.

- GlaxoSmithKline (gsk.com) announced that it is planning to voluntarily withdraw the indication of Zejula® (niraparib) for the treatment of adult patients with advanced ovarian, fallopian tube, or primary peritoneal cancer who have been treated with three or more prior chemotherapy regimens and whose cancer is associated with homologous recombination deficiency+ status.
Improving Patient Communication Using the Ask Me 3® Tool

Ask Me3® encourages patients to ask 3 simple questions each time they talk to their care team. ACCC has created a video to demonstrate how the cancer care team can most effectively use this tool with patients.

Watch the ACCC Video!

1. What is my main problem?
2. What do I need to do?
3. Why is it important for me to do this?

Visit accc-cancer.org/ask-me-3-tool to view this video

In partnership with:

The Association of Community Cancer Centers (ACCC) is the leading education and advocacy organization for the cancer care community. Founded in 1974, ACCC is a powerful network of 25,000 multidisciplinary practitioners from 2,100 cancer programs and practices nationwide. As advances in cancer screening and diagnosis, treatment options, and care delivery models continue to evolve—so has ACCC—adapting its resources to meet the changing needs of the entire oncology care team. For additional strategies to improve patient-provider communication, please visit accc-cancer.org/health-literacy.

Funding and support provided by Lilly Oncology.
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Remote Patient Monitoring: The New Frontier in Telemedicine

Opportunities for improving health equity in cancer care
Remote Patient Monitoring: The New Frontier in Telemedicine

Opportunities for improving health equity in cancer care and patients may report feeling unprepared to recognize treatment-related side effects.9,10 The use of telemedicine, specifically remote home monitoring of vital signs, may lead to early recognition of worrisome conditions, such as sepsis, and ultimately lead to earlier intervention and improved patient outcomes.

Patients of historically underrepresented groups with hematological malignancies are particularly disadvantaged, because they have higher rates of morbidity and mortality compared to their White counterparts.11 Social determinants of health, such as access to quality care, likely explain much of this variation.12 Telemedicine has the potential to enhance the quality of cancer care delivery by improving access to care and early intervention, but there are also concerns that it may exacerbate existing disparities. There is a critical need to define best practices in the implementation of telemedicine to ensure equitable access for all patients with cancer. In this article, we describe early insights from implementing a remote patient monitoring platform at The Mount Sinai Hospital in New York City.

Implementation research in remote patient monitoring must examine effects on disparities in cancer care and identify modifications to reduce these disparities.

Telemedicine and Health Equity

About 1.3 million people in the United States are living with hematological malignancies, namely multiple myeloma, lymphoma, and leukemia.6 Patients with hematological malignancies and those undergoing bone marrow transplant have higher hospitalization and mortality rates compared to patients with solid tumors.7,8 Patients with hematological malignancies are often admitted to the hospital due to acute clinical deterioration, and patients may report feeling unprepared to recognize treatment-related side effects.9,10 The use of telemedicine, specifically remote home monitoring of vital signs, may lead to early recognition of worrisome conditions, such as sepsis, and ultimately lead to earlier intervention and improved patient outcomes.

Patients of historically underrepresented groups with hematological malignancies are particularly disadvantaged, because they have higher rates of morbidity and mortality compared to their White counterparts.11 Social determinants of health, such as access to quality care, likely explain much of this variation.12 Telemedicine has the potential to enhance the quality of cancer care delivery by improving access to care and early intervention, but there are also concerns that it may exacerbate existing disparities. There is a critical need to define best practices in the implementation of telemedicine to ensure equitable access for all patients with cancer. In this article, we describe early insights from implementing a remote patient monitoring platform at The Mount Sinai Hospital in New York City.
Remote Patient Monitoring: The New Frontier of Telemedicine

A particular type of telemedicine, remote patient monitoring, represents the next frontier in technological innovation in virtual longitudinal patient care. Remote patient monitoring involves the transmission of health data, such as vital signs, from patients’ homes to healthcare providers via wearable devices, a mobile app, and/or home hub (where the cancer care team can see inputted patient data and track trends). Studies have shown promising results for remote patient monitoring, with a recent meta-analysis demonstrating a reduction in hospitalizations. However, most of these studies neither included patients with cancer nor evaluated the implementation of remote patient monitoring among vulnerable patient populations, and widespread implementation of this technology has been limited. A recent prospective observational study showed the benefits of an interdisciplinary remote patient monitoring program for patients with cancer diagnosed with COVID-19. Remote patient monitoring was associated with a 78% relative risk reduction in hospital admissions. As such, the expansion of telemedicine utilizing remote patient monitoring is promising for patients with hematological malignancies who are at an increased risk of hospitalization.

A Remote Patient Monitoring Quality Improvement Project

In 2021, our team implemented a quality improvement project to develop and evaluate the feasibility of using the Current Health remote patient monitoring platform among patients with cancer. We selected this platform because it includes a hub for establishing an internet connection, making it possible for patients without a Wi-Fi-enabled device or internet in their home to connect with their medical team. This platform is also available in many languages.

To establish initial feasibility and create appropriate workflows, our team conducted weekly meetings with the disease groups, one disease group at a time, over the course of several months. In these meetings, we discussed potential challenges and necessary changes to the workflows of our inpatient oncology teams, enrolling 258 total cancer center users to date into the platform, including physicians, nurse practitioners, physician assistants, and nurses. We established a centralized team of advanced practice providers and nurses who provide care in our Oncology Care Unit, a 24/7 urgent care unit in our cancer center. The meetings also included developing workflows and training Oncology Care Unit staff on appropriate steps if patients have an alert on their remote patient monitoring device and similarly established protocols for escalation of abnormal vitals to patients’ primary oncology teams. Furthermore, we worked with the hospital information technology team to integrate the program with our electronic health record to ensure immediate data availability for clinical decision-making.

Over the course of one year, we enrolled more than 26 patients with hematological malignancies, including 27% Black and 8% Hispanic patients. Some patients reported enjoying the devices, with a few patients using them for longer than three months. Other patients declined to participate after initial consent because using multiple devices felt too overwhelming for them.

A Remote Patient Monitoring Quality Improvement Project

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potential to mitigate healthcare disparities among patients with cancer. Our quality improvement project's interim results demonstrate that recruiting underserved patient populations is feasible. As with all technological innovations, remote patient monitoring requires a dedicated team and involvement of all stakeholders to ensure clinician and patient acceptance. Our team is conducting an evaluation to identify best practices of remote patient monitoring implementation in oncology with a focus on structurally disadvantaged patients—those from diverse racial and ethnic groups—and others without reliable access to the internet or Wi-Fi-enabled devices. Next steps include evaluating patient and clinician experience and preliminary effectiveness of the technology. Though remote patient monitoring has many obvious advantages, like any technology, it carries the risk of increasing disparities in health due to existing social inequities. Therefore, any remote patient monitoring evaluation must come from the place of health equity throughout the project's phases: project design, data collection, analysis, implementation, and dissemination. Our study helps demonstrate that a remote patient monitoring solution for patients with cancer can be scalable, equitable, and clinically actionable.

Ksenia Gorbenko, PhD, is an assistant professor, and Alaina Kessler, MD, MPH, is a fellow at the Icahn School of Medicine at Mount Sinai, New York, N.Y. Mark Liu, MHA, is director of Strategic Initiatives, Oncology Service Line; Madhu Mazumdar, PhD, is director of Biostatistics; and Cardinale B. Smith, MD, PhD, is professor, Division of Hematology/Medical Oncology and Geriatrics and Palliative Medicine at Mount Sinai Health System & Tisch Cancer Institute, New York, N.Y. Melanie Besculides DrPH, is assistant professor, Institute for Healthcare Delivery Science, Mount Sinai Health System; Department of Population Health Science and Policy, Icahn School of Medicine at Mount Sinai, New York, N.Y. Carol Kisswany, MHA, MS, is program manager, Strategic Initiatives and Reporting, Mount Sinai Health System, New York, N.Y.

References
Changing the Tune for CAR T-Cell Therapy

A Music City Experience in Remote Patient Monitoring
Even seizures. The American Society of Transplant and Cell Therapy recommends performing a neurological assessment called the “ICE score” every shift (every 12 hours) on these patients to assess their neurological status and ensure that no significant changes have occurred. If neurological changes are noted, corticosteroids should be initiated.

Table 1, page 22, shows the incidence of cytokine release syndrome and immune effector cell-associated neurological syndrome for each CAR T-cell therapy product that was FDA-approved as of June 27, 2022.

Implementing Remote Patient Monitoring
Traditionally, patients being treated with CAR T-cell therapies require a hospital admission to manage their toxicities. To avoid these hospitalizations during the COVID-19 pandemic, Vanderbilt-Ingram Cancer Center developed and implemented a remote patient monitoring and telehealth model that allowed patients to be safely treated in the outpatient clinic setting. Developing this model took buy-in from many different players, including physicians, advanced practice practitioners (APPs), nursing, administrators, and patients. With nocturnist APPs performing nightly telehealth visits at 10:00 PM, no additional staff were needed prior to program implementation.
So how does the model work? At the initiation of a CAR T-cell therapy, all patients receive the remote monitoring device. Though the technology is provided at no additional cost, patients must sign a consent form saying that they will return the device and all associated equipment at treatment completion or they may be charged for the cost of the technology. The patient care coordinator educates patients and caregivers on how to use the technology by practicing hands-on with the device and troubleshooting possible issues that may occur. A pre- and post-test to measure competency and knowledge about taking vital signs with the monitoring device ensures that patients’ caregivers fully understand how to use the technology.

Patients are then seen daily in the outpatient clinic. After their in-person morning clinic appointment, patients check in with providers virtually at multiple touchpoints (see Figure 1, right). With this telehealth model, clinicians monitor vital signs and can quickly intervene as clinically indicated. Patient care coordinators and APPs monitor patients’ vital signs during the day and after-hours; as mentioned earlier, the nocturnist APP monitors patients’ vital signs throughout the night. The remote monitoring system automatically generates alerts—via a mobile app and email—about any medical issues patients experience.

Remote monitoring of patients being treated with CAR T-cell therapies allows these patients to be treated safely in the outpatient setting, while the technology enables providers to watch for subtle clinical signs that would indicate a potential presentation of toxicity. This early identification allows for early intervention. In turn, early intervention has been shown to reduce toxicity burden on patients. For example, if the clinical team notes an increasing body temperature while patients are at home (or at local lodging if they must travel for treatment), providers can communicate immediately with patients and initiate appropriate intervention(s).

<table>
<thead>
<tr>
<th>Therapy</th>
<th>Indication(s)</th>
<th>Clinical Trial</th>
<th>Cytokine Release Syndrome Incidence</th>
<th>Immune Effector Cell-Associated Neurological Syndrome Incidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tisagenlecleucel (Kymriah®)</td>
<td>Relapsed/refractory diffuse large B-cell lymphoma or acute lymphoblastic leukemia in patients 25 years and younger</td>
<td>JULIET (NCT02445248)</td>
<td>93</td>
<td>64</td>
</tr>
<tr>
<td>Axicabtagene ciloleucel (Yescarta®)</td>
<td>Relapsed/refractory diffuse large B-cell lymphoma or follicular lymphoma</td>
<td>ZUMA-1 (NCT02348216)</td>
<td>93 (diffuse large B-cell lymphoma); 84 (follicular lymphoma)</td>
<td>64 (diffuse large B-cell lymphoma); 77 (follicular lymphoma)</td>
</tr>
<tr>
<td>Brexucabtagene autoleucel (Tecartus®)</td>
<td>Relapsed/refractory mantle cell lymphoma or relapsed/refractory acute lymphoblastic leukemia in patients 18 years and older</td>
<td>ZUMA-2 (NCT02601313)</td>
<td>91 (mantle cell lymphoma); 92 (acute lymphoblastic leukemia)</td>
<td>81 (mantle cell lymphoma); 87 (acute lymphoblastic leukemia)</td>
</tr>
<tr>
<td>Lisocabtagene maraleucel (Breyanzi®)</td>
<td>Relapsed/refractory diffuse large B-cell lymphoma</td>
<td>TRANSCEND (NCT02631044)</td>
<td>46</td>
<td>35</td>
</tr>
<tr>
<td>Idecabtagene vicleucel (Abecma®)</td>
<td>Relapsed/refractory multiple myeloma</td>
<td>KarMMa (NCT03361748)</td>
<td>84</td>
<td>18</td>
</tr>
<tr>
<td>Ciltacabtagene autoleucel (Carvykti™)</td>
<td>Relapsed/refractory multiple myeloma</td>
<td>CARTITUDE-1 (NCT03548207)</td>
<td>95</td>
<td>23</td>
</tr>
</tbody>
</table>
Another benefit: the outpatient CAR T-cell therapy remote monitoring program allows inpatient units greater bandwidth to care for the general oncology population. In a traditional care delivery model, patients on CAR T-cell therapies are admitted to the hospital for up to 14 days to monitor for cytokine release syndrome and immune effector cell-associated neurological syndrome. Transitioning these patients to remote monitoring in the outpatient clinic setting frees up inpatient beds for acutely ill patients.

Finally, treating these patients in the outpatient clinic setting versus the more expensive inpatient setting provides significant cost savings to patients, the hospital, and healthcare system.

**Improving the Patient Experience**

Not only is remote monitoring of patients on CAR T-cell therapies safe and effective for them and their caregivers, but Vanderbilt-Ingram Cancer Center has found that this model of care delivery improves the overall patient experience. Patients remain in the comfort of their homes or local lodging with their caregivers, avoiding a prolonged hospitalization marred by ringing alarms, lack of privacy, and ongoing COVID-19 safety concerns.

The remote patient monitoring platform is both patient- and clinician-friendly and has not placed a large burden on patients, caregivers, clinicians, or staff. The vital signs automatically load into the dashboard in 15-minute increments from an armband that patients wear with a device that tracks pulse oximetry, heart rate, respiratory rate, and temperature in real time. Patients and/or their caregivers have to place and activate a blood pressure cuff to input this metric, but after their blood pressure is taken, the value is pushed to the dashboard for healthcare providers to view. The healthcare provider is responsible for viewing patients’ vitals and assessing whether any are out of the normal range, which may warrant hospital admission or some other intervention.

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**Figure 1. Daily Schedule of Patients on Remote Patient Monitoring**

- **8:00 AM** In-person clinic visit
- **10:00 AM** Vital signs
- **12:00 PM** Vital signs
- **4:00 PM** Telehealth visit
- **6:00 AM** Vital signs
- **8:00 PM** Vital signs
- **10:00 PM** Telehealth visit
The use of remote monitoring for patients undergoing CAR T-cell therapy allows the cancer care team to note subtle clinical changes that would potentially go unnoticed until a scheduled clinical touchpoint.

Patient compliance has been very high because patients want to stay out of the hospital as much as possible. Because CAR T-cell therapy treatment is already a large stressor, it was important that this technology not add another layer of stress to patients and caregivers. Instead, patients have expressed increased security because they are being monitored around the clock.

**Improving Toxicity and Side Effect Management**
The use of remote monitoring for patients undergoing CAR T-cell therapy allows the cancer care team to note subtle clinical changes that would potentially go unnoticed until a scheduled clinical touchpoint. For example, during the night, remote patient monitoring technology may alert providers that a patient’s oxygen levels are decreasing. All vital signs are pushed to the dashboard without the patient having to manually enter the data into the portal. This reduces the burden on patients, caregivers, and cancer program staff. The technology also reduces the risk of human error during input. Providers can call the patient immediately and assess the need for intervention in real time. Without this technology, providers would not yet know about this clinical change until a scheduled vital sign check.

Vanderbilt-Ingram Cancer Center has also implemented a standard operating procedure that allows providers to differentiate patients who need to be admitted for fever and those who can be treated as an outpatient for their cytokine release syndrome.

**Financial Impact on the Cancer Program**
As the use of CAR T-cell therapies continue to expand in the outpatient setting, providers have found it difficult to navigate the financial components of this costly treatment. Developing an effective billing model has been greatly challenged by the lag in payers recognizing CAR T-cell therapy as standard of care. Most payers still treat it as experimental and follow Medicare guidelines for payment.

When patients being treated with CAR T-cell therapies are admitted as inpatients within 72 hours of infusion, Vanderbilt-Ingram Cancer Center is impacted financially by inadequate reimbursement. Preventing those inpatient admissions is not only better for patients, but it also helps protect the financial viability of the cancer program. Adoption of remote patient monitoring technology will inform providers about the slightest changes in patients’ vital signs, allowing patients to be brought into the outpatient clinic for evaluation and supportive care versus receiving those services in the more costly inpatient setting.

Brittney M. Baer, BSN, RN, is a patient care nurse coordinator for the Immune Effector Cell Program, and Nancy C. Long, MSN, AGACNP-BC, is a nurse practitioner and team lead in the Hematology-Oncology/Stem Cell Transplant and Cellular Therapy Department at Vanderbilt University Medical Center, Vanderbilt-Ingram Cancer Center, Nashville, Tenn.

**References**

ACCC is the leader in optimizing the delivery of cancer immunotherapies for the entire oncology care team. For more information, visit accc-cancer.org or call 301.984.9496. Follow us on Facebook, Twitter, and LinkedIn; read our blog, ACCCBuzz; and tune in to our podcast, CANCER BUZZ.
Survivorship Resources

The evolution of immunotherapies have given rise to a new class of cancer survivors who require unique tools and resources.

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- **PUBLICATION:** Survivorship Care Plans for Patients Receiving Immunotherapy
- **PDF:** IO Medical Wallet Card
- **LECTURE SERIES:** Survivorship in the Era of IO
- **PODCAST:** Survivorship Care After Immunotherapy

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The ACCC Immuno-Oncology Institute is supported by Bristol Myers Squibb (charitable donation) and Merck & Co. (Care Coordination educational grant).
Improving Cancer Care Teamwork:

Five Patient-Centered Strategies to Strengthen Care Coordination
This article outlines five common challenges experienced by patients with cancer and their caregivers and provides potential solutions for overcoming these obstacles. Authors share discussion topics and tools that providers can use in patient discussions to empower patients and caregivers to participate in shared decision-making and care management.

To ensure that patients receive safe, quality, and equitable cancer care, provider efforts must be coordinated efficaciously. Care coordination entails deliberate, organized care activities between multiple parties to facilitate the appropriate delivery of healthcare services. When cancer care is coordinated effectively, meta-analytic evidence suggests that care efforts lead to improved outcomes (e.g., patient experience and quality end-of-life care). Conversely, poorly coordinated cancer care results in a host of negative outcomes, including adverse drug interactions, unnecessary tests and procedures, disparate information, and higher healthcare costs. Further, inadequate coordination can result in miscommunication, conflicting advice, delays in care, and conflicting or incompatible treatments. These issues can ultimately cause substantial psychological distress in patients. Put simply, subpar care coordination results in suboptimal processes and outcomes.

Unfortunately, subpar care coordination is not uncommon due to the vast network of providers involved in cancer care, with care coordination challenges observed at both the health system and clinician level. Treating cancer requires nursing, medical, and allied professionals—from diverse care settings—to work together over extended periods of time due to the multitude of tests and treatment modalities (surgery, adjuvant chemotherapy, and radiotherapy) available. In fact, providers are dynamically affiliated with multiple hospitals, networks, and insurance plans but are not necessarily affiliated with each other. Some studies estimate that approximately 10 different provider types with different backgrounds and training are involved in cancer care, and others posit that as many as 28 providers work independently to provide quality cancer care to a single patient. Arguably even more critical is that patient records and data are not integrated between multiple clinic locations and across health information technology systems. Given the diverse nature and involvement of providers, medical institutions, and healthcare plans, an optimal care coordination model remains elusive, resulting in extensive, heterogeneous care coordination models. This problem will likely be further compounded given that care coordination becomes more difficult for patients with comorbidities, and there is an expected increase in an aging population with comorbidities.

Due to the heterogeneity of models and the difficulties in coordinating care, patients with cancer are often tasked with coordinating their own care. Because patients and caregivers typically do not have any formal training, they may struggle with navigating the complex landscape of cancer care delivery. With this foundation in mind, this article offers providers prescriptive guidance that can be discussed with patients and caregivers who are faced with the daunting task of coordinating and managing their own care. Specifically, we outline five challenges that patients with cancer and their caregivers often experience and provide potential solutions for overcoming these obstacles. It is hoped that understanding these challenges and being equipped with strategies to overcome barriers will result in patients and caregivers who are knowledgeable, engaged, prepared, and assertive regarding their own cancer care.
**Challenge: For patients with cancer, managing their own care can be complex.**

**Solution: Patients with cancer should organize and maintain a log of important information, dates, and follow-up plans.**

Medical appointments inherently involve abundant information; patients arrive with various concerns, and providers deliver considerable details and instructions. Although patients with cancer experience multiple concerns, many remain unspoken or unrecognized, resulting in reduced patient satisfaction and poorer outcomes. Additional providers often have extensive follow-up plans to guide patients through their care, but patients may inadequately execute these follow-up plans. Lack of adequate communication between specialists and primary care providers surrounding follow-up plans has been identified by oncology physicians as the major reason why patients with cancer experience delays and “fall through the cracks” in terms of treatment. Poor compliance to prescribed care plans or even unaddressed concerns and unasked questions may be attributable to patients’ lack of comprehension around complex medical information; however, these behaviors may also be attributable to failures in prospective memory (i.e., intentions to act in the future).

A seemingly obvious but underutilized strategy to adequately answer questions, address concerns, and record pertinent care information is for patients with cancer and their caregivers to keep a log of questions, record the answers to their questions, and take notes during patient and provider discussions. A potential question for patients to ask, especially when multiple providers are actively involved in their care delivery, is, “Can you please make sure my primary care physician receives this information, or is there a way that I can get this information to them?” Maintaining and using an organized log of questions and answers has been demonstrated to increase patient-centered care by ensuring that patients’ primary concerns are addressed. Moreover, the literature shows that incorporating plans into a patient-held record improves understanding by patients and families.

One example of a tool that can be used by patients to keep track of their own care and follow-up plan is the personal health record. Updated by patients and/or caregivers, these records can help them keep track of appointments, diagnoses, medications, and similar information pertinent to their care history and trajectory. Personal health records can be paper or electronic-based and may have varying levels of integration with hospital-maintained electronic health records. For a review of personal health record system architectures, see Roehrs et al. These tools are noted to be particularly important for improving care during emergency situations and transitions in care when transferring to new providers and/or in multidisciplinary care team situations.

Given the complexity of cancer care and multitude of providers involved, it stands to reason that these benefits could be particularly notable for patients with cancer. Although the benefits of personal health records have been thoroughly modeled and their utility supported by government agencies like the Office of the National Coordinator for Health Information Technology, many barriers hinder widespread adoption (e.g., technological issues related to interoperability of systems, patient factors affecting use). Several studies cite provider- or organization-initiated education and emphasize the increasing usage of personal health records. Personal health records that are available for use will vary over time and across providers, but providers should educate patients with cancer about personal health records and, where possible, educate patients and caregivers on specific systems that may be available. Patients or caregivers should bring a copy of their personal health record to all appointments irrespective of clinical specialty. For providers, confirming the accuracy of these records and assisting patients in revision of their personal health record when necessary is critical.

**Challenge: Often, patients with cancer do not feel heard.**

**Solution: Open communication between patients and providers should be encouraged and cultivated.**

In addition to health record organization, patients and clinicians need to make a collaborative relationship with effective communication a high priority and a core value in cancer care delivery. In a seminal review, Ong et al. identified three basic functions for communication in cancer settings: 1) exchanging information, 2) fostering treatment decisions, and 3) facilitating interpersonal processes to create a positive relationship between the patient and provider. Despite the functionality and importance of communication, earlier work indicates that the physician-patient relationship is one of the most common difficulties in medicine. Although challenging, patients and clinicians need to speak capably and comfortably about various facets of clinical care. A 2020 National Cancer Survey by the American Society of Clinical Oncology revealed a lack of these types of conversations; for example, only 26 percent of patients discuss end-of-life care with their provider(s).

A significant amount of research demonstrates that the quality of medical practice and treatment outcomes depend on positive interactions between providers and patients. Simply put, open and effective communication is essential. Poor communication can lead to high unnecessary cost burden, with one study suggesting that communication inefficiencies cost U.S. hospitals $12 billion annually. Poor communication has also been related to refusal, noncompliance, and abandonment of treatment, as well as late relapse in cancer when it leads to treatment noncompliance. Additionally, poor communication has a negative influence on symptom management, treatment decisions, and patients’ experiences and quality of life. In contrast, effective communication can lead to many benefits, including increased treatment adherence and compliance, adjustment of expectations, self-regulation, and coping, which can result in increased return-to-work rates and improved function. Effective patient-provider communication is especially important in the treatment of chronic diseases, such as cancer, which necessitates regular encounters with medical professionals and complex healthcare decisions.
Prior to an appointment, providers, patients, and caregivers can elevate their encounters by arriving with a mindset of understanding, respect, and empathy.64 Though all parties contribute to an encounter, patients with cancer can leverage specific tools and actions to facilitate better communication with providers. During the appointment, patients should start by setting concrete boundaries and expectations early in their appointment.55,59 Being clear about expectations allows the provider to know what the patient hopes to accomplish during the current interaction, and it also fosters strategies for improving future encounters. Additionally, one systematic review suggests that patients should seek confirmation that they have the correct understanding from their providers and encourage their providers to repeat their exact words.64 In addition to setting expectations, patients can leverage specific phrases that are useful for uncovering information and expanding communication. For instance, Barrier et al.29 recommends employing the phrase “what else?” to aid in acquiring deeper information and building positive relationships. Beyond the actual encounter, patients can engage in reflection. Specifically, patients should reflect on what aspects went well and what aspects went poorly56 and share this information with providers at their next appointment.

**Challenge:** Patients with cancer do not always see themselves as integral to their health.

**Solution:** Patients with cancer should assert themselves in their care and care decisions.

Even though healthcare professionals certainly play a role in promoting patient involvement in clinical care and there are numerous research efforts aimed to target improvement in this area (e.g., Bergeson et al.23), it is imperative that patients advocate for themselves and seek to participate in the decision-making process alongside their providers. Bergeson et al. posited that as care becomes more complex, patient involvement becomes increasingly paramount, given the potential consequences.23 Patient disengagement may lead to preventable illness, suboptimal outcomes, and wasted resources.50 Researchers have shown that individuals who play an active role in their care achieve better outcomes. In fact, Griffiths et al. demonstrated that greater patient involvement during consultation leads to greater satisfaction and, perhaps more important, better health.51 The benefits of patient involvement can be linked to Bandura’s social cognitive theory of behavior.52 Essentially, by getting involved in their own care, patients may grow increasingly confident in their abilities to manage their care (self-efficacy), which may result in greater likelihood that their goals will be achieved (outcome expectancy).51

One way for patients to be more engaged and involved in their care is to be more assertive. Research has long demonstrated that assertiveness may change provider behavior.65 Andersen et al. found that patients who were more assertive actually received more interventions, compared to their less assertive counterparts.65 Some explain the relationship between assertiveness and care with Street et al.’s ecological theory of patient-centered communication, which states that multiple levels should be considered (e.g., mutual interactions between clinicians and patients, social context, and clinical context).65 When the interaction between patients and clinicians is such that patients exhibit assertive behaviors and clinicians counteract with facilitative behaviors, that interaction fosters ongoing participation and engagement from patients.66 Patients can demonstrate assertiveness by making requests, asking questions, and expressing opinions.57 As with everything, balance is important; providers should discuss the benefits and potential side effects of all evaluations and interventions with their patients to avoid unnecessary and/or harmful care activities.

**Challenge:** Maintaining motivation is often difficult for patients with cancer.

**Solution:** Patients with cancer should establish an actionable plan to remain in control.

Cancer is not simply a physiological disease; it has psychological ramifications as well.64 Studies have repeatedly demonstrated a link between cancer and depression.69 In fact, depression and anxiety are more common in patients with cancer, as opposed to the general population, and as many as 70 percent of patients being treated with chemotherapy report experiencing depression.61 As a result of these psychological effects, it can be challenging for individuals with cancer to maintain their motivation. In some populations, a lack of motivation is associated with development of cancer information overload.62,63 As the name suggests, cancer information overload is a negative disposition that occurs when patients become inundated with information pertaining to their diagnosis and care plan.62 Consequently, patients who lack motivation and experience this type of overload may have difficulty processing information, which may ultimately detract from knowledge. Such confusion and gaps in knowledge lead to poor retention, recall, and adherence to recommendations.64,66

Goal setting is one mechanism patients can use to facilitate motivation, self-management (i.e., the patient’s ability to organize, plan, and support their own care), and behavior change.23 Goal setting serves to motivate and provides a foundation for patients to care for themselves and remain in control of their health. Goal setting and action plans are integral elements within self-management programs that enable patients to effectively steer their care and cope with their illnesses.65
...having another person at an appointment can reduce the burden on the patient because the family member can function as a scribe or record keeper to update documents like a personal health record, while the patient focuses on their interactions with the provider.

Gardner et al. use the SMART approach to assist patients with goal setting.66 This framework includes five components that individuals should adhere to while creating objectives: specific, measurable, achievable, realistic, and time bound (SMART). Being specific requires participants to provide details in terms of exactly how, when, where, and what they are going to do. For instance, if a patient’s goal is to achieve medication compliance, they could specify what medication(s) they need to take, when they will take it, where they will take it, and how they will take it. The measurable aspect is indicative of how the participant will be able to track their goal progress and completion. Continuing with the medication example, a patient could use a tracking tool to log their progress. The achievability element involves considering the participant’s abilities and resources to determine whether the individual can realistically achieve the specified goal. To determine whether the medication goal is achievable, one should evaluate the patient’s ease of access to the medication, associated memory aids to remind the patient to take the medication, and the patient’s cognitive ability to understand the context of the medication’s use (where and how to take it). The realistic piece of this framework is heavily influenced by the previous element—an individual’s ability to complete a goal depends upon their abilities, resources, and potential challenges. To ensure that the medication compliance goal is realistic, one would assess the patient’s relevant abilities, resources, and anticipated obstacles to compliance. The final aspect of the SMART approach is time bound, and this has to do with the time frame that is being associated with the goal. This will largely depend on the goal that is being set. For instance, the period in which the patient is seeking to comply with the medication regimen can range from the short to long term, depending on the time frame they need to take the given medication.

Challenge: Support is key for patients with cancer to maintain active involvement in their care.

Solution: Patients with cancer should seek support in peer groups, among their family, and through community resources.

Cancer is an all-encompassing illness, making it difficult to deal with it alone. Some outlets that are available to patients, where they can seek support, include patient support groups, family members, and educational programs to aid in managing one’s self-care. Coping with and managing a chronic illness like cancer is cognitively and emotionally taxing, necessitating support.67 According to Jerant et al., patients identify low family support and lack of awareness of support resources, such as self-management programs, as some of the most frequently noted barriers to active self-care.68 Patients who have a strong family support system seem to cope with their conditions better than those who do not.68 Thus, speaking with a clinician or researching online for self-management support services and programs is beneficial. Patients who are involved in these types of programs speak very highly of the information and emotional support these services provide.69 Patients with familial and caregiver support also report greater satisfaction with their care coordination.69 A good first step to get better support for a patient with cancer is for them to request the contact information of social workers and/or patient advocates at their cancer program or practice.

There are many additional avenues of support for patients with cancer. One option is support groups, which can lighten the emotional load that family members might not understand by providing experiential insights. Several studies have found evidence touting the benefits of patient-to-patient mentorship.70,71 In fact, such mentorship demonstrates improvement in well-being, self-efficacy, behavior change, and health outcomes.72 Importantly, support groups can be face-to-face or virtual, with those who are supported by social media experiencing many of the same beneficial outcomes.73 Another option for support is designating a family member to help patients navigate their care. Because family members have intimate knowledge of the patient, family members may be able to ease communication between patients and their providers.74 If patients have expressed difficulty communicating with their providers, family members can act as interpreters, especially when patients cannot effectively communicate their needs or communicate at all.74 Even for patients who can communicate, having another person at an appointment can reduce the burden on the patient because the family member can function as a scribe or record keeper to update documents like a personal health record, while the patient focuses on their interactions with the provider. Clinicians are uniquely qualified to provide support as well because patients do not always know the correct questions to ask.74

Finally, the internet has a wealth of useful self-management educational programs.75 As with any information provided online, patients should consider the credibility of the sources and check with their provider to ensure their validity and applicability. One integrative review found that such self-management programs are helpful for individuals with cancer.76 Another systematic review found that clinicians see self-management programs as desirable.77 These programs empower patients and their families to accomplish their own goals.78 One theory is that these programs increase patients’ self-efficacy by increasing their engagement.71 Specifically, self-management education can provide patients with the necessary tools to recognize issues with their treatments or the disease itself and take initiative to pre-emptively solve problems.73
5 TIPS TO IMPROVE YOUR CANCER JOURNEY

Managing your own care can be complex. Make an effort to organize by maintaining a log of important information, dates, and follow-up plans.
• Keep a log of questions
• Talk to your providers about personal health record tools
• Ask direct questions to make sure information gets where it needs to when it needs to

Make yourself heard. Encourage and cultivate open communication between yourself and providers.
• Arrive with a mindset of understanding, respect, and empathy
• Set concrete boundaries and expectations early in the appointment
• Seek confirmation from providers that they have the correct understanding and encourage them to repeat your exact words
• Ask open questions like, “What else?”
• Reflect on what things went well and what things went poorly

You are integral to your health. Assert your involvement in your care and care decisions.
• Make requests, ask questions, and express opinions
• Discuss the benefits and potential side effects of all evaluations and interventions

Maintaining motivation is difficult. Establish an actionable plan to remain in control.
• Set goals for yourself and remember the acronym “SMART.” Each goal you set should be:
  – Specific (think through how, when, where, and what you are going to do)
  – Measurable (find a way to track when you complete your goal)
  – Achievable and realistic (make sure you have the abilities and resources to complete your goal)
  – Time-bound (goal has a clear start and end)

Support is imperative in maintaining your active treatment. Seek support in groups, your family, and other resources.
• Ask about resources available in your area or on the internet/social media
• Check with your provider to make sure the resources are credible, safe, and helpful
• Designate a family member to help navigate care
Concluding Thoughts

Quality care necessitates that a network of providers all seamlessly coordinate their efforts. However, due to a multitude of issues (e.g., confusion in roles and responsibilities, barriers to multidisciplinary team meetings, and poor communication during care transitions), effective care coordination is often not achieved and the “gold standard” of care coordination remains largely unanswered. Consequently, the responsibility of care coordination can sometimes fall upon patients and caregivers. Even though this responsibility should not be solely placed on patients and their caregivers, the current state of cancer care remains in crisis. Until substantial change is made, patients and caregivers need tools and resources—like the five solutions presented in this article—to effectively coordinate their care. Figure 1, page 31, is a replicable tool for providers to share these strategies with their patients.

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Ongoing advances in targeted therapies, molecular biology, and immuno-oncology are leading to more complex pathology and ancillary test reports, so cancer clinicians have a tremendous opportunity to improve the delivery and communication of pathology information to provide more patient-centric care.

**Improving Pathology Reports [Podcast]**

Hear one provider’s suggestions for simplifying and standardizing pathology reports so patients can be better informed, understand their prognosis, and own the progress of their therapies.

**Considerations for Pathology Reporting**

Find aspirational concepts and practical ideas to achieve a coordinated pathology reporting approach, reduce risk of medical errors, minimize delays to treatment, and improve communication between pathologists and other members of the cancer care team.

**Patient-Centered Care: Reporting and Communicating Pathology and Ancillary Test Results**

Read how improving the information contained in pathology and ancillary test results for patients can help them better understand their diagnosis and more fully engage in shared decision-making conversations about personalized treatment options.

**Access resources** that pinpoint the challenges—and opportunities—to improve pathology reporting for patients and providers at ACCC-CANCER.ORG/PATHOLOGY or scan this QR code.

Resources produced as part of the “Precision Medicine: Integration of Pathology with the Cancer Care Team” education project. In partnership with the Association for Molecular Pathology, American Society for Clinical Pathology, and the National Society for Genetic Counselors. Supported by AbbVie, Amgen, Bristol Myers Squibb, Lilly, and Pfizer.

The Association of Community Cancer Centers (ACCC) is the leading education and advocacy organization for the cancer care community. For more information, visit accc-cancer.org
Best Processes for Development of a Successful Cardio-Oncology Program in a Community Hospital
In Brief
Cardio-oncology is a multidisciplinary field that aims to address the effects of anti-cancer treatment on the cardiovascular system. However, access to cardio-oncology programs is often limited to large academic cancer centers. In 2015, Lehigh Valley Hospital, a community hospital in Allentown, Pa., started a cardio-oncology program to implement best practices and guideline-based care with minimal resource utilization. The program started with a multidisciplinary team comprised of two cardiologists, a nurse practitioner, medical oncologist, and clinical pharmacist. With support from administrative leadership, this cardio-oncology team established an internal workflow for consults that resulted in an average growth in patient volume of 50 percent per year.

Many novel cancer therapies have potentially cardiotoxic side effects. With the growing number of cancer survivors, it has become increasingly important to optimize cardiovascular outcomes for these patients. Cardio-oncology specialists can help prevent and manage acute cardiotoxicity related to anti-cancer therapy, as well as follow survivors of cancer to prevent long-term cardiovascular complications.

Specialized cancer research centers and large academic medical centers are at the forefront of cardio-oncology program development. However, these cancer programs are not accessible to all patients. As of 2017 only 400 of the 6,210 hospitals in the United States were academic or major teaching hospitals. Therefore, patients with cancer who develop or have pre-existing cardiovascular disease will likely seek care at community-based programs or practices.

Lehigh Valley Health Network is a community hospital network in Pennsylvania that operates the Lehigh Valley Cancer Institute, which conducted 55,000 visits and evaluated 5,000 new patients with cancer in 2019. In 2015, Lehigh Valley Health Network opened a cardio-oncology program at Muhlenberg Hospital in Bethlehem, Pa., to offer specialized cardio-oncology care in a local community hospital. (Prior to this, the closest cardio-oncology program was 66 miles away.)

Approach and Methodology
The Lehigh Valley Health Network team used the Model for Improvement to implement its multidisciplinary cardio-oncology program. The first step was to identify physician champions within cardiology and oncology. These physician champions attended national and local cardio-oncology meetings to learn the latest recommendations in this new and evolving field. The next step was to put together the core team, which included three physician champions (two cardiologists and an oncologist), a nurse practitioner, and a clinical pharmacist.
Next, this multidisciplinary team turned its focus on increasing referrals to the newly developed cardio-oncology program. The team’s goal: to achieve an annual growth rate of 25 percent. (Initially, cardio-oncology referrals averaged approximately two per month.) To raise awareness of the new service, the team developed educational material and shared this information with internal medicine, family medicine, cardiology, and oncology providers. Expert-led, consensus-driven guidelines were used to establish criteria for inpatient and outpatient consults to the cardio-oncology program.10,11 Team members spoke regularly at educational symposia and continuing medical education events to further promote the cardio-oncology program. To raise awareness in the community, patient and physician testimonials about the program’s multidisciplinary care were shared in the community newsletter Healthy You. Other means to increase public awareness included team members speaking at the American Heart Association’s “Go Red Luncheon,” cancer survivorship summits, and breast health community events (Figure 1, below and Figure 2, right).

Pamphlets and educational materials with information about appropriate patient referrals served as valuable reminders about the cardio-oncology program. Referrals primarily came from cardiology and oncology colleagues.

Upon request for a consult, a cardio-oncology team member evaluates patients in either the outpatient or inpatient setting, depending on the urgency of the evaluation. Patients are then informed that their case will be discussed with the full cardio-oncology team and clinical consensus recommendations would be shared with the referring provider. Documentation of the cardio-oncology consult and treatment recommendations are standardized using note templates in the electronic health record (EHR). These templates ensure consistency across the cardio-oncology program and embed appropriate references guidelines that support decision-making.

The cardio-oncology team reviews patient cases monthly. Referring providers and colleagues with interest in the field are invited to attend the meeting. When there is an urgent case that requires collaborative decision-making, the cardio-oncology team uses the EHR to facilitate communication among providers.

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**Figure 1. Process for Developing and Growing a Cardio-Oncology Program**

1. **Initiate multidisciplinary discussion between Cardiology and Oncology departments to establish mutual goals for a formal Cardio-Oncology Program**
2. **Identify a physician champion within each department to serve as the main point of contact for referring providers, as well as for providers within and across respective Cardiology and Oncology departments**
3. **Disseminate pamphlets and educational materials to internal medicine, family medicine, cardiology, and oncology providers that detail the services provided by the Cardio-Oncology Program**
4. **Establish a structured multidisciplinary meeting with representatives from Cardiology and Oncology departments to discuss cases, review relevant literature and guidelines, and share decision-making regarding appropriate management course and diagnostic testing**
5. **Identify colleagues within Cardiology and Oncology departments who express clinical interest in the program to facilitate growth via clinical and medical education at cardio-oncology seminars, symposiums, and conferences**

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Outcomes
Lehigh Valley Health Network’s institutional review board approved the use of the patient registry to track referral volume. Patients referred to the cardio-oncology program were enrolled in this registry using REDCap software. Data showed that the cardio-oncology program surpassed expectations by growing an average of 50 percent annually. In the four years since inception, the cardio-oncology program referral rate grew from two patients per month to approximately seven patients per month. In total, the program saw 354 patients over 4 years.

Patient Characteristics
Table 1, right, summarizes the characteristics of the 354 individuals. Approximately two-thirds of referred patients were initially seen in the outpatient setting, and the remainder were inpatient consults. Breast cancer and lymphoma were the first and second most common cancers referred. From a cardiology perspective, 16 percent of patients were referred for either decreased left ventricular function or clinical heart failure, 17 percent were referred for arrhythmia, and 15 percent were established cardiology patients who required collaborative decision-making. Common management scenarios included instituting and titrating heart failure medications, determining when to appropriately interrupt and subsequently resume anti-cancer therapy, and managing late-onset heart failure or coronary artery disease in survivors of childhood cancer. The diversity and complexity of the patients referred to the cardio-oncology program (Table 2, page 40) supports the need for these services in a community hospital like Lehigh Valley Hospital.

Shared Insights
The Lehigh Valley Health Network experience has shown that building a multidisciplinary cardio-oncology program is feasible in the community setting. Successful development and implementation requires committed cardiology and oncology specialists, as well as support from hospital leadership.

To guide the decision-making process for cardio-oncology referrals, create a best practice algorithm within the EHR. This algorithm should incorporate treatment- and chemotherapy-related risks and patient-related risk factors into a cardiotoxicity risk score that will help providers identify patients at high risk for cardiotoxicity and guide decision making for cardio-oncology referrals.

Early success of this cardio-oncology program demonstrates that access to high-quality, collaborative care can be done in smaller and/or less resourced facilities. Moving forward, Lehigh Valley Health Network hopes to grow and expand its cardio-oncology program in its satellite locations in East Stroudsburg and Hazleton, Pa. The REDCap registry will allow providers to measure and monitor their performance in adherence to best practices and patient outcomes. The biggest benefit to this multidisciplinary cardio-oncology program is that it allows patients with cancer who are already struggling with the high burden of care to receive high-quality cancer and cardiology care close to home.
### Table 2. Location of Evaluation, Primary Diagnosis, and Therapeutic Agents for Cardio-Oncology Consultations

<table>
<thead>
<tr>
<th>Location of Cardio-Oncology Referrals</th>
<th>N (total 354)</th>
<th>% of Total Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outpatient referral</td>
<td>235</td>
<td>66</td>
</tr>
<tr>
<td>Inpatient consult</td>
<td>119</td>
<td>34</td>
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</table>

<table>
<thead>
<tr>
<th>Reason for Referral*</th>
<th>N*</th>
<th>% of Total Patients</th>
</tr>
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<tbody>
<tr>
<td>Arrhythmia</td>
<td>61</td>
<td>17</td>
</tr>
<tr>
<td>Decreased ejection fraction</td>
<td>57</td>
<td>16</td>
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<tr>
<td>Decompensated heart failure</td>
<td>44</td>
<td>12</td>
</tr>
<tr>
<td>Chest pain</td>
<td>42</td>
<td>11</td>
</tr>
<tr>
<td>Cardiovascular risk factor management</td>
<td>36</td>
<td>10</td>
</tr>
<tr>
<td>Hypertension</td>
<td>29</td>
<td>8</td>
</tr>
<tr>
<td>Edema</td>
<td>23</td>
<td>6</td>
</tr>
<tr>
<td>Pre-chemotherapy assessment</td>
<td>21</td>
<td>5</td>
</tr>
<tr>
<td>Immune-related adverse events</td>
<td>14</td>
<td>4</td>
</tr>
<tr>
<td>Acute myocardial infarction</td>
<td>12</td>
<td>3</td>
</tr>
<tr>
<td>Unstable angina</td>
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<td>2</td>
</tr>
<tr>
<td>Myocarditis</td>
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<table>
<thead>
<tr>
<th>Therapeutic Agent</th>
<th>N**</th>
<th>% of Total Patients</th>
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<tbody>
<tr>
<td>Taxanes</td>
<td>120</td>
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<td>Anthracycline</td>
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<tr>
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<tr>
<td>Cyclophosphamide</td>
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<tr>
<td>Other</td>
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<td>23</td>
</tr>
<tr>
<td>Vinca alkaloids</td>
<td>46</td>
<td>13</td>
</tr>
<tr>
<td>Other antibodies</td>
<td>44</td>
<td>12</td>
</tr>
<tr>
<td>Pyrimidine analogs</td>
<td>40</td>
<td>11</td>
</tr>
<tr>
<td>Anti-HER2 antibodies</td>
<td>40</td>
<td>11</td>
</tr>
<tr>
<td>Anti-VEGF antibodies</td>
<td>24</td>
<td>7</td>
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<tr>
<td>Other tyrosine kinase inhibitors</td>
<td>24</td>
<td>7</td>
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<tr>
<td>Checkpoint inhibitors</td>
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</tr>
<tr>
<td>Folate analogs</td>
<td>10</td>
<td>3</td>
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<tr>
<td>BCR-ABL kinase inhibitors</td>
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<tr>
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<tr>
<td>IMiDS</td>
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<tr>
<td>mTOR inhibitors</td>
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<tr>
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*Patients may have had more than one diagnosis; **Many patients received more than one chemotherapy agent. ABL = abelson murine leukemia; BCR = breakpoint cluster region; EGFR = epidermal growth factor receptor; HER2 = human epidermal growth factor receptor 2; IMiDS = immunomodulatory drugs; mTOR = mechanistic target of rapamycin; VEGF = vascular endothelial growth factor.
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References
Pre- and Post-treatment Clinic: Providing Psychosocial Care from Diagnosis to Survivorship
The concept of a pre- and post-treatment clinic emerged with the Commission on Cancer’s (CoC) Survivorship Program Standard 4.8. The CoC survivorship standard has changed throughout the years, transitioning from a focus on the number of survivorship care plans given to patients to a focus on offering a more holistic survivorship program. Since the CoC survivorship standard went into effect in 2016, many cancer programs and practices have struggled to meet its requirement of providing a survivorship care plan to at least 50 percent of cancer survivors who received treatment with a curative intent. Successful survivorship programs adopted a model that began at the start of the patients’ cancer journey—diagnosis—and then supported patients throughout their treatment trajectory.

The Charleston Area Medical Center Cancer Center Model

The cancer center’s multidisciplinary treatment clinic is staffed by the Comprehensive Assistance to Resources and Education (CARE) team, which includes nurse navigators, advanced practice providers (APPs), financial navigators, a dietitian, social worker, psychologist, and chaplain. The clinic schedules newly diagnosed patients with cancer to meet all CARE team members in a single visit. The clinic also offers two visit types: a pre-treatment visit and a post-treatment visit; the CARE team provides patient education and assistance with barriers to care at both visits.

The Pre-Treatment Clinic Visit

The pre-treatment clinic visit is staffed by an oncology mid-level provider (an APP), nurse navigator, financial navigator, social worker, and dietitian. Currently, this multidisciplinary clinic supports newly diagnosed patients with breast, colorectal, head and neck, and/or lung cancers. Patients meet many members of the CARE team in this first visit. Nurse navigators are disease-specific; patients who will be treated with an oral oncolytic meet with an oral chemotherapy nurse navigator.

Patients are scheduled for the pre-treatment visit after they meet with their medical oncologist and sign consent for their chemotherapy or immunotherapy treatment. Meeting with a medical oncologist and processing the amount of information that is provided can be overwhelming. Consenting to chemotherapy or immunotherapy is a rigorous process. Patients are provided information related to their treatment schedule, potential treatment-related side effects, treatment intent (curative or palliative), administered drugs and chemotherapy agents, education on each drug, symptom management, risks and benefits to treatment, and additional instructions like the importance of checking temperature after treatment, contact information, etc. Patients and caregivers often experience “information overload.”

Typically, patients are seen for their pre-treatment clinic visit 10 to 14 days after signing their consent. The space between treatment consent and this visit is intentional, giving patients time to process the information that was provided and prepare questions about their treatment. This time is also used to conduct any additional testing that is needed prior to the start of treatment.

Ideally, bringing patients back no sooner than 1 week (5 days) and no later than 2 weeks (14 days) after the consent process means that patients are better equipped to participate in the pre-treatment visit and process treatment-related information. Patients and caregivers have had time to read through the educational material that was provided at their initial visit with their

In Brief

An academic comprehensive cancer program, Charleston Area Medical Center Cancer Center is the largest cancer program in southern West Virginia. In 2021, the cancer center saw 3,007 new patients (oncology and hematology) and provided chemotherapy and/or immunotherapy treatments to 1,583 new patients. Approximately 75 infusion visits are scheduled daily. The cancer center opened a new treatment clinic to offer pre- and post-treatment visits to better help patients navigate their cancer journey.
oncologist and write down any questions or concerns they may have. Essentially, patients and caregivers receive chemotherapy or immunotherapy information and education twice before their treatment begins.

Preparing for the Pre-Treatment Clinic Visit
Prior to this visit, patients receive an email or text on their mobile device requesting that they complete a patient questionnaire from the comfort of their home. Provided by navigational software that integrates with the cancer center’s electronic health record (EHR), the questionnaire includes the National Comprehensive Cancer Network Distress Thermometer and several other questions that help identify barriers to care.

Patients can take their time thinking through their concerns and are often more forthcoming about their challenges on the questionnaire compared to when they are asked these questions in person. Self-report questionnaires can be an invaluable addition to comprehensive assessment. Completion of the questionnaire prior to clinic also significantly reduces the clinic appointment time because the CARE team is made aware of patients’ barriers and can research available resources or solutions ahead of the clinic visit.

Nurse navigators review this information, along with the physician note, and create a detailed treatment plan with tailored, disease-specific educational information and resources.

Though most patients access and complete the questionnaire at home, some lack the technology or internet service to do so, or they may have low literacy skills. These patients are given an iPad to complete the questionnaire in the clinic prior to meeting with the CARE team. The psychosocial support coordinator assists patients who exhibit low literacy or who need assistance for various other reasons. The psychosocial coordinator also ensures that all demographic and contact information is up to date to ensure that patients do not fall through the cracks.

The Nurse Navigator Role
During the pre-treatment clinic visit, patients first meet with their assigned nurse navigator for an initial assessment and educational session.

Prior to clinic, nurse navigators review the patient’s medical record to ensure all referrals have been placed and that any ordered testing is either scheduled or completed prior to the scheduled treatment start date. This one step decreased the number of rescheduled appointments in the infusion clinic, thus decreasing treatment delays. Nurse navigators then formulate a patient-centered treatment plan using EHR data and the patient questionnaire.

During the pre-treatment clinic visit, nurse navigators meet with patients to:
- Review National Comprehensive Cancer Network Distress Thermometer results and provide education on the distress screening program
- Identify any barriers to care
- Provide a written individualized treatment plan
- Ensure that chemotherapy infusion orders are up to date
- Ensure that patients have all necessary adjunct medication
- Provide education on caring for a port site
- Provide education on percutaneous endoscopic gastrostomy tube and care
- Provide education on regimen-specific symptom management
- Provide lab orders that are needed for infusion (labs are taken on the same day if possible)
- Provide treatment calendars when regimens are complicated
- Ensure that ordered diagnostic tests, such as scans, labs, port placements, and genetic testing, are pre-authorized and scheduled
- Offer referrals to the psychologist, chaplain, or dietitian as needed
- Provide a brief overview of what to expect during patients’ cancer treatment journey
- Schedule the post-treatment clinic visit for patients who qualify. (Appointments are scheduled at six weeks after treatment ends.)

“The pre-treatment clinic visit builds rapport with the patient that is hard to obtain without meeting face to face,” said Lori Russell, a nurse navigator who focuses on patients diagnosed with lung, head and neck, and esophageal cancers at Charleston Area Medical Center Cancer Center. “It is an opportunity for the patient and caregiver to ask questions and receive much-needed education. Many patients have expressed their gratitude for the clinic for easing anxiety that surrounds starting [anti]-cancer treatment. Knowledge is power, which can bring much comfort in a time of chaos.”

Emma Gilham, a nurse navigator who focuses on patients diagnosed with colorectal cancers at Charleston Area Medical Center Cancer Center, shared a similar sentiment: “Patients love that they can share their story and discuss their concerns with us. We have been able to review processes to ensure that patients are scheduled and seen in a timely manner.”

The Financial Navigator Role
Prior to clinic, financial navigators research patients’ insurance to ensure adequate coverage. If there are out-of-pocket costs, financial navigators run the treatment plan on a computer program, NEXT Bar, to obtain a breakdown of patients’ insurance plan details, including benefits and total out-of-pocket costs. Armed with this information, financial navigators can assist patients with their healthcare costs. Options may include internal and/or external patient assistance, pharmaceutical manufacturer-based assistance, and Medicaid as secondary coverage. Financial navigators also help file claims for cancer and critical illness policies, and they counsel patients on applying for Social Security Disability.

Meeting with the financial navigator at the onset of patients’ treatment journey helps ease anxiety about treatment-related costs. The literature shows that patients often receive less information related to treatment costs than other aspects of treatment. By meeting with financial navigators prior to treatment, patients have a chance to address any cost-related concerns.
The Social Worker Role
The oncology social worker assesses patients’ social and economic situations, identifying barriers to their healthcare to help identify needed services, including:

- Home health services
- Outpatient palliative care
- Medicaid waiver for caregivers
- SNAP (Supplemental Nutrition Assistance Program) benefits
- Medicaid application assistance
- Durable medical equipment
- Transportation arrangements
- Lodging assistance (based on need and guidelines)
- Advanced medical directives
- Available community resources.

The Dietitian Role
The dietitian provides nutrition education before, during, and after patients’ anti-cancer treatment. All patients who have head and neck cancers meet with the cancer center’s dietitian; all other oncology patients are offered appointments as needed. During the pre-treatment clinic visit, the dietitian:

- Provides education on healthy eating and how to shop for and prepare healthy meals
- Provides education on the potential nutritional side effects of specific anti-cancer treatments and offers tips on managing those nutritional side effects
- Dispels common nutrition myths that contribute to nutritional anxiety during treatment
- Educates patients with prophylactic feeding tubes on nutrition via the feeding tube
- Schedules follow-up appointments as needed.

“The pre-treatment clinic visit is extremely beneficial for the patient and support person,” said Margaret Loftis, a registered dietitian at Charleston Area Medical Center Cancer Center. “It allows the patient and support person to meet members of the CARE team, have questions and concerns addressed, and receive crucial information that will assist them throughout treatment. Several patients have expressed to me the benefits of the pre-treatment clinic visit. They feel less stressed and more prepared for treatment. Some patients have mentioned that because of the amount of information received, it can feel a little overwhelming at times. These patients are encouraged to follow-up to review information as needed.”

The Mid-Level Provider Role
The APP (nurse practitioner or certified physician assistant) provides medical care during the pre-treatment clinic visit. This care may include:

- Conducting physical assessments
- Entering orders for any referrals (port placement, physical therapy, etc.)
- Reviewing lab work
- Prescribing needed medications
- Addressing health concerns
- Counseling and/or educating patients on their expected treatment course.

Referrals to Psychological and Spiritual Support
These referrals are made on an as-needed basis. The pre- and post-treatment clinic visits incorporate a large amount of information, and patients often need time to digest this information before participating in additional appointments.

Patients are referred to behavioral health services when habits, behaviors, stress, worry, and/or emotional concerns about physical or other life problems interfere with their daily life or anti-cancer treatment. Patients can meet with the clinical psychologist to participate in individual or group-based, cancer-specific behavioral health treatments either in person or via telehealth. Presenting concerns include anxiety about treatment, anxiety about recurrence, depression, loss of meaning, and other mental health concerns. The psychologist works closely with the medical oncologist to evaluate the mind-body-behavior connection and provide brief, solution-focused interventions.

Often, patients exhibit spiritual concerns throughout their cancer journey. They question, “Why me? Why now? What have I done wrong? What happens next? Why does God hate me?” Ken Toler—the chaplain at Charleston Area Medical Center Cancer Center—helps people through this dark time in their lives. By providing spiritual intervention, he brings a sense of hope and light into their situation. Toler said, “I help them [patients and caregivers] work through the questions they have. As we walk these paths, we find out that bad things happen to good people. No matter how hard we try, we live in a world that sometimes is hard and hard to understand. We do our best to shed a little light on the dark place to see our future a little clearer.” Patients can schedule in-person or telehealth visits with the chaplain and seek chaplaincy support during infusion services.

The Post-Treatment Clinic Visit
Prior to implementation of the pre-treatment clinic visit, identifying and scheduling appropriate patients for a post-treatment clinic visit presented a huge challenge. Now all patients who receive treatment with a curative intent are scheduled for a post-treatment clinic visit at their estimated completion of treatment, ensuring that survivorship care is introduced early on and patients are not missed.

The post-treatment visit focuses on:

- Identifying and managing long-term and late treatment effects
- Educating patients about the importance of monitoring for cancer recurrence
- Screening for new cancers.

Patients receive a survivorship care plan, and the visit includes education on how to optimize their health and quality of life. A copy of the survivorship care plan is provided to patients’ primary care providers for coordinated, patient-centered care. Patients are scheduled six weeks to eight weeks out at their anticipated post-treatment completion, which allows enough time for them to complete scans and follow-up appointments with their medical oncologist. Survivorship care plans are prepared by the nurse...
Another limitation includes time spent by the CARE team when preparing for clinic. Preparation by the navigators for the clinic can be intensive, and it can be frustrating when patients do not attend the visit. Though there is a preferred vendor add-on software to the clinic’s EHR that pulls data for plan preparation, many data fields still require manual transfer of patient information, which is vital for building an individualized patient care plan.

Telehealth. The option of telehealth services has helped ensure that more and more patients attend these pre- and post-treatment clinic visits. However, there are limitations to telehealth use. Many patients do not have access to computers or mobile devices. Some who do have access to these devices may not have the needed data or internet service for proper use. Telemedicine hubs are available at four locations in the state to connect patients with telehealth clinic visits.

Staffing. Serving all cancer diagnoses requires additional staffing and clinic space. Additional nurse navigators, as well as a dedicated APP and medical assistant, are needed for clinic expansion. Availability of additional clinic rooms within the cancer center to expand scheduling days has stunted the growth of pre- and post-treatment clinic because we are often scheduled to capacity for oncology clinic appointments.

Billing. When staffed by the mid-level provider, these visits are billable; however, due to staffing issues, there are times when the APP is pulled to cover other areas of the cancer center. When this occurs, patients are still seen in the clinic by the CARE team, which ensures that all education and referrals are made, but the appointment cannot be billed.

The CoC survivorship program standard encourages continual goals related to supporting survivors of cancer. By starting at diagnosis with the pre-treatment clinic, we can identify and provide care throughout the cancer care continuum, including at the post-treatment clinic visit. We are excited to see where the future takes this clinic.

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References
QUALITY IMPROVEMENT OUTCOMES FOR STAGE III/IV NSCLC

As part of a national multi-phase effort to provide guidance on key issues related to the optimization of care for patients diagnosed with stages III and IV non-small cell lung cancer (NSCLC), six ACCC Cancer Program Members released quality improvement (QI) plans focused on areas most relevant to their practice setting and specific ways to incorporate the latest evidence and clinical practice guidelines.

- Enhancing Molecular Testing Workflows
- Identification and Management of irAEs
- Elevating Palliative Care Programs
- Tracking & Improving Biomarker Test Results
- Improving Smoking Cessation Programs
- Discovering Gaps in Biomarker Testing

Cancer programs and practices that wish to assess alignment with quality measures relating to advanced NSCLC and begin their own QI projects can start on the ACCC website:

1. **Read** the project outcomes summary and the ten questions your cancer team needs to consider.

2. **Watch** participant videos to hear the benefits of participating in this QI program and access specific details regarding how changes were implemented.

3. **Download** project specific data sheets from each site to replicate their study at your institution.

Download Tools to Implement Your Own QI Efforts at ACCC-CANCER.ORG/NSCLC-QI

If you have questions or would like more information, please email ACCC at resources@accc-cancer.org.
A patient’s journey through cancer is more than the sum of its parts; while diagnosis, treatment, and outcomes chart the path, the people—physicians, nurses, navigators, social workers, and caregivers—who are integrally involved in decision making, knowledge sharing, and cancer care support shape the patient experience. Although treatment options for patients with chronic lymphocytic leukemia (CLL) have improved outcomes and prolonged survival, it is important to consider other aspects of the patient journey to understand how providers can better serve their patients. The Association of Community Cancer Centers (ACCC) conducted an educational initiative focused on garnering insights into the journey of patients with CLL and to dive deep into the conversations and perceptions of providers and patients. This article explores its findings across a broad spectrum of issues, including knowledge sharing and support on diagnosis and treatment, the use of telehealth, biomarkers, the impact of the COVID-19 pandemic on disease management, and quality of life (QOL).

Provider and Patient Surveys

Patient and provider surveys were conducted in early 2022 to identify barriers and challenges to care experienced by patients with CLL, as well as pinpoint disparities in the patient and provider perceptions of the care journey, with the aim of developing targeted education, resources, and training to improve overall care. Both surveys posed similar questions to participants to determine if gaps exist between the patient and provider perspectives of the patient journey.

The patient survey garnered 114 responses from patients diagnosed with CLL. All patients were at least 21 years of age. The provider survey garnered 99 responses, comprising medical oncologists (42 percent), advanced practice providers (13 percent), oncology nurses (10 percent), and a mix of social workers, radiation oncologists, pharmacists, surgeons, nurses, financial counselors, patient navigators, and administrators (35 percent). Excluding training years, 47 percent of providers reported having 5 to 10 years of experience as a healthcare professional in a cancer program, while 22 percent had 11 to 20 years, 21 percent had 1 to 4 years, and 9 percent had more than 20 years of experience.

With regards to the number of patients with CLL treated per year, 48 percent of providers reported treating 51 to 75 patients, 21 percent treated 76 to 100, 16 percent treated 1 to 25, 11 percent treated 26 to 50, and 3 percent treated more than 100 patients per year.

Most providers were affiliated with cancer programs located in an urban area, while just 8 percent and 4 percent of providers were in suburban and rural areas, respectively. Cancer programs were community-based (52 percent), academic and/or a National Cancer Institute (NCI) cancer program (24 percent), private practice (19 percent), or part of a Veterans Affairs program (4 percent).

Patient Education and Support

Work-up and diagnosis of CLL marks the beginning of the patient journey. Cancer care teams provide patient and caregiver education on the disease and what it means to the patient, which creates an important foundation for shared decision making for treatments. While these provider-patient discussions are consistently taking place, there is a clear disconnect between what information is shared by providers and what information is received by patients. Most providers (76 percent) maintained that they answered all patient questions, yet just over half of patients (54 percent) reported that all (or nearly all) of their questions had been addressed at the time of diagnosis. Because patients are often overwhelmed at their initial visit and may not fully retain information shared by their provider about their disease and treatment options, it is therefore critical that patients are informed on where and how to access evidence-based CLL-specific information from other trusted resources. While providers (58 percent) reported that they provided a direct referral to ancillary services for additional support and over half stated they supplied printed materials and shared supportive resources, such as Patient Power, the CLL Society, the Leukemia and Lymphoma Society, and CancerCare, nearly all patients (95 percent) reported that they did not receive a direct referral and an overwhelming majority of patients (75 percent–85 percent) stated they were not provided with printed material or lists of supportive resources.
Telehealth

Telehealth services rapidly expanded during the COVID-19 pandemic, owing to the need to reduce in-person visits to minimize the risk of viral exposure and transmission, as well as a shift in government and payer policies. The U.S. Centers for Disease Control and Prevention identified a 154 percent increase in telehealth visits among four of the largest telehealth providers during the last week of March 2020 compared with the same week in 2019. Similarly, centers funded by the Health Resources and Services Administration demonstrated a 95.4 percent increase in telehealth visits in mid-July 2020 compared with the same week in 2019. However, despite these reports, nearly 50 percent of patients who participated in the ACCC survey indicated that they had not interacted with any of their cancer care providers through telehealth visits. Of the 52 percent of patients who had used telehealth, 34 percent stated a continued preference for in-person visits. Among providers, 65 percent reported using telehealth with their patients, but that most patients prefer in-person visits. Just 13 percent of providers stated that they had not used telehealth with their patients. Post-pandemic, patients were divided on whether they preferred future healthcare visits to be held only in-person or a hybrid model of in-person and telehealth visits, while 75 percent of providers preferred a hybrid model.

Among all survey respondents (patients and providers) who had not participated in telehealth visits, the primary reason provided was a preference for in-person interaction and that the healthcare practice/institution did not offer a telehealth option.

Biomarkers and Treatment

The National Comprehensive Cancer Network (NCCN) clinical practice guidelines for CLL/small lymphocytic lymphoma recommend biomarker testing for chromosome 17p deletion (del(17p)) by fluorescent in situ hybridization (FISH), TP53 and IGVH mutation status through DNA sequencing, and CpG-stimulated karyotype to provide important prognostic information.

In the ACCC survey, most patients (71 percent) and providers (65 percent) confirmed that biomarker testing had taken place before treatment options were discussed. However, while 65 percent of patients reported that they understood the critical importance of biomarker testing before any treatment decisions are made, many providers underestimated their patients understanding of this critical importance. One-third of providers (34 percent) believed that their patients understood biomarker testing to be “somewhat important,” while 20 percent of providers believed that their patients were “not sure if it [testing] is important.

With regards to treatment, the initial strategy is based primarily on Rai Stage. For patients with a low to intermediate risk Rai Stage (0-II) who are asymptomatic, have good organ function, and do not have hematologic signs for therapy, the recommended treatment approach is “watch and wait” or active surveillance. While eligible patients indicated that their providers explained the meaning of this approach, many providers had misperceptions about the feelings that this treatment elicits among patients. Providers believed that confusion was the most typical response of their patients, when in fact most patients (48 percent) reported feeling relieved more than any other emotion, followed by anxiety (37 percent) and then confusion (25 percent).

While both patients and providers agreed that one of the biggest personal challenges for patients during the “watch and wait” approach was anxiety and worry about what may happen in the future, there was a disconnect between providers and about what other personal challenges patients faced. Many providers (70 percent) believed that patients found the task of explaining the “watch and wait” approach to others a major challenge, however, only 42 percent of patients identified that as a personal challenge. Instead, 62 percent of patients identified anxiety and worry about the future as their biggest personal challenge, with others being maintaining good mental health (32 percent) and concern about potential financial and health insurance impacts (27 percent). As a result, these differences may impact the type of education, support, and other resources that providers offer or recommend to their patients.

For patients who show indications for a need for treatment, NCCN first-line treatment recommendations include acalabrutinib with or without obinutuzumab, venetoclax plus obinutuzumab, ibrutinib, or zanubrutinib. Treatment selection among these options include considerations about efficacy, safety, administration, and costs. Patients reported overall survival after treatment, limited treatment duration, and treatment location (orally at home vs. infused center) as the most important factors when considering treatment options (see Figure 1, last page of this article). Patients also rated a chemotherapy-free regimen, and the severity of side effects as important. Treatment costs were considered less important. By contrast, providers considered the efficacy of treatment as the most important consideration, followed by treatment cost, and severity of treatment side effects.

Furthermore, while more than half of providers (54 percent) recognized that patients preferred to seek a second opinion from a CLL expert before making a treatment decision, an overwhelming majority of patients (80 percent) indicated this preference.
Finally, both patients and providers indicated that at least half of patients were somewhat knowledgeable about clinical trial participation at their initial consultation. This highlights an opportunity for providers to educate patients about clinical trials and whether they may be eligible.

**Impact of the COVID-19 Pandemic**

In the initial period of the COVID-19 pandemic, there was great concern that patients with CLL might be at higher risk for contracting the virus and for developing severe COVID-19 or death because patients with CLL are typically older, with a median age of 70 at diagnosis, and are likely to have comorbidities. In addition, clinicians hypothesized that the immunosuppressed state due to hematologic malignancy and its treatment could put patients at greater risk. It is now known that patients with CLL do not appear to be at any greater risk of contracting COVID-19 compared with the general population, but if patients contract the virus, they are at greater risk of poor outcomes. Hematologic malignancy results in a reduced immune response to the virus and its vaccine.

In the ACCC survey, both patients (82 percent) and providers (66 percent) rated increased mortality risk associated with COVID-19 as the greatest challenge that impacted patients personally. Patients were also concerned about contracting COVID-19, including more than half of patients reporting concerns about what might happen if or when they needed to go out in public or needing to go to healthcare visits during the pandemic. Patients also expressed frustration around the lack of information about the effect of COVID-19 on patients with CLL (43 percent).

While providers reported similar concerns for their patients, they also felt that their patients were challenged by social isolation and had concerns about vaccines.

At the time of the survey, 86 percent of patients reported that they had already been vaccinated against COVID-19, while another 11 percent indicated that they planned to get vaccinated. Only 2 percent of providers stated that they did not believe there was adequate clinical data to recommend COVID-19 vaccination for their patients with CLL who were undergoing active treatment.

**Quality of Life**

Overall, most patients (78 percent) rated their QOL as very good or good while living with CLL. Just 8 percent of patients reported that their QOL was poor or very poor. Interestingly, providers generally underestimated patient QOL, as 51 percent of providers believed their QOL was good and 23 percent believed QOL was poor. Only 8 percent of providers reported that their patients had a very good quality of life while living with CLL.

**Conclusion**

Supporting patients with education materials, training, lay navigation, and community resources promote patient autonomy and respect the patient’s role as co-equal partner in shared decision making on the best course of care. Gaps in perception between patients and providers with respect to beliefs and attitudes about quality of life, the need for patient education and provision of materials and resources, the use of telehealth, the impact of the COVID-19 pandemic on disease management, and understanding challenges related to biomarkers and treatment options were identified through the ACCC surveys.

While both providers and patients value shared decision making, differences persist. These differences may be attributed to a gap in communication, underestimating patients’ knowledge and experience, and understanding and addressing expectations, and may result in misinterpretation of needs. These findings suggest that while progress has been made in aligning patient preferences and providers’ delivery of quality cancer care that respects patients as an equal partner in shared decision-making, there remains significant room for further improvements. Understanding and analyzing where these gaps persist can aid providers in bridging the divide and developing targeted education, resources, and training to improve the overall patient care journey.

**References**

**FIGURE 1. Which is the most important factor when considering treatment options?**

<table>
<thead>
<tr>
<th>Factor</th>
<th>Provider’s perception</th>
<th>Patient’s perception</th>
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<tbody>
<tr>
<td>Overall survival after treatment</td>
<td>57%</td>
<td>Extremely important</td>
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<tr>
<td>Treatment costs</td>
<td>12%</td>
<td>Very important</td>
</tr>
<tr>
<td>Severity of treatment side effects</td>
<td>10%</td>
<td>Moderate important</td>
</tr>
<tr>
<td>Treatment location, orally at home vs. infusion center</td>
<td>9%</td>
<td>Slightly important</td>
</tr>
<tr>
<td>Non-chemotherapy agent treatment</td>
<td>7%</td>
<td>Not at all important</td>
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<tr>
<td>Limited duration treatment (not prescribed indefinitely)</td>
<td>4%</td>
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<tr>
<td>Number of visits</td>
<td>0%</td>
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In partnership with: [CLL Society](https://www CLLsociety org)  

Supported by: [Patient Empowerment Network](https://www.patientempowerment network org)  

A publication from the ACCC education program, "Multidisciplinary Chronic Lymphocytic Leukemia Care." Learn more at [accc-cancer org](https://www accc-cancer org/dl-care) or scan this QR code.

**The Association of Community Cancer Centers (ACCC)** is the leading education and advocacy organization for the cancer care community. For more information, visit [accc-cancer.org](https://www accc-cancer org).

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Researchers have made great strides in identifying genetic mutations that drive uncontrolled cellular growth and, ultimately, cancer. However, there remains a well-recognized disconnect between guideline-concordant testing and real-word clinical practice. Medically underserved populations, in particular, face significant challenges in accessing the latest advances in cancer diagnostics and appropriate biomarker testing.\(^1\) To address this shortcoming, the Association of Community Cancer Centers (ACCC) developed the project “Precision Medicine Stewardship.” Through this project, ACCC explores how some cancer programs are addressing the challenges and barriers around cancer biomarker testing.

One approach is to designate a cancer care team member as a “precision medicine steward,” that is, a promoter and navigator for biopsy samples and/or biomarker testing processes and results. This individual serves as the point person to ensure biomarker testing moves forward in a timely and efficient manner. The steward also helps ensure patients are equipped with everything they need to fully participate in shared decision-making about their treatment choices.

ACCC shares how Sanford Health introduced its own “precision medicine steward” through the development of a pilot Oncology Nurse Navigator, Genomics (ONNG) role, which has improved coordination of its biomarker testing program.

**Innovation to Action**
Sanford Health, the largest rural health system in the United States, offers comprehensive cancer services through four major cancer centers located in Sioux Falls, South Dakota; Fargo, North Dakota; Bismarck, North Dakota; and Bemidji, Minnesota. These centers serve as regional hubs to offer cancer services to a large rural community of patients. At Sanford Health, many patients with advanced cancers receive broad genomic sequencing and are discussed at genomics tumor board (held twice each week; remote clinicians participate virtually). Recognizing the need to centralize and improve coordination around biomarker testing, Sanford piloted the role of an ONNG starting with one site (Sioux Falls) in early 2021.

Under the leadership of the Cancer Genomics Steering Committee, Sanford developed a job description and designed the role so that the ONNG works closely with medical oncology, laboratory operations, pathology, testing vendors, and genetic counseling to improve coordination around the cancer biomarker testing process.

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**Biomarker Testing: Multigene Panels**

In February 2022, the American Society of Clinical Oncology (ASCO) released a provisional clinical opinion on somatic genomic testing for patients with metastatic or advanced cancer.\(^2\) The authors wrote, “Patients with metastatic or advanced cancer should undergo genomic sequencing in a certified laboratory if the presence of one or more specific genomic alterations has regulatory approval as biomarkers to guide the use of, or exclusion from, certain treatments for their disease. Multigene panel-based assays should be used if more than one biomarker-linked therapy is approved for the patient’s disease… Multigene testing may also assist in treatment selection by identifying additional targets when there are few or no genotype-based therapy approvals for the patient’s disease.”
Improved Patient Care

The Sanford team designed the role of the ONNG to address several common challenges around cancer biomarker testing, including:

<table>
<thead>
<tr>
<th>CHALLENGE</th>
<th>SOLUTION</th>
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<tbody>
<tr>
<td>Patients may not understand why biomarker testing is needed.</td>
<td>The ONNG meets with the patient to explain the clinical importance of biomarker testing.</td>
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<tr>
<td>Staying current on genomic testing options, vendor portals, and patient testing results may be unmanageable for clinic nurse staff and may result in missed tests, long wait times, delays in communication, and corrections in the ordering process.</td>
<td>The ONNG is one point of contact for the medical oncologist, patient, pathology, and genomic testing vendor, and stays current with genomic testing options, vendor portals, and patient test results.</td>
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<tr>
<td>Each testing vendor has their own portal, order forms, coverage, genomic panel, and variant nomenclature.</td>
<td>The ONNG meets with each testing vendor, develops a facility account, and serves as the main point of contact for the vendor on issues related to testing, orders, billing/insurance, and product/service updates.</td>
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<tr>
<td>Insurance companies may not cover certain biomarker tests (or specific labs may be out-of-network). As a result, the insurance company may deny testing. The patient may receive a surprise medical bill from the reference lab.</td>
<td>The ONNG reviews the patient’s insurance coverage to determine whether the test is covered and confirms that the selected reference lab is in-network. Then, they complete financial assistance forms to assist the patient and help to identify out-of-pocket expenses prior to test ordering.</td>
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<tr>
<td>Coordinating and tracking the status of the test (e.g., sample received, testing in-process, etc.) can be difficult.</td>
<td>The ONNG works with IT and pathology to build templated electronic test orders for specific labs to ease coordination and tracking, along with ensuring the genomic test results get uploaded into the patient’s EHR.</td>
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Oncology Nurse Navigator, Genomics

The Oncology Nurse Navigator, Genomics is a working title for a precision medicine steward at Sanford Health and is not to be confused with other nursing titles and credentials, such as:

- Advanced Genetics Nurse (AGN-BC)
- Advanced Practice Nurse in Genetics (APGN-BC)
- Clinical Genomics Nurse (CGN)
- Advanced Clinical Genomics Nurse (ACGN)

Note: This is not meant to be a comprehensive list and does not include older credentials (e.g., APNG) that have been retired or renamed.
Two main types of tumor markers that have different uses in cancer care:

A tumor marker is anything present in or produced by cancer cells or other cells of the body in response to cancer or certain benign (noncancerous) conditions that provides information about a cancer, such as how aggressive it is, whether it can be treated with a targeted therapy, or whether it is responding to treatment. Tumor markers can be found in the blood, urine, stool, tumors, or other tissues or bodily fluids of some patients with cancer. Increasingly, genomic markers such as tumor gene mutations, patterns of tumor gene expression, and nongenetic changes in tumor DNA, are being used as tumor markers. (NCI, 2019)

Circulating tumor markers (NCI, 2019)
- Detect cancer that remains after treatment (residual disease) or that has returned after treatment
- Assess the response to treatment
- Monitor whether a cancer has become resistant to treatment

Tumor tissue markers (NCI, 2019)
- Diagnose, stage, and/or classify cancer
- Estimate prognosis
- Select an appropriate treatment (eg, treatment targeted therapy)

### Other Responsibilities

**Key Performance Indicator (KPI) Reports**

The ONNG participates in this KPI review process. Through team collaboration and interdisciplinary work groups, the Laboratory Business Operations Advisor developed a report that captures key performance indicators related to biomarker testing. The report captures the answers to these questions:
- Which reference labs are used least/most?
- What are the minimum, average, and maximum turnaround times for test results from each of the reference labs?
- How often does each reference lab report that the sample quantity was not sufficient?
- What are the minimum, average, and maximum out-of-pocket costs for patients when they receive testing from different labs?

### Other Responsibilities

The Laboratory Business Operations Advisor collects data from each vendor and generates a report that is reviewed by the Cancer Genomics Steering Committee. The committee also uses these reports to determine which reference labs are best for biomarker testing. The ONNG uses this report to guide patient care and optimize genomic program services.

**Patient Education**

The ONNG develops education materials designed to help oncology clinic staff understand the role of biomarker testing. (See Figure 1, above.)

**Electronic Order Templates**

The ONNG works closely with IT to build new electronic order templates as reference labs are vetted and approved by the
Cancer Genomics Steering Committee. These orders incorporate the use of EHR-enabled SmartPhrases (templates or blocks of text pulled directly from the patient’s health record) to expedite the process.

**Future Direction**

As the use of cancer biomarker testing continues to expand, cancer programs may find that a precision medicine steward can improve the clinical workflow and ensure that patients are receiving timely testing. Sanford has seen the value of the ONNG and has been exploring ways to expand this role. One option is to hire and train ONNGs at all Sanford locations. Another possibility is to centralize the ONNG role and incorporate telehealth visits when needed. These decisions may be impacted further as more biomarker testing occurs in-house and fewer samples are sent out for testing. Moreover, the use of liquid biopsy is expanding and certain patients with cancer may receive sequential biomarker testing throughout the treatment journey to identify resistance genes or new genomic alterations, making the addition of precision medicine stewards more important than ever.

**References**


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Learn more at: accc-cancer.org/precision-medicine-stewardship

The Association of Community Cancer Centers (ACCC) is the leading education and advocacy organization for the cancer care community. Founded in 1974, ACCC is a powerful network of 30,000 multidisciplinary practitioners from 1,700 hospitals and practices nationwide. As advances in cancer screening and diagnosis, treatment options, and care delivery models continue to evolve—so has ACCC—adapting its resources to meet the changing needs of the entire oncology care team. For more information, visit accc-cancer.org. Follow us on social media; read our blog, ACCCBuzz; tune in to our CANCER BUZZ podcast; and view our CANCER BUZZ TV channel.

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ACCC Welcomes Its Newest Member

St. Anthony Regional Hospital, Cancer Center
Carroll, Iowa
Delegate Rep: Lori Pietig MHA, CT, RT(R)
Website: stanthonyhospital.org/services/cancer-oncology

“Click” Into the ACCC Legislative Action Center

No one knows better than ACCC members how policy changes and legislative action can positively (or negatively) impact the cancer care community. ACCC’s Legislative Action Center is a one-stop-shop for sharing these critical perspectives with key policymakers—all with the click of a button.

Since launching the Legislative Action Center in August, members have sent more than 100 letters, and the top advocacy actions have focused on encouraging prior authorization reform to reduce delays in cancer care.

On Sept. 14, The Improving Seniors’ Timely Access to Care Act (H.R. 3173) passed unanimously in the House of Representatives. ACCC members should encourage their U.S. senators to support the passage of the Senate version of this bill (S. 3018) before the end of the year by sending a letter through the Legislative Action Center.

Make your voice heard today at: accc-cancer.org/LAC2022.

Meet the ACCC 2022 Annual Award Recipients

Each year, ACCC confers several annual awards to recognize distinguished individuals and organizations that have made significant contributions to cancer care. In 2022, the association was proud to honor three extraordinary cancer care professionals—and celebrate their accomplishments—at the ACCC 39th National Oncology Conference, Oct. 12–14, 2022.

The Annual Achievement Award

This ACCC award has been given since 1980 to distinguished individuals or organizations in a wide variety of fields, who have reflected the values of community cancer care through their outstanding contributions. This year’s Annual Achievement Award recipient, Lola Fashoyin-Aje, MD, MPH, is a medical oncologist and deputy director in the Division of Oncology 3 in the Office of Oncologic Diseases at the Center for Drug Evaluation and Research, U.S. Food and Drug Administration (FDA). In this role, Dr. Fashoyin-Aje provides scientific and policy guidance and oversight to the multidisciplinary teams who review drugs and biologics under development for the treatment of solid tumor malignancies. Dr. Fashoyin-Aje is also an associate director at the FDA’s Oncology Center of Excellence, leading scientific and policy initiatives to address disparities and other regulatory science issues in oncology drug development.
The Clinical Research Award

This ACCC award recognizes individuals whose research has significantly and positively impacted the oncology patient, family, and/or community. This year’s recipient, Carmen Guerra, MD, MSCE, FACP, is the Ruth C. and Raymond G. Perelman professor of medicine at the Perelman School of Medicine at the University of Pennsylvania. Dr. Guerra is a general internist and cancer equity researcher. She is also the vice chair of Diversity and Inclusion for the Department of Medicine and the associate director of Diversity and Outreach for the Abramson Cancer Center.

Dr. Guerra’s research has focused on developing and evaluating interventions to increase the participation of underserved populations in cancer screenings and cancer clinical trials. She implemented the National Cancer Institute’s colorectal cancer “Screen to Save” program and the Centers for Disease Control and Prevention’s Breast and Cervical Cancer Early Detection Program, mobile mammography, and a drive-through “Flu-FIT” program in partnership with Philadelphia’s Black churches. These programs have engaged thousands of underserved and diverse residents in cancer screenings. Dr. Guerra established programs to increase participation of Black patients in cancer clinical trials, including a peer-to-peer cancer clinical trials ambassador program and the “Lazarex Improving Patient Access to Cancer Clinical Trials” program, a financial reimbursement program for patients participating in cancer treatment trials.

She co-chaired two ASCO-ACCC work groups that developed an implicit bias training and site self-assessment tool for cancer research teams and authored the ASCO-ACCC research statement “Increasing Racial and Ethnic Diversity in Cancer Clinical Trials.”

The David King Community Clinical Scientist Award

This ACCC award recognizes active community clinical research leaders. Award winners have demonstrated leadership in the development, participation, and evaluation of clinical studies and/or are active in the development of new screening, risk assessment, treatment, or supportive care programs for patients with cancer. This prestigious award is named after David K. King, MD, FACP, an ACCC past president, who died after a brief battle with cancer. Dr. King spent his entire career caring for individuals with cancer and advocating for access to quality care, while also championing the Community Clinical Oncology Program and the value of clinical research in the community setting.

This year’s recipient, Leana Cabrera Chien, MSN, RN, GCNS-BC, GNP-BC, is a nurse practitioner at the City of Hope Center for Cancer and Aging in Duarte, Calif. In 2019, with two advanced practice nursing colleagues, Chien developed and launched an advanced practice nurse geriatric oncology clinic called the Aging Wellness Clinic. In this clinic, a team of advanced practice nurses provide a holistic approach to wellness, offering specialized care for older adults with cancer.

Additionally, through a UniHealth grant, Chien offers telemedicine services to a rural community site to create a model of care for older adults with cancer via telemedicine. Through a Pfizer grant, Chien co-leads a program to evaluate geriatric oral adherence and longevity surveillance for older adults with metastatic cancer.

Chien is an active participant in the ACCC “Multidisciplinary Approaches to Caring for Older Adults with Cancer” program, serving as faculty for several webinars, including the recent “Digital Bridges: Telehealth Solutions for Older Adults.”
The Cambridge English Dictionary defines a friend as “a person who you know well and who you like a lot, but who is usually not a member of your family.” So, yes, Lois Utterback, former CFO of the Association of Community Cancer Centers (ACCC), was a friend. But these words do a poor job of describing who Lois was as a friend and colleague. Many, many more words are needed: true-blue, dedicated, integrity, mentor, leader—and yet that is still insufficient. Lois was all these things and so much more.

When I lost my 39-year-old brother Jean-Paul to testicular cancer in 2009, Lois was a rock. Not only did she take care of work-related details like activating my bereavement benefits so that I would get a paycheck at a time when money was my last concern, Lois somehow managed to track down the church in rural Georgia where my family held Jean-Paul’s memorial service, find a florist who would do same-day delivery, and ask that the arrangement be made with red, white, and blue flowers in recognition of my brother’s distinguished military service. That was Lois.

**Who Lois Was—and Was Not Outgoing** was not a word I would use to describe Lois. After working together for 20 years, I did not need Myers-Briggs to tell me that Lois was an introvert. In groups, Lois did not do a lot of talking, but she did a lot of listening—and she did it well. And that’s not as easy as it sounds. As an extrovert, I find listening more challenging than talking. Lois was an advocate for those with less-voluble speaking styles. She wanted to ensure that ACCC staff gave everyone a chance to be heard, even those most uncomfortable with speaking up.

Most people would not describe Lois as “the life of the party,” and yet she had a great sense of humor and—when comfortable with the people and the situation—she could really shine. (Exhibit A: the pictures of Lois I’ve shared in this article.)

Several “foodies” work at ACCC. Lois was the exact opposite of that. A colleague recently shared a story about Lois at an ACCC Board and Executive Committee dinner. After a wonderful meal, featuring a delectable assortment of canapés like foie gras and steak tartare, Lois exited the restaurant and immediately asked for directions to the nearest McDonald’s. We all enjoyed that shared recollection.

Lois was an accomplished accountant and skillful leader. Still today, the percentage of women CPAs who arise to the role of CFO remains low. A 2021 survey of S&P 500 and Fortune 500 companies found that 15 percent of CFO positions were held by women. Lois was supportive and always the first person to offer colleagues praise for an idea or a job well done. (In all fairness, Lois was also one to roll her eyes at a subpar idea.)

Lois adored huskies. All dogs, really. So much so that for many years ACCC’s headquarters office was “dog-friendly.” On any given day, visitors might be greeted by a well-trained huskie, miniature long-haired dachshund who was apt to forget his potty training, or another staff member’s beloved rescue dog. Over the years, staff bonded over a parade of well-behaved furry faces, and these occasional canine colleagues made our office a fun place to work.

Lois loved HEAs (Happily Ever Afters) on TV or in movies, books, and real-life. Yet thanks to her love of serial dramas and telenovelas, she also liked stories of evil twins, back-from-the-dead spouses, and killing sprees—as long as they weren’t overly gruesome.

Lois considered ACCC staff her “family” and was deeply invested in creating a work culture of inclusion. Lois talked the talk, and she also walked the walk. She was ahead of her time in terms of creating a workplace that encouraged staff engagement at every level. During her 30+ years with ACCC, Lois

(Continued on page 60)
With ACCC Executive Director Christian Downs at ribbon cutting of new ACCC headquarters

At an ACCC staff event

With Deb Lumpkins at Washington Nationals game

With Monique J. Marino (left) and Amanda Patton (center) at a General Hospital fan event

With the ACCC Administrative Team at a holiday party

With a pet therapy dog at the ACCC 34th National Oncology Conference
was a mentor to so many—both personally and professionally.

**Missing Lois**

If we are lucky, our friendships mature as life unfolds over the months and years. Lois and I had much in common—from our personal experiences with cancer to our love of books and a shared lifelong addiction to *General Hospital*. (An aside: Lois introduced me to the online Goodreads platform. If you are an avid reader, I highly recommend you check out goodreads.com. Lois would support me on this.)

Lois always called me a storyteller. And a storyteller’s greatest superpower is that their words can live on after the storytellers, themselves, are gone. To try and tell the story of Lois in one page is impossible and would be a disservice to this complex, caring, careful, candid, curious, and courageous person. (That’s just the “Cs”, readers. There are 25 other letters—24 if we don’t count “X”.)

But my hope is that these 961 words offer a glimpse of Lois Utterback. For those who did not know her and for those whose only introduction is this column, know this: Lois was quite simply wonderful. For the 30+ years she worked for ACCC, Lois directly touched the lives of so many ACCC members and—by extension—the patients and families they served.

The last time I saw Lois, she told me, “One of the best things about retirement is that I don’t have to be your boss anymore. Now I can just be your friend.” A friend indeed.

*Monique J. Marino is the managing editor, Oncology Issues, and senior director of Content and Strategy at the Association of Community Cancer Centers.*

**Reference**

ACCC has developed a comprehensive precision medicine resource library that aims to put personalized cancer care into focus—transforming the complex into something clear, actionable, and impactful—for multidisciplinary providers and their patients.

No matter your learning style—podcasts, on-demand webinars, videos, blogs, or publications—the ACCC Precision Medicine Library provides essential knowledge that bring clarity to complex patient care decisions.

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