

# **Nursing & Nurse Navigator Roundtable March 9, 2019 MEETING SUMMARY**

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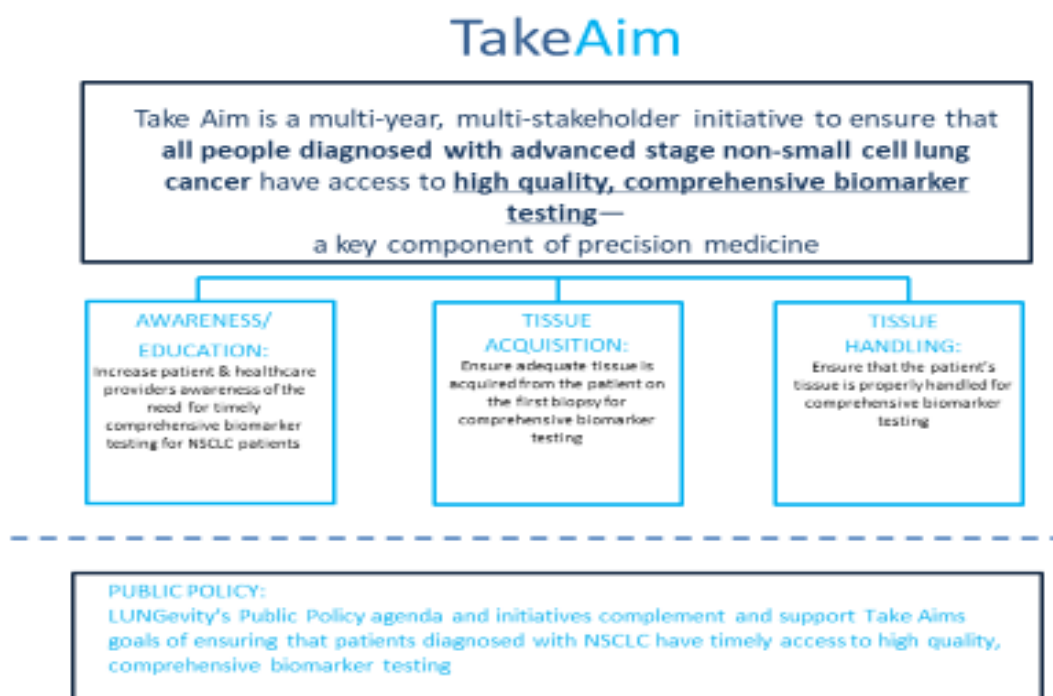


## Overview

On March 9, 2019 LUNgevity Foundation ([www.lungevity.org](http://www.lungevity.org)) convened its first-ever Nursing and Nurse Navigator Roundtable, a full-day meeting in Bethesda, MD. This event brought together stakeholders from across the lung cancer ecosystem in the US to focus on opportunities to enhance biomarker testing for Non-Small Cell Lung Cancer (NSCLC) patients by leveraging the efforts of nurses, nurse navigators, patients and organizations that represent key provider groups.

## Background

LUNgevity has long been a strong advocate for comprehensive biomarker testing, particularly through its Take Aim initiative. Take Aim began in 2015 and works to ensure that patients have access to biomarker testing to help guide their treatment decisions in a timely way. Despite the benefits of testing, many patients are still not tested. Take Aim's five-year goal is to ensure *all* lung cancer patients are tested at the point of diagnosis.



As part of Take Aim, initial research was conducted with academic and community hospital nurses and nurse navigators through which LUNgevity confirmed the important role they play in conducting critical conversations with patients about biomarker testing, providing education and reassurance about the role of testing in finding the right treatment path. Among other

findings from this research, LUNGeivity determined that nurses found these conversations “stressful” and patients “anxious” and that additional information and resources on the benefits of biomarker testing are needed to assist and enhance these conversations.

Since Take Aim began, LUNGeivity has made positive strides forward in breaking down barriers for patient access to biomarker testing. LUNGeivity has worked with key stakeholders, from pharmaceutical companies and professional societies (who provide education on testing), to pulmonologists and pathologists (who acquire and test the tissue). It is hoped that proactive inclusion of nurses and nurse navigators in the dialogue will accelerate progress and move the needle on biomarker testing.

### **Roundtable Meeting Purpose**

The goal of the Roundtable was to identify barriers nurses and nurse navigators face when discussing biomarker testing with their advanced stage NSCLC patients and identify potential actionable solutions for these issues. The meeting agenda was structured to facilitate discussion about patient-nurse/nurse navigator interactions regarding biomarker testing within a range of communities, including minority and underserved patient populations.

In preparation for the Roundtable, LUNGeivity conducted individual outreach with several nurses, genetic counselors and oncology patient navigators from community and academic hospitals, as well as several pharmaceutical industry leaders. These discussions were designed to elicit information about the challenges facing nurses and nurse-navigators in engaging with lung cancer patients to encourage biomarker testing. The feedback from these interactions helped to frame the agenda for the March 9, 2019 Roundtable meeting.

LUNGeivity Foundation is grateful to its the advisory committee members who help design this meeting: Gina Hollenbeck, Anne Gallagher, Lavinia Dobreá, Kerri Medeiros, Gigi Smith, Mary Ellen Hand, and Enza Esposito-Nguyen. In addition, LUNGeivity thanks ONS, ACCC, and AONN for partnering to deliver this Roundtable, as well as the leaders from industry, the nurse and nurse navigator communities, and the patients who participated in this meeting, see **Appendix A**. The meeting agenda is included in **Appendix B**, meeting sponsors are listed in **Appendix C** and case study examples are found in **Appendix D**. **Appendix E** contains notes from the background prep work LUNGeivity undertook for this meeting.

## **Key Takeaways**

**LUNGeivity Foundation President & CEO Andrea Ferris** began the meeting with a call to action for the group, noting that lung cancer can be a “pilot” or “beta” test case for many cancers and other diseases in the pursuit of making “biomarker-driven care” the standard of care for all patients. She described the evolution of thinking about biomarker testing, beginning with single analyte tests (EGFR, ALK, ROS1, BRAF and PDL1) and moving now to the need to do a comprehensive multi-gene panel that not only identifies what therapies patients may be eligible for today but what clinical trials and other avenues may be relevant for them in the future. Noting that nurses and nurse navigators are at the forefront of engagement with patients and care providers, she described how LUNGeivity and its partner organizations decided to convene this group to better understand where there are gaps in information, resources, tools and communication opportunities.

Roundtable participants were asked to collaborate and leverage their unique expertise to define barriers, learn from successful models, evaluate best practices, and design a framework for moving toward a more ideal patient journey that includes access to comprehensive biomarker testing for all stages of lung cancer at the time of diagnosis. Key themes emerged that resonated with the multi-stakeholder participants, chiefly the need for additional training, materials, resources and opportunities for cross-functional communication within healthcare settings. Participants identified multiple barriers to the shared vision of enhanced access to and use of biomarker testing in the lung cancer patient population and worked throughout the day to prioritize concrete approaches to address those barriers and best practice solutions.

## **Barriers and Best Practice Solutions**

*Provider Education: Keeping Up with the Rapidly Changing Landscape for Biomarker Testing*

“Nurses talk to one another and learn from one another and I think that's the best way. It's just whomever you work with; everybody has something to offer to the other person on education.”  
- ***Nurse who works in an urban area with an underserved patient population on the benefits of learning from peers on the fast-paced advancements in lung cancer***

“I felt a lot of times I was kind of ahead of the knowledge base than what our community providers were (offering) because I was involved in an organization that was the forefront of that knowledge base.”

**- Lung cancer patient who is also a Hospital Quality Administrator in a rural area on her experience learning about the clinical advancements in lung cancer and applying that knowledge within her hospital**

Participants discussed a challenge for nurses and nurse-navigators (as well as many other providers) in keeping up to date with the evolving landscape of biomarker testing (See case study example in Appendix D – Kerri Medeiros).

The group identified a best practice of engaging multi-disciplinary teams to participate in regular tumor boards and use those events to educate colleagues and one another about opportunities with biomarker testing. Additionally, there are options for hosting Journal Clubs and leveraging attendance at national or international conferences to bring information back to colleagues. Nurses and nurse navigators often need to be proactive in identifying such opportunities to engage with providers from various disciplines, especially those not in oncology (including ER doctors, palliative care professionals etc.) (See case study example in Appendix D – Enza Esposito-Nguyen, Lavinia Dobraea.)

#### *Timeliness to Testing/ Insufficient Tissue/Unsuccessful Testing*

“Timeliness to testing is a problem for everybody. So, how can we as a group, here today, figure how can we improve that? How can we get a patient tested sooner? And maybe see what some other places have. Have they improved that? Because I would like to see what other pathways people have developed. Then I can go back to my community and say, ‘This is what has shown to really work in other places as a good pathway for testing and when to test. Can we incorporate this now?’”

**- Lung cancer patient who is also a Hospital Quality Administrator in a rural area on the need for the roundtable participants to address ensuring patients have speedy access to their testing results**

There is a near-universal need to press for earlier biomarker testing of patients and identifying best practices for streamlining the process for sample collection. There are multiple approaches to testing being used across institutions, with some leveraging NGS and others using different approaches for tumor testing, and/or liquid biopsies. Issues with tissue insufficiency and failed samples can cause delays and the need for re-biopsy.

Sometimes there is a breakdown in communication with the testing companies, so nurses and nurse navigators need to be proactive in following up for results. It was noted that it can be very important to have biomarker test information quickly to guide the treatment discussion with a patient and family. Individual institutions often create processes (some called them “work arounds”) to expedite moving tissue to the lab and getting it sent off for testing (See case study example in Appendix D – Candice Graham-Adderton).

There is a significant need to educate the patient and family/caregiver about this process to explain what the purpose of the test is and why it is important to wait for the results to help direct treatment decisions.

#### *Incentives/Expediting the Process within Institutions*

The group discussed the challenges associated with cost concerns and mis-aligned incentives within the healthcare delivery system and their impact on biomarker testing. For example, adherence to the CMS Oncology Care Model (OCM) can create opportunities within an institution to ensure that all providers are properly referring patients to testing. While there are potential limitations within the Value-Based-Care Model, participants noted there are also opportunities given the focus on better outcomes for patients. Nurses and other providers recognize that taking the best care of a patient can also be cost effective (especially if ER visits are reduced and diagnosis/treatment decisions can be made efficiently). Nurses and nurse navigators are often the ones who need to be proactive in leveraging these process tools to advance care that is in the patient’s best interest, including biomarker testing in general, and ensuring that there is timeliness in testing, sending of samples for evaluation, receipt of the results and communication back with the patient.

## Patient Education

“I had a patient the other day for whom we had actually done the NGS testing. We were going to targeted therapy, going over the consent, reading everything, and she looked at me and she said, ‘I can't read.’ I read with her and she looked at me and she said, ‘But I trust you and my doctor. You don't need to read it to me.’”

**- Nurse who works in an urban area with an underserved patient population on the challenges with patient education on biomarker testing**

“I always try and remind my team that the engaged patient is not the average patient. The average patient is freaked out, doesn't understand all the words we're saying to them, and really just wants to put their trust in us and say, ‘I trust you. Just do what you think is best for me.’ And that's a huge burden for us to take on as health care providers and figure out what to do with them. So, I always think about that even when it comes to patient education materials. You have to bring this down a lot more or this is not going to work in educating a patient.”

**- Lung cancer patient who is also a Hospital Quality Administrator in a rural area on getting through to the patient with simple language at a time of acute stress**

There is consensus that genomics and the role of biomarkers are highly complex topics that can be difficult to explain to patients and their caregivers. Participants highlighted the critical need for general materials and resources that can make these subjects understandable, even for patients with low literacy and educational levels. In addition, effective messaging is needed to assist with the discussion about the importance of waiting for the biomarker test results to determine best treatment options, as some patients are often eager to begin their treatment right away and become anxious about waiting. Other patients come in with the hope that they have the biomarker (See case study example in Appendix D –Enza Esposito-Nguyen. Lavinia Dobrea) associated with a specific treatment they have heard about and can become disappointed to learn that they are not eligible for that treatment.

### *Access to Results: Using the EMR*

“Many patients are not all being shown their biopsy/ biomarker testing results. For instance, the patient could create an account and have access to the results, but as providers we have to click that button that says 'Release the results to the patient.' We educate patients when they sign the consent and everything to expect results in seven to ten days, register, make an account so you could have access to your records, but that is still just giving more responsibility to the patient.”

***- Nurse who works in an urban area with an underserved patient population on patient barriers to accessing biomarker testing results report***

The group discussed barriers associated with ensuring that all providers and patients can appropriately access biomarker testing results, pointing to opportunities to leverage an EMR as a possible solution. Many institutions use EPIC for their electronic medical records. If biomarker testing results are properly entered into patients’ records, this should assist in streamlining treatment discussions and empowering patients to understand their potential options (including participation in clinical trials). It was noted that despite the test results being in an EMR, many patients do not seek or gain access to this information. The NCI Clinical Center has a unique model for storing and retrieving testing data as all tests are ordered and conducted in-house.

### *Reimbursement, Financial, Transportation & Paperwork Issues:*

“The navigator calls the company they're sending the tissue sample to and works with their billing and they take it right away and just expedite because they know what's going to get denied. They know they're going to have issues. And then we're, having... intimate discussions with the companies were sending to saying, 'Hey, can we get this agreement that we can just process it. We'll deal with the billing on the back end.' The delays were just getting bigger and bigger and it's stupid little paperwork. Someone didn't see this and left it or denied it and then it's another five days. We are trying to build that intimate close connection with the labs that we're sending to.”

***- Nurse who works in an urban area with an underserved patient population on financial and bureaucratic barriers to patients accessing biomarker testing***

There is widespread recognition that patient access to biomarker testing is sporadic and can be negatively impacted by insurance, cost factors, transportation and other logistical challenges.



Nurses and nurse navigators are often on the front lines of these conversations with patients to understand their limitations and help them get the care they need – including traveling to another institution for biomarker testing. Depending on the demographics of the population served by an institution, issues of reimbursement and transportation may be major barriers to access. As the paradigm for precision cancer treatment continues to evolve, coverage will need to expand, and testing capabilities will need to become more ubiquitous among care delivery centers. One opportunity for institutions to keep in mind is to consider sending patients to the NCI Clinical Center, which has instituted protocols for monitoring, tracking and testing patients at every stage of disease. Because it is federally funded, the Clinical Center does not charge patients or deal with insurance.

### **Elements of the Ideal Patient Biomarker Journey:**

A central part of the Roundtable meeting agenda focused on eliciting from participants their view of elements within an “Ideal Patient Biomarker Journey” leading into and through biomarker testing. Meeting participants worked in break-out groups to consider this topic as posed by these questions:

- Discuss what an “ideal patient biomarker journey” looks like and the top opportunities to advance that vision
- Identify areas for ongoing collaboration/focus to address pain points
- Identify which stakeholder(s) should take charge of the work
- Determine which issues patient advocates can be involved with to create better access for patients

Once re-convened, each break-out group reported their feedback and a collective picture of a framework for defining an “Ideal Patient Biomarker Journey” (and related needs) emerged:

**Priority Aspects of an “Ideal” Biomarker Testing Process:**

- Ensure adequate biopsy (enough tissue is collected)
- Ensure appropriate Tissue Handling
- Ensure complete, quick and accurate staging
- Biomarker test results should be available within 2 weeks (eliminate the 14-day rule)
- Aim for NGS or most relevant biomarker testing at time of diagnosis (reflex testing to occur before oncologist visit)
- Seamless streamlined process within every institution
- Partner with screening centers/programs to encourage biomarker testing
- Develop top-down incentives within institutions to encourage biomarker testing

**Provider Education:**

- Leverage tumor boards
- Engage broad range of providers: pathologists, oncologists, interventional radiologists, hospitalists, nurses, palliative care and hospice providers
- Encourage IASLC to partner to educate other providers
- Support enhanced genomic education and in medical schools and for nurses

**Patient Education:**

- Patient receives information about biomarker testing regardless of where lung cancer diagnosis is made and what stage diagnosis is given
- Patient education is based on up-to-date content
- Accurate information comes up first during Google searches for lung cancer (SEO for validated content)
- Patient’s receive education to assist with test interpretation

**Leveraging Patient Navigation:**

- Patients meet with a navigator in-person before the first doctor meeting, although emphasis on an in-person meeting should be allowed to delay receipt of test results. In that case, navigator meeting should happen virtually or by phone.
- The first visit should be sufficiently long to allow for comprehensive discussion, and navigation should be available beyond first visit
- Nurses and nurse-navigators have access to latest data for new therapies (targeted therapies, Immuno-Oncology therapies, combinatorial treatment approaches)
- Additional navigation resources are secured to ensure patient needs are met, including enhanced shared-decision-making tools

**Address Access Barriers:**

- Eliminate financial barriers to biomarker testing, including ensuring efficient insurance review and automating prior authorization process
- Address transportation needs of patients

### Top Priorities for Action Toward the Ideal Patient Biomarker Journey

“You know how we used to do HIV testing? If their mouth swab comes back positive, the next thing you do a Western Blot. I mean, there was no two ways about it. And it seems to me if you have non-small cell lung cancer, you get biomarker testing. There’s no two ways about it.”

**– Lung cancer patient and a former nurse on the need for reflexive biomarker testing for NSCLC patients**

“I think biomarker testing does need to be part of the system, but I don't think the patient should have to be asking for it. I think we should be beyond that at this point. But this group, nurses, patient navigators, they should absolutely be educated because it is this person’s job to advocate for the patient and go to the provider and say, ‘Would you consider doing this testing for this patient?’ And having actually that group really educated on what should be the standard now would be the most helpful.”

**- Lung cancer patient who is also a Hospital Quality Administrator in a rural area on the importance of empowering nurses and navigators to be an advocate for biomarker testing**

Roundtable participants identified a series of top priority actions for the community to undertake to advance toward further defining and achieving an “Ideal Patient Journey” with biomarker testing. These include:

- Moving toward reflex testing at time of diagnosis for all patients (even those with earlier stage diagnoses).
- Further exploring “best practice” for testing type. The group acknowledged disparate practices among various institutions regarding use of NGS testing, liquid biopsy and other approaches.
- Enhancing biomarker testing education for providers and making it more accessible to a range of providers, including developing online tools with current and emerging biomarkers in lung cancer mapped to current indications and therapies.
- Leveraging industry outreach channels (including MSL networks) to disseminate resources and tools that can expand provider biomarker testing education
- Promoting high-functioning multi-disciplinary teams, including enhancing opportunities to expand the reach/influence of nurses and nurse navigators within tumor boards, pathologists, and other care team provider touch points (ER, hospice etc.).

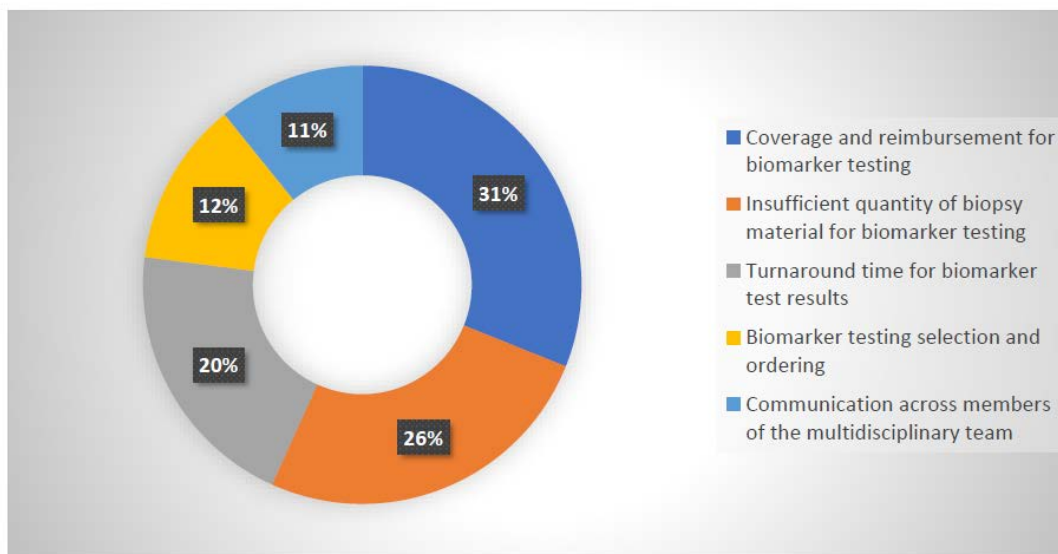
- Facilitating and incentivizing the successful use of biomarker testing by leveraging accreditation bodies to look at biomarker testing as part of how they evaluate institutions.
- Focusing on timeliness of testing and ways to minimize testing failures, including improving sample collection and focusing on communication with testing providers.
- Promoting reimbursement for patient and nurse-navigators to expand their availability and support their efforts to expand the use of biomarker testing.
- Sharing best practices from academic centers and other institutions where biomarker testing has expanded to reach more patients.
- Advancing a public campaign to educate patients and the broader public about the importance of genomics (as distinct from genetics) and the value of biomarker testing. Encourage industry to collectively consider an approach focused on these cross-cutting messages rather than product/company specific direct-to-consumer (DTC) advertising. Focus on disparate populations and geographies less likely to have this information.

## Panel 1: Societies' Work in Advancing Precision Medicine & Biomarker Testing

"We're right now in an era where Americans trust their doctors less than they ever have before, but they trust nurses. I think from that vantage point, helping educate the patient and tell them about their options, that critical communication point lies on the shoulders of the nurses and the rest of the multi-disciplinary team."

- **Marianne Gandee, Association of Community Cancer Centers**

**Marianne Gandee of ACCC** presented her organization's work in support of advancing biomarker testing within community cancer centers. In discussing the vitally important role of nurses in advancing multidisciplinary care, Ms. Gandee cited annual Gallup data indicating that nurses remain the most trusted medical professionals. ACCC has been focusing on promoting precision medicine and biomarker testing within Value-based Care for many years. In 2018 the organization conducted research among its members to understand "what good looks like" in integrating pathology within the cancer care team. That effort yielded important insights about key barriers that exist within the community cancer ecosystem, including five most frequently cited barriers:



Ms. Gandee described ACCC efforts to address these barriers, including hosting a Stakeholder Leadership Summit focused on this topic in 2018 which prioritized seven action opportunities:

- Empowering pathologists and the oncology team for culture change
- Standardizing the testing order process
- Improving tissue and blood handling and management

- Optimizing virtual molecular tumor boards
- Strengthening the alliance between pathology and genetic counseling
- Generating “One Standardized Pathology Report”
- Educating and empowering patients

In 2019 ACCC is creating a Precision Medicine Checklist tool for the oncology care team, taking a cue from the surgery field in providing a simple tool to evaluate precision medicine activities and understand the areas of gaps. The goal of this effort is first to raise awareness and understanding, and then to engender behavior change. To this end, ACCC is conducting a visiting expert series on the topic of biomarker testing. Finally, the organization is developing a “One Pathology Report” designed to be standardized from the multi-disciplinary team level, to help with some of the communication between different disciplines and understanding gaps in practice training in molecular pathology in an era of precision medicine.

In emphasizing the importance of nurses and nurse navigators in the community cancer care ecosystem and the opportunity to leverage their role to advance precision medicine, Ms. Gandee presented survey data about the responsibilities of Advanced Practitioners. She highlighted the importance of their work conducting in-person follow up and one-on-one education with patients.

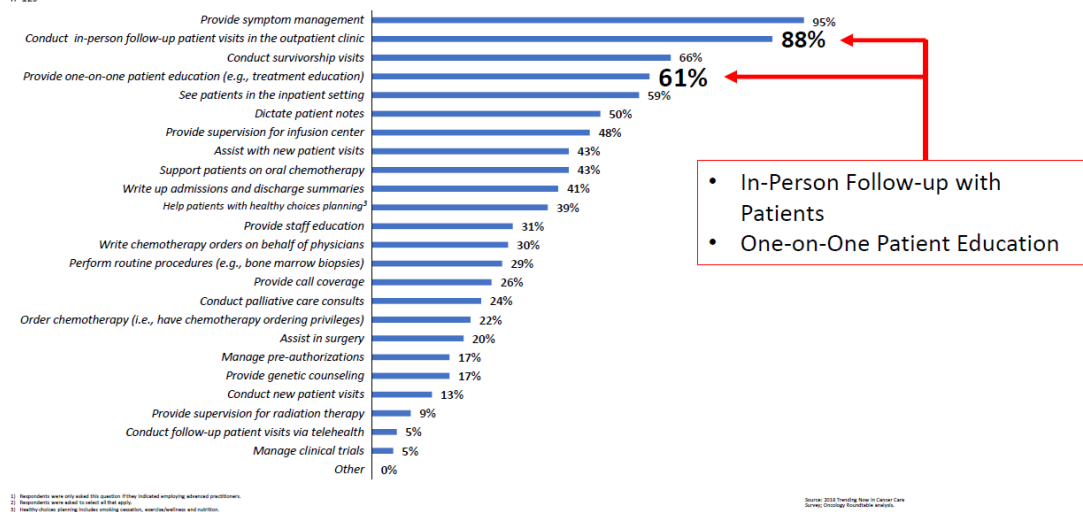
## Advanced Practitioner Responsibilities

Symptom Management and Outpatient Follow-Up Visits Most Common Tasks

Which of the following tasks are regularly performed by advanced practitioners in the cancer program or practice?<sup>1,2</sup>

Percentage of respondents, 2018

n=129



Ms. Gandee noted that the top “pain point” ACCC has identified for its members in adopting biomarker testing is related to reimbursement (a challenge that has now surpassed the costs of drug as barriers to efficient operation). Practices are hiring multiple staff members just to handle reimbursement paperwork. There is a need for a person who can be the financial advocate to help providers understand how to use tools within their program and then also within their community to support the cancer patients to make sure that they're getting access and coverage. Additionally, some pharmaceutical companies are using their medical science liaison (MSL) networks and other channels to help support the biomarker testing connection to products. All of these efforts point to the need to be engaged with payers as well to get everyone aligned about the importance of biomarker testing.

“Nurses and nurse navigators are on the interprofessional team. I love it when I see nurse navigators presenting at tumor boards, putting together all the information, advocating for patients from the moment they're diagnosed and into treatment, and increasingly, into survivorship.”  
– **Lisa Kennedy Sheldon, Oncology Nursing Society**

**Lisa Kennedy Sheldon of ONS** noted that there are approximately 100,000 people that identify as oncology nurses in the United States (as compared with about 14,000 medical oncologists). This does not include 5,000-7,000 Advanced Practitioners and others in related fields. Nurses take care of 1-5 patients a day, meaning there are almost 1 million “touch” opportunities between nurses and cancer patients. This large workforce has significant training needs, which ONS is working to fill, especially in areas of genomics and biomarker testing. For 2019 ONS has three major strategic priorities:

- Preparing nurses to lead the delivery of quality cancer care
- Increasing the generation and implementation of evidence to improve quality cancer care
- Leveraging technology and partnerships to maximize ONS resources

Ms. Sheldon emphasized the importance of training nurses in general communication skills, as well as providing specific training about topics such as biomarker testing. Nurses are key players in helping patients deal with anxiety over wait times and results that may not point to a specific approved therapy. ONS is exploring creative approaches to advance these efforts, including conducting role-play trainings and leveraging social media and novel technologies to develop more ways to present complex contents in more “bite-sized” formats. ONS is also focused on reaching underserved and vulnerable populations, especially within the community settings. The organization is exploring opportunities to use advanced practice nurses in clinical

trials and tele-health to reach more patients in the community setting. ONS is also leveraging its policy work to advocate for reimbursement for navigation for care coordination and biomarker testing.

## Roles of Nurses in Transforming Cancer Care

### *Nurses working in many roles to transform cancer care*

**Oncology nurses** – educators, clinicians, telephone triage, oral adherence, home care, clinical trials nurses

**Oncology nurse navigators** – screening, diagnostic workup, care coordination

**Advanced practice nurses** – screening, diagnostic process, ordering tests, prescribing authority, symptom assessment and management, survivorship care, palliative care

**Nurse Scientists** – generating evidence, serving as faculty, leading research teams in novel, translational and pragmatic studies, clinical trials

**Quality Improvement Specialists** – translation of evidence into clinical practice to track and improve quality indicators



“We’ve all seen those cases where they got treated too quickly. They didn’t get the right tests done. The med onc may have ordered testing, but they didn’t do a full panel or specific ones, so they just burned the patient’s insurance. We know they should have had these tests done in addition. Or which one of PD1 did they have done? It’s the wrong one. That’s not the drug they were supposed to get. We’ve all seen that background, so I think it’s critical to today’s discussion to discuss how are we really going to fill this gap?”

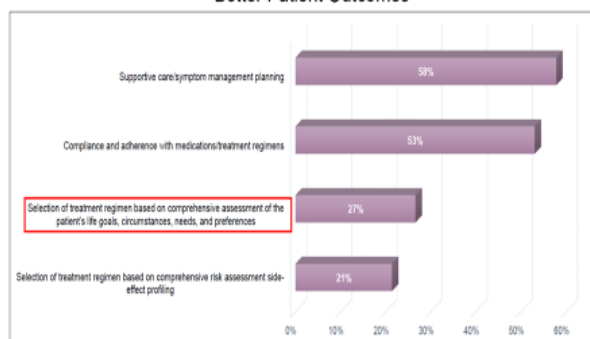
– **Lavinia Dobrea, Academy of Oncology Nurse and Patient Navigators**

**Lavinia Dobrea of AONN** provided an overview of the important roles of nurse navigators within the oncology care team, especially within the community practice setting. A pivotal point of entry for nurse navigators in the patient journey occurs at the time of initial diagnosis and first physician visit. The role of the navigator is a specialized one focused on educating the patients and the team, and making things happen. Ms. Dobrea also emphasized the central role that pathologists have come to play within tumor boards. However, she noted that many



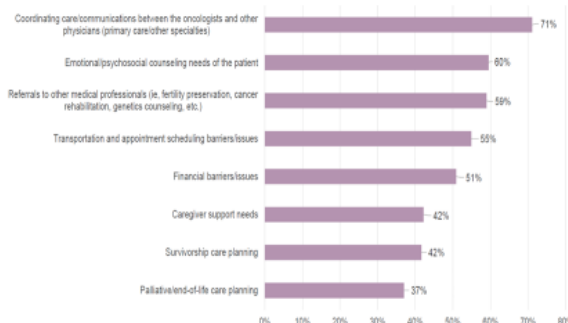
pathologists still stick with standardized guidelines or hospital policies relating to biomarker testing and this means that some patients are still not getting the testing that they need to best define their treatment options. There are process barriers as well to be addressed, including ensuring the right test is ordered from the beginning, to avoid insurance denials for subsequent testing and insufficient tissue samples.

### Clinicians Engage Navigators in Clinical Conversations to Help Define Therapeutic Intentions and Select Course of Therapy for Better Patient Outcomes



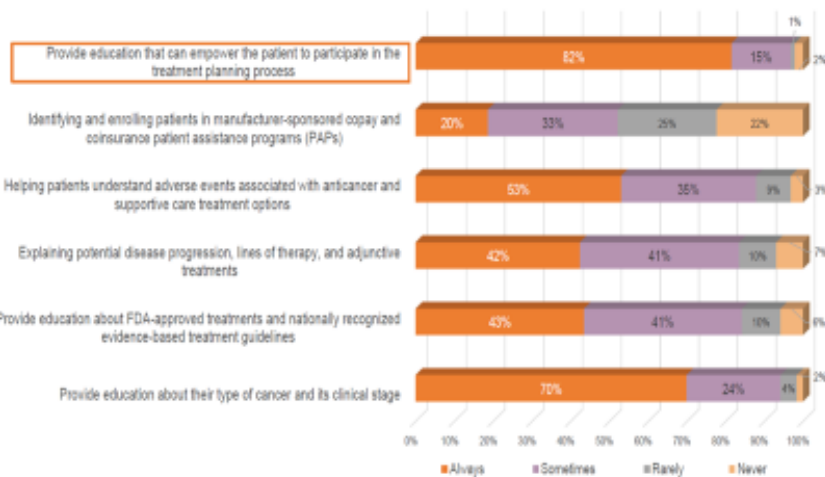
Question: What are the most typical reasons for a consultation with an oncology specialist (purpose, medical oncologist, radiation oncologist, about you patient)? Data on file with the Academy of Oncology Nurse & Patient Navigators (AONN). 11

### Navigators Also Help Clinicians and Their Patients Break Down Barriers to Care for Better Patient Outcomes



Question: What are the most typical reasons for a consultation with an oncology specialist (purpose, medical oncologist, radiation oncologist, about your patient)? Data on file with the Academy of Oncology Nurse & Patient Navigators (AONN). 12

### Navigators Provide Critical Patient Education, Consultation, and Guidance Support for Better Patient Outcomes



Question: Throughout the care continuum, how often do you provide patient education, consultation, or guidance support on the following subjects? Data on file with the Academy of Oncology Nurse & Patient Navigators (AONN). 17

Panel 2: Nurses and Nurse Navigators: Everyday Experience with Biomarker Testing

“In my role, I often speak with every new lung cancer patient. The second question is, do you have the type of insurance we take? And if you don't, let me help you find somewhere where you can go.”

– **Kerri Medeiros, Oncology Nurse Navigator**

**Kerri Medeiros, Oncology Nurse Navigator at Maine General Hospital**, described the characteristics of the patients served by her institution, especially the high rates of lung cancer incidence and death among the rural, over-65 and predominantly white population. In her center, 100% of cancers are tested for major genomic mutations, although NGS is not used. Tumor boards are multi-disciplinary and include nurse navigators, as well as experts from other institutions to provide additional insights and resources. Ms. Medeiros described the top barriers for nurse navigators in her practice as discussing the complex topic of biomarker testing with patients, with materials that are appropriately aimed for the education and comprehension level of her patients. She also emphasized the challenge of staying current on latest developments in the field to be able to de-bunk myths and being equipped to help patients understand why they must wait for testing results to ensure they get the best treatment recommendations.

“Is the patient really ever going to be well enough to come to an outpatient visit and to help guide that conversation for their family? Or maybe they will, but if they're only really going to be eligible for a targeted therapy, let's get that information quickly. We created a system where our fellows will go and facilitate that biopsy in the hospital and then bring up the tissue, or bring the sample back to the office, process it and send it. By the time the patient needs to make a decision we have that information. Because sometimes the person is not even going to be leaving the hospital.”

– **Mary Ellen Hand, Nurse Coordinator RN3**

**Mary Ellen Hand, a Nurse Coordinator RN3 of Rush University Medical Center in Illinois** described her patient population as significantly urban, minority, uninsured. Her center uses the OCM and more than 95% of patients are offered biomarker testing. Rush uses Tempus and is evolving its use of platforms to meet the changing science. There are times when a liquid biopsy is used (with a 72-hour turnaround) and then results are confirmed using a tissue sample test. Patients are re-biopsied at progression. Rush has a multi-disciplinary approach in

its clinic, allowing the patient to see all the specialists in the same day. She described a two-week turnaround for results from biomarker tests but stressed that there can be delays in getting the samples sent out from the hospital. Nurses need to keep an eye on wait times to ensure that there are no delays in the process.

“If a patient has a mutation, receives targeted therapy and then progresses, we ought to retest. You have to explain that to a patient. ‘Why are we doing this?’ Well, we do it to see if they have developed a resistance mutation or have they developed a new mutation?”

– **Laura McHugh, Nurse**

**Laura McHugh, a Nurse at Baptist Cancer Center in Memphis** described her patient population as rural, minority, underserved and majority with advanced stage lung cancer. She described the standard at her community center of performing biomarker testing on presentation and again at progression (which is something that needs to be carefully explained to the patient). Ms. McHugh noted that there have recently been issues with failed tissue tests (generally caused by insufficient tissue), leading the center to do more liquid biopsies. For her a significant barrier lies in having a strong partnership with a diagnostic company that can facilitate successful tissue sampling and testing.

### Panel 3: Patients’ Personal Stories: Advocating for Biomarker Testing

“I had brain surgery, lung surgery, radiation, and I wanted to advocate for other patients. So I became part of this Facebook group called ALK+ Outreach...We’ve made some really big strides as a patient advocacy group. Everybody in that group is ALK+ or a caregiver. I was able to speak and give our voice at several different organizations. This (photo) was at the National Press Club, just talking about lung cancer and how far biomarker testing has come, and why I’m standing right here is because of biomarker testing”

– **Gina Hollenbeck, Patient and Nurse**

**Gina Hollenbeck, a patient, President of ALK Positive patient group, and a nurse** described her experience with ALK positive lung cancer, beginning with the diagnostic odyssey that took her through multiple potential (incorrect) reasons for her symptoms before she was accurately diagnosed and including the extraordinary measures she had to take to convince her insurance company to pay for the targeted therapy indicated for her tumor’s genomic profile. These experiences and her own professional background as a nurse, led her to become an

impassioned advocate for cancer patients, especially those whose tumors have the ALK mutation.

“I've always used my experience as a navigator and now in Quality trying to figure out a way to take better care of people, use what I've learned at events like this to try and take it back to my community, and figure out a better system. I am a very stubborn person and just can't give up on trying to provide better care for patients.”

– **Anne Gallagher, Patient and Hospital Quality Administrator**

**Anne Gallagher, a patient and a Hospital Quality Administrator**, described her experience having been diagnosed with lung cancer in the pre-biomarker testing era after an incidental finding during an unrelated medical exam. At the time, there was a very different standard approach to timeliness of diagnosis and treatment options. However, over the years, she has relapsed and undergone various treatments for her lung cancer, leading her to become an empowered patient advocate. In her professional life, Ms. Gallagher has been a hospital administrator in quality improvement and a patient navigator, so she has multiple vantage points from which to consider ways to improve the patient’s biomarker testing journey.

#### Case Studies: Best Practices: Case Studies that Advance Biomarker Testing

“It is imperative that, regardless of what care we provide to a patient, we need to be ‘Johnny on the Spot’ and up our game, because patients come to us hoping that we have those answers. We've heard time and time again how we are looked at as being the unsung hero, being able to spend the time with patients, to be able to educate them. Regardless of what our background is, whatever it is we're looking to do, we need to embrace that and educate ourselves and it may be that, as a group we need to constantly be throwing the data in front of everybody saying ‘This is how you need to use this. This is why it is important. This is what patients are asking.’ Sometimes it's a matter of saying ‘This is what your patients want to know, why don't you know it?’”

– **Amy Jo Pixley, Thoracic Oncology Nurse Navigator**

**Amy Jo Pixley, a Thoracic Oncology Nurse Navigator at Lancaster General Health in Pennsylvania** presented the “Crooked Path” case study, describing the evolution of standard

practice for diagnosing and treating lung cancer patients over her many years of experience as a Nurse Navigator at the Lancaster General Health Borshinger Cancer Institute. Using several actual patient cases, she highlighted a variety of areas of challenge she sees in the biomarker testing arena, including the tissue sample needs associated with NGS, delays in diagnosis and development of a treatment plan caused by a lack of reflex testing, quirks in CMS guidelines that cause coverage issues for biopsies and testing, problems caused by the 14-day rule and the challenge of working with patients/family members in cases where there is no actionable biomarker (educating that biomarkers are important even if they are not actionable for a specific therapy at that time).

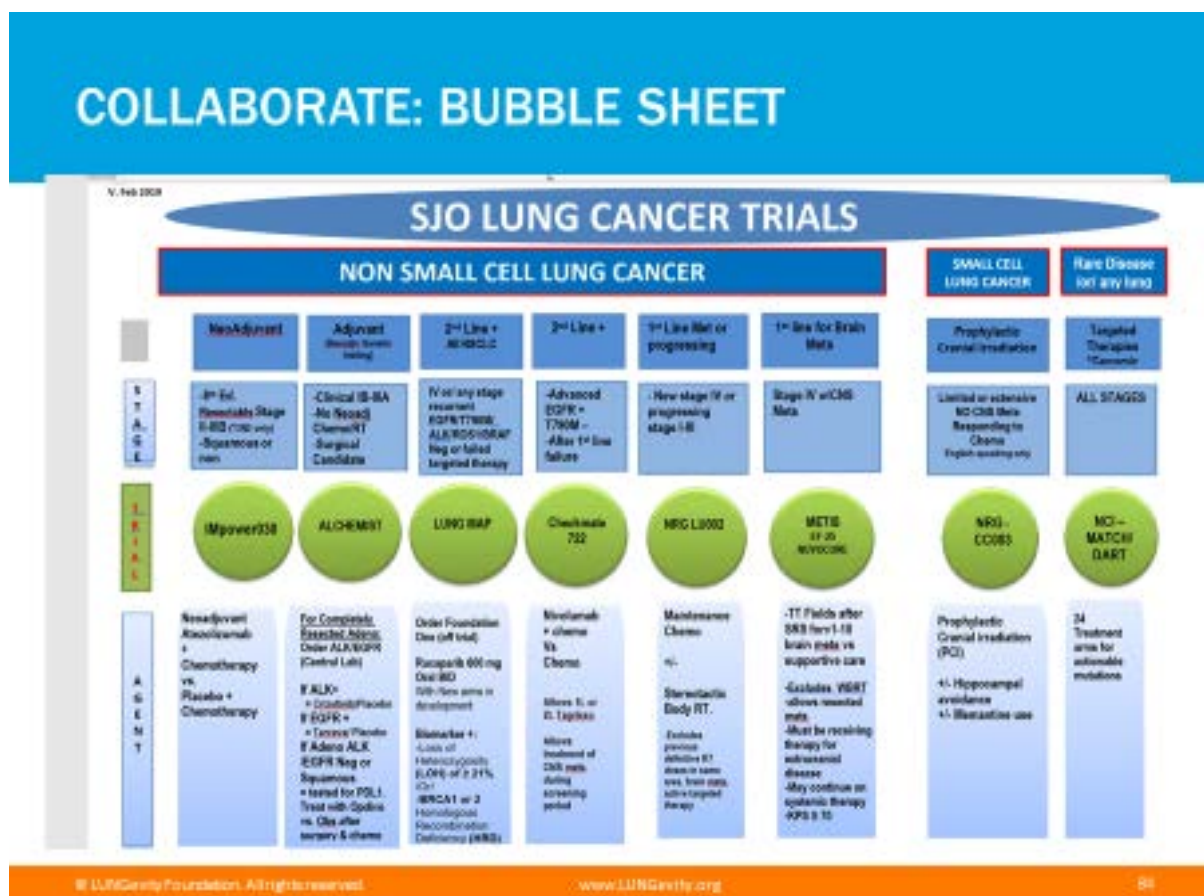
“(Having access to their biomarker testing results report) is empowering the patient to have the information, and it is allowing for portability of their care.”  
**-Mary Ellen Hand, Nurse**

**Mary Ellen Hand** kicked off a discussion about EMR/EHR Access to Testing Reports and integrating biomarker testing information into these electronic records. She described and demonstrated for the group how her team at Rush University Medical Center successfully created an order set within EPIC, including processes for standardizing consent and tracking within the medical record. She noted that using EPIC makes sense in Chicago, where about 85% of hospitals use the same system. The group discussion included comments about ways to ensure that patients have access to their biomarker testing information, which can be a problem as many patients do not currently access their own electronic medical record.

“We're getting so much information, amazing information to educate navigators, nurses, advanced practice nurses on biomarker testing, and tissue acquisition and the handling of tissue, and the different treatments out there. We have all that knowledge available at our feet. I think the missing piece that I see sometimes, is arming the nurses with the courage, the confidence of having a voice, within a tumor board or with a physician in the hallway. And sometimes maybe building a tool like this and having a piece of paper with you and saying, ‘I think this patient could potentially qualify for this trial’ or ‘How about we do this?’ or printing out the page from the NCCN guidelines and saying, ‘This patient fits here.’”  
**– Enza Esposito, Thoracic Oncology Nurse Practitioner and Navigator**

**Enza Esposito-Nguyen a Thoracic Oncology Nurse Practitioner and Navigator at Providence St. Joseph Hospital in Orange** presented the third and final case study focused on empowering

nurses and nurse navigators. In discussing the Impact of Our Voice, Ms. Esposito-Nguyen described efforts she has undertaken at her community center to advance use of biomarker testing and enhance treatment and clinical trial opportunities for their patients. They created a ‘‘bubble sheet’’ to help guide discussions during tumor board meetings, where the multi-disciplinary team would attempt to match each patient with a place on the chart.



### Conclusion and Next Steps

Nurses and nurse navigators are often referred to as the glue that keeps the multi-disciplinary cancer care team focused on addressing the needs of the patient. Given their important role, it’s critical that the healthcare community invest in supporting this group so they can continue to improve patients’ timely access to comprehensive biomarker testing. This roundtable showcased the many pressures that nurses and nurse navigators are under to stay up to date on the changing lung cancer landscape, manage aspects of the patient’s testing journey, and ensure patients understand the need for having and waiting for the results of comprehensive biomarker testing before making treatment decisions. Yet in spite of these inordinate pressures, many roundtable attendees provided clear evidence that they don’t always have the

correct or adequate resources to fully address these challenges and make sure that timely, high quality biomarker testing happens.

In addition to understanding the landscape that nurses and nurse navigators are operating in, the roundtable shed light on the ideal patient biomarker journey from the perspective of nurses and nurse navigators. The challenge coming out of the roundtable's energetic sharing and collaborative envisioning for a better biomarker experience is to bridge the delta between the current barriers to testing and deliver on making comprehensive biomarker testing a reality for all advanced stage NSCLC patients. In collaboration with ONS, AONN, ACCC, LUNGeivity is eager to bring more discussion and strategic action to bear on the key barriers taking their toll on nurses and nurse navigators' ability to effectively support patient access to testing.

#### *Next steps*

LUNGeivity will solicit feedback from the roundtable attendees to prioritize the barriers to biomarker testing that serve as the biggest challenges to patient access to better biomarker testing experiences. Once the barriers are prioritized, workstreams will be established to create strategies and tactics to address these pain points. Other nurses and nurse navigators as well as societies and patient advocacy groups interested in collaborating on the workstreams will be invited to share in this effort.

A tentative goal is set to re-convene the roundtable in the spring of 2020 to discuss ongoing barriers – particularly as the landscape continues to change at such a rapid pace – and discuss progress made since the 2019 roundtable in addressing key challenges.

## Appendix A – List of Participants

First and Last Name	Institution	Title
Dylan Ashley	LUNGevity Foundation	Grants Assistant
Colleen D. Bond, CRNP-AC, CCNS, PCCN	National Institutes of Health Thoracic and GI Oncology Branch (TGIB)	Nurse Practitioner, Thoracic Surgery
Katie Brown	LUNGevity Foundation	Vice President, Support and Survivorship Programs
Nabil Chehab	AstraZeneca	Medical Head, Lung Cancer
Lavinia Dobrea, RN, MS, BSN, OCN	Providence St. Joseph Hospital in Orange / Academy of Oncology Nurse & Patient Navigators (AONN) / International Association for the Study of Lung Cancer (IASLC)	Manager, Oncology Research and Biospecimen Program / AONN+ Leadership / Co-Chair of AONN+ National Clinical Trials Committee / Committee Member, Member at Large
Stacey Douglas	Genentech	Senior Medical Science Liaison
Meriam Driss	LUNGevity Foundation	Vice President, Strategic Partnerships
Enza Esposito-Nguyen, DNP, RN, ANP-BC, AOCNP	Providence St. Joseph Hospital in Orange / International Association for the Study of Lung Cancer (IASLC)	Thoracic Oncology Nurse Practitioner and Navigator / Committee Member, Member at Large
Andrea Ferris	LUNGevity Foundation	President and CEO
Carol Fier	Genentech	Senior Medical Science Liaison
Angela Fulford RN, BSN	Baptist Memorial Health Care Memphis	Nurse Navigator for Thoracic Oncology Multidisciplinary Program/Clinic
Anne Gallagher	Willamette Valley Cancer Institute	Quality Administrator/ Lung Cancer Patient



Marianne Gandee	Association of Community Cancer Centers (ACCC)	Director, Development and Strategic Alliances
Candice Graham-Adderton, MPH, BSN, RN, CHES	Johns Hopkins Sidney Kimmel Cancer Center at Sibley Memorial Hospital	Cancer Nurse Navigator
Mary Ellen Hand, RN, BSN, OCN	Rush University Medical Center and Rush University Cancer Center/ International Association for the Study of Lung Cancer (IASLC) / LUNGeivity Foundation	Nurse Coordinator RN3, Chest Tumor Clinic / Committee Member, Member at Large / Former Board Member
Gina, Hollenbeck RN, BSN	ALK Positive Outreach	President / Lung Cancer Patient
Lisa Justen	LUNGeivity Foundation	Grants and Partnerships Manager
Lisa Kennedy Sheldon, PhD, APRN-BC, AOCNP, FAAN	Oncology Nursing Society (ONS) / St. Joseph Hospital	Chief Clinical Officer / Oncology Nurse Practitioner
Nikki Martin	LUNGeivity Foundation	Director, Precision Medicine Initiatives
Laura McHugh, RN	Baptist Memorial Health Care Memphis	Physician Nurse for Dr. Raymond Osarogiagbon, Medical Oncology
Kerri Medeiros, RN, BSN, OCN, ONN-CG (T)	Maine General Harold Alfond Center for Cancer Care	Oncology Nurse Navigator
Sarah Moseley	AstraZeneca	Medical Director, Diagnostics Oncology
Gigi Smith, BSN, RN	Medical City McKinney	Director, Physician and Provider Relations
Amy Jo Pixley, MSN, RN, OCN, ONN-CG (T)	Penn Medicine, Lancaster General Health, Ann B.	Thoracic Oncology Nurse Navigator / AONN+ Leadership

	Barshinger Cancer Institute / Academy Of Oncology Nurse & Patient Navigators (AONN)	
Emily Prince	Bristol-Myers Squibb	Biomarker Diagnostics, Medical
Jackie Rosenbaum	Bristol-Myers Squibb	Associate Director, Advocacy and Policy
Kristen Santiago	LUNgevity Foundation	Senior Director, Public Policy Initiatives
Wendy Selig	WSCollaborative	Founder and CEO
Neil Sheehy	Guardant Health	Product Manager
Nikole Ventra	LUNgevity Foundation	Support Services Manager
Cheryl Warga, CRNP-Family	National Institutes of Health Thoracic and GI Oncology Branch (TGIB)	Nurse Practitioner, Thoracic Surgery
Mike Zincone	Pfizer Oncology	Director/Team Lead, Advocacy and Professional Relations

## Appendix B – Meeting Agenda



Nursing and Nurse Navigator Roundtable Agenda  
 Saturday, March 9, 2019  
 Bethesda North Marriott Hotel & Conference Center  
 5701 Marinelli Road, Rockville, MD 20852  
 8:00 AM – 4:00PM

8:00	<b>Breakfast/Registration</b>
9:00	<b>Welcome</b> <i>Andrea Ferris, President &amp; CEO, LUNGEVITY</i>
9:05	<b>Take Aim Overview and Activities to Date</b> <i>Nikki Martin, Director, Precision Medicine Initiatives, LUNGEVITY</i>
<b>Panel Presentations</b>	
9:20	<b>Societies' Work in Advancing Precision Medicine &amp; Biomarker Testing</b> Moderator: <i>Katie Brown, VP, Support and Survivorship Programs, LUNGEVITY</i> <ul style="list-style-type: none"> <li>- <i>Precision Medicine at Community Cancer Centers, Marianne Gandee, Director of Development and Strategic Alliances, Association of Community Cancer Centers (ACCC)</i></li> <li>- <i>The Role of Professional Organizations in Supporting Precision Oncology, Lisa Kennedy Sheldon, PhD, APRN-BC, AOCNP, FAAN, Chief Clinical Officer, Oncology Nursing Society (ONS)</i></li> <li>- <i>AONN's Work with Sub-Specialty Navigators, Lavinia Dobre, NR, MS, BSN, OCN, Manager, Oncology Research &amp; Biospecimen Program, St. Joseph Health</i></li> </ul>
10:05	<b>Nurses and Nurse Navigators: Everyday Experience with Biomarker Testing</b> Moderator: <i>Andrea Ferris, President &amp; CEO, LUNGEVITY</i> <ul style="list-style-type: none"> <li>- <i>Mary Ellen Hand, RN BSN OCN, Nurse Coordinator, Rush University Medical Hospital</i></li> <li>- <i>Kerri Medeiros RN, BSN, OCN, ONN-CG (T), Oncology Nurse Navigator, Maine General Hospital</i></li> <li>- <i>Laura McHugh, RN, Physician Nurse for Dr. Raymond Osarogioagbon, Medical Oncology, Baptist Memorial Health Care Memphis</i></li> </ul>
<b>10:50-11:05 BREAK</b>	
11:05 AM	<b>Patients' Personal Stories: Advocating for Biomarker Testing</b> Moderator: <i>Linda Wenger, SVP, Marketing &amp; Communications</i> <ul style="list-style-type: none"> <li>- <i>Gina Hollenbeck, RN, BSN, President, ALK Positive Outreach</i></li> <li>- <i>Anne Gallagher, Quality Administrator, Willamette Valley Cancer Institute</i></li> </ul>
<b>Best Practices / Case Studies that Advance Biomarker Testing</b>	
11:45	<b>Crooked Path to Molecular Analysis</b> <i>Amy Jo Pixley, MSN, RN, OCN, ONN-CG(T), Thoracic Oncology Nurse Navigator, Penn Medicine, Lancaster General Health, Ann B. Barshinger Cancer Institute</i>
12:05	<b>EHR Access to Biomarker Testing Reports</b> <i>Mary Ellen Hand, RN, BSN, OCN, Nurse Coordinator, Chest Tumor Clinic RN3, Rush</i>



	University Medical Center
<b>12:25-12:55 LUNCH</b>	
12:55	<b>Impact of Our Voice</b> <i>Enza Esposito Nguyen, MSN, RN, ANP-BC, Thoracic Oncology Nurse Practitioner/Navigator; Committee Member/Member at Large, IASLC</i>
<b>Breakout Groups/Report Back</b>	
1:15	<b>Workgroup Breakouts</b> <ul style="list-style-type: none"> <li>- Discuss what an ideal patient biomarker journey looks like and the top opportunities to advance that vision</li> <li>- Identify areas for ongoing collaboration/focus to address pain points</li> <li>- Identify which stakeholder(s) should take charge of work</li> <li>- Determine which issues patient advocates like LUNGeVity can be involved in to create better access for patients</li> </ul>
<b>2:30-2:45 BREAK</b>	
2:45	<b>Report back</b> <ul style="list-style-type: none"> <li>- Each workgroup reports back their findings</li> <li>- As a collective roundtable, prioritize the top areas of focus</li> </ul>
3:45	<b>Next Steps</b> <i>Nikki Martin</i>
4:00	<b>Closing Remarks</b> <i>Nikki Martin</i>

## Appendix C – Meeting Sponsors

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## Appendix D: One Page Case Study Summaries

Nurses and nurse navigators have provided specific best practices within their own institutions for overcoming select barriers to biomarker testing.



### Stay Up-to-Date with Biomarker Testing and Precision Medicine to Effectively Communicate with Patients

Kerri Medeiros, RN, BSN, OCN, ONN-CG (T)  
Oncology Nurse Navigator, MaineGeneral Medical Center's Harold Alfond Center  
for Cancer Care

#### **Situation Overview**

A nurse navigator is on the frontlines of cancer care and is often one of the first contacts patients have when entering the oncology world. The treatment of lung cancer is a rapidly advancing field and it is up to individual nurse navigators to stay current in evidence-based best practices to communicate effectively with the patient. Nurse navigators – particularly those in remote areas – may find staying in touch with the latest advancements in lung cancer and biomarker testing additionally challenging.

Lung cancer navigators regardless of where they work should stay up to date on biomarker testing and associated treatments. The nurse should know and be able to explain to the patient, not only biomarker testing, but also when testing is appropriate and likely to be incorporated into the patient's care. This can be challenging for nurses as genomics is not an easy subject to understand, let alone explain to a patient. In addition to this, patients often come with questions such as "Can I get what is advertised on the TV commercials to treat my lung cancer?" or "Can I take a pill like my neighbor takes for their cancer?" To add to this complexity, the nurse must be careful not to offer false hope that there will be a mutation that is actionable. Addressing this with the patient and their family requires a strong background in the latest science.

#### **Goal**

Seek knowledge and stay up-to-date on oncology care and biomarker testing in order to educate patients and caretakers on issues like performing biomarker testing, waiting for testing results, and why in some cases standard of care chemotherapy, not a targeted therapy, may still be the best treatment option for them.

### **Approach**

Utilizing local experts at one's institution and national oncology and nursing/nurse navigator organizations can provide a wealth of support and knowledge so that nurse navigators can confidently and accurately provide patient education in biomarker testing and precision medicine.

- At MaineGeneral Medical Center's Harold Alfond Center for Cancer Care there are multidisciplinary tumor board conferences held twice-a-week and genomic tumor boards held monthly. Attending these meetings is critical for staying up-to-date with biomarker testing, what tests are done reflexively, and the treatments associated with the biomarkers.
- Another valuable source of information regarding biomarkers and treatments is utilizing local experts such as pathologists, medical oncologists, and research staff to provide education and answer questions.
- National nursing and oncology organizations are also available for locating best practice information. The Oncology Nursing Society (ONS) and Academy of Oncology Nurse Navigators + (AONN) send out monthly journals and have online webinars that are available for nurses to stay current in their field. Membership to these organizations comes at a low annual cost. Biomarker testing and the latest treatments associated with testing are automatically shared with you as a member through emails with links to register for webinars, or to current articles.
- ONS and AONN often have local chapters that offer meetings that include a didactic portion provided by an expert speaker in an area of oncology. Members can request educational topics for the program chair to arrange. Education may be branded or unbranded. For example, the North Eastern ONS and AONN chapters provide educational topics on tissue and serum testing, as well as precision medicine treatment education. Education on biomarker testing and somatic mutation identification that leads to treatment selection is included in the lecture, which enables the nurse to understand the science behind the treatment determination. An overview of clinical trial data is also shared.
- Association of Community Cancer Centers (ACCC) sends emails with links to webinars and articles. There are also forums where members can pose questions and other members and experts offer their knowledge.
- National Comprehensive Cancer Network (NCCN) website has guidelines posted that are kept up to date with best practices of biomarker testing and approved treatments.

### **Outcome**

Nurse navigators along with the medical oncologist and advanced care providers provide patients with education regarding biomarkers and assure that patients have timely biomarker testing. The impact of nurses and nurse navigators staying abreast of advancements in biomarker testing and precision medicine contributes to the biomarker testing trends at Maine General Medical Center:

- In 2017, Maine General Medical Center treated 225 patients with lung cancer, of which 81 patients were stage IV. One hundred percent of the stage IV adenocarcinoma patients were tested for EGFR, ALK, ROS 1 and PDL 1.
- More recently stage1V squamous cell lung cancers have started to receive testing for PDL 1.
- Biomarker testing is done on all stage IV adenocarcinoma lung cancers and patients that have enrolled in clinical trials. In addition, 17 lung cancer patients enrolled in clinical trials received next generation sequencing for an opportunity to be treated with a targeted therapy in clinical development.
- Patients that progress to metastatic disease are brought before the tumor board to discuss re-biopsy or sending original pathology for biomarker testing.





## **Nurses and Nurse Navigators' roles in educating non-oncology providers**

Enza Esposito Nguyen, DNP, RN, ANP-BC, AOCNP, Thoracic Oncology Nurse Practitioner  
Lavinia Dobrea, RN, MS, OCN, Manager of Oncology Research & Biospecimen Program

### **Situation Overview**

Quick and accurate screening, diagnosis and treatment planning is essential in lung cancer care. Efficient coordination of care requires healthcare providers and hospital administrators to adapt to the challenging and critical steps in high-quality, timely biomarker testing by caring for patients within a fully functional multidisciplinary team (MDT). Oncology nurses and nurse navigators play a critical role in serving as the glue that coordinates care across this group of specialists and generalists and advocates for patients' biomarker testing needs. However, it's not unusual for some non-oncology providers to have less familiarity with the need to conduct timely comprehensive biomarker testing and what it means for connecting patients to biomarker-driven therapies, including immunotherapies, as well as clinical trials for actionable mutations. Some challenges they may face include communicating to lab techs and pathologists on the impact on patient survival and increase in appropriate treatment options when comprehensive biomarker testing is performed; working with the oncologist to understand all necessary steps to acquire adequate tissue to perform comprehensive biomarker testing; multiple tissue processing and specialty labs that may be used to determine clinical trial eligibility. Lack of basic knowledge and a poor understanding of the appropriate biomarker testing steps for optimal patient care, along with complex insurance processing may be the only challenges that keep providers from collaborating within the MDT.

### **Goal**

Spread basic key know-how about precision medicine, biomarker testing, and clinical trials in lung cancer to all stakeholders including patients, lab technicians, specialty non-oncology physicians, and other nurses involved in care to understand the importance to test in a timely manner; how tissue is handled and by whom; where and how tissue is to be sent; and how much tissue is needed to conduct the necessary biomarker testing. In addition, advocate for the MDT to become familiar with and commit to time tables and testing turnaround time in order to avoid misunderstandings and disappointment.

### **Approach**

- Proactively communicate with patients, family about goal of care and standard of care.

- As patients move through the continuum of care, discuss the expectations with everyone involved, foresee possible roadblocks, possible needs, or assistance you may need from colleagues.
- Review and share clinical trial information at monthly program meetings and via email blasts.
- Invite non-oncology providers to tumor board to learn about how their help and involvement can affect care positively.
- Invite non-oncology providers to Journal Clubs.
- Hold grand rounds/ best practice highlights that could also help other specialties streamline any processes.
- Identify a champion who can help the nurse/nurse navigator secure buy-in to conduct an in-service or quality improvement (QI) project. In today's world where hospitals and centers need to provide results and quality outcomes for reimbursement or certifications, these types of collaborations can be very beneficial to both patient outcomes and cancer programs.

### **Outcome**

These interventions can lead to some of the outcomes listed below and increased cohesiveness of the MDT:

- Team up with Pathology Department to track rates of testing or quantity not sufficient (QNS) rates
- Anecdotal reports from oncologist about testing rates/outcomes
- Discuss testing and review guidelines with every case presented at tumor board
- Review each case for clinical trial consideration

When oncology nurses and nurse navigators take steps to increase provider education about biomarker testing, it can lead to increased awareness and patient participation in clinical trials and advance other types of valuable collaboration within the MDT that drive a stronger team approach to precision medicine.

**These are all initiatives/ activities that could be launched by nurses/nurse navigators.**



## **Speaking to patients without hyping the promise of precision medicine**

Enza Esposito Nguyen, DNP, RN, ANP-BC, AOCNP, Thoracic Oncology Nurse Practitioner  
Lavinia Dobra, RN, MS, OCN, Manager of Oncology Research & Biospecimen Program

### **Situation Overview**

Oncology Nurses and nurse navigators face challenges speaking to newly diagnosed advanced stage non-small cell lung cancer patients and their family members about the benefits of biomarker testing and waiting for test results before making a treatment/care plan decision. With increased publicity of buzz words like “precision medicine”, commercials and internet advertising, many patients ask about targeted therapies and immunotherapy at their initial oncology appointments. Some patients directly ask for these highly publicized treatments without knowing first if they will be effective for them or having an understanding of how physicians determine personalized treatment options based on an individual’s unique cancer. One critical barrier nurses may face in creating clear expectations for patients around biomarker testing and appropriate care plans is that many patients misunderstand or don’t absorb the medical expectations their oncologist communicated to them. Some topics that cloud patient expectations include timing of biomarker testing, the need for sufficient quantity of tissue to perform comprehensive biomarker testing, timing for receiving results, and how these results impact their eligibility to participate in a clinical trial. Nurses and nurse navigators must overcome these gaps in communication to newly diagnosed patients. Having the full multi-disciplinary team provide clear, transparent information on biomarker testing and the impact on the patient’s treatment selection can play a major role in establishing realistic patient expectations on the biomarker process, care recommendations and availability to participate in a clinical trial.

### **Goal**

Oncology nurses and nurse navigators work with multi-disciplinary team to establish clear expectations between physicians, patients, family members and all other staff regarding the biomarker testing process for optimal patient care.

### **Approach**

- Offer clear information regarding biomarker testing, clinical stage, and treatment options including clinical trials
- Establish clear expectations regarding goal of care

- If possible, encourage these conversations with oncologist of treating physician present
- Refer patient to reliable, accurate resources for information and support
- Always remind the patient, this is a team collaboration with the multi-disciplinary healthcare team members, but ultimately they are the 'boss'
- Conduct a clear discussion about the goals of care during tumor board discussions so all members of the multi-disciplinary team have the same understanding of next steps.

### **Outcome**

The aim is for all members of the team to be clear about expectations, timelines, and goals. This avoids misunderstanding and disappointments. Once information on biomarker testing is received and staging is complete, it is helpful to meet with each patient to review options based on NCCN guidelines, so they understand standard of care approved treatment and clinical trial treatment options.

**Oncology nurses and nurse navigators are pivotal at starting these discussions and guiding these discussions with physicians and patients.**



## Peer Pressure

Candice Graham-Adderton, MPH, BSN, RN, CHES  
Cancer Nurse Navigator, Sibley Memorial Hospital- Washington, DC

### **Situation Overview**

One of the greatest challenges we face in our thoracic practice is obtaining next-generation sequencing (NGS) test results from referring providers. The majority of our patients are referred to us after a lung cancer diagnosis is made and a significant number of our patients come for a second opinion. In both scenarios, most of the patients have already undergone a biopsy, a necessary requirement for the medical oncologist to create a treatment plan or give an opinion based on the tumor's genetic makeup. However, we face many barriers to obtaining biomarker testing reports on the initial biopsy. The most common barriers we see are incomplete biomarker testing reports, and biomarker testing not performed at all.

### **Goal**

Our goal is to ensure biomarker testing is done for every patient with non-small cell lung cancer through tissue samples and/or liquid biopsies before making care plan decisions.

### **Approach**

NGS testing (300+ gene panel) is standard of care at our facility. It is an automatic process facilitated by the pathology department. For patients that seek a second opinion or are transferring care to our center from a different facility, we request all biomarker test reports. If the report appears incomplete, it is the responsibility of the nurse navigator to investigate further into the cause of this variant. A report is considered incomplete if it is missing results for actionable driver mutations or PD-L1 protein testing. The results of this type of testing help determine whether any of the FDA-approved targeted therapies or immunotherapies should be incorporated into the treatment plan.

If possible, the nurse navigator will make a formal request to the ordering provider or testing facility for the missing mutation/and or protein to be tested. If biomarker testing was not done by the referring provider, the Nurse Navigator would make a formal request via email to the ordering provider, interventional radiologist and pathologist to perform biomarker testing.

1. Identify the provider who ordered the tissue biopsy, the physician who acquired the sample and the pathologist now handling the tissue.
2. Identify the best method of communication, usually email.
3. Draft a letter that gives a brief introduction, state the request, end with the promise of follow-up.

Feedback is usually in our favor, and testing information is provided or additional testing is performed. Other times it turns into a learning experience. For other hospitals to replicate this approach it will require a designated person such as a Nurse Navigator to follow up with outside facilities to facilitate testing to reduce delays in patient care.

**Outcome**

We have had great success with this approach. We are strong supporters of biomarker testing, and we encourage this to be standard of care for all patients with lung cancer. At this time we have not quantified the impact of this intervention on our patient population. However, we appreciate the value and influence biomarker testing contributes to improved patient outcomes.

## Appendix E: Background Notes from Roundtable Prep Work

### October 2018

**Goals:** Speak to several nurses, genetic counselors and pharma/biotech partners to confirm top challenges facing nurses for discussing biomarker testing with patients in order to plan proposed Take Aim Nursing Roundtable in Q1 2019

#### Conversations:

- 7 discussions with nurses, genetic counselors and oncology patient navigators from community and academic hospitals (4 community, 3 academic)
- 2 discussions with pharma partners' nurse-facing field staff

#### Four Key Takeaways from the Conversations:

1. Nurses stressed a need for improved hospital/health system processes for testing. Nurses in community hospitals said their top concern is advocating for reflex testing for lung cancer patients. They feel that finding their voice and a venue to share it, such as a tumor board is key to advocating for patients' access to biomarker testing.
2. Nurses are responsible for having critical conversations about biomarker testing that educate and reassure patients about the role of testing in finding the right treatment path, including chemo. Many nurses referenced these conversations as "stressful" and the patients as "anxious." The academic center nurse referenced the most challenging conversations happening with patients referred to academic centers from community cancer hospitals where limited testing was performed. In those cases, patients need to re-start the testing (and waiting) process and those conversations can be very challenging.
3. Genetic counselors have experience counseling patients on different types of tests and the meaning of their test results. In some cases, they share this knowledge with nurses and other specialties, but always with the goal of helping them better discuss genetic testing with patients, not to discuss biomarker testing.
4. Genetic counselors aren't currently focused on lung cancer patients, but this could change as more is learned about germline mutations in lung cancer.

#### Summarized Highlights from Calls:

#### Nurses and Genetic Counselors Seek Process Change to Increase Patient Access to Testing and Counseling

- Not all nurses and genetic counselors worked at hospitals/health systems with good processes for biomarker testing and/or genetic counseling. These individuals stressed that having the right process for molecular testing and genetic testing inside hospitals is a bigger concern than the pain points about biomarker conversations. These people recognize there is a need for process change and would like to drive that conversation inside their places of work. Some feel that tumor boards and molecular tumor boards are a good way to start the conversation, assuming they are invited to attend.
  - Nurses in hospitals with good processes have had good internal champions leading the way – ie pulmonologists or oncologists encouraging/leading other specialties to get on board with a better system for biomarker testing.
  - Nurses in community hospitals are a voice advocating for reflex testing for lung cancer patients – although it is hard to know how to have one’s voice heard and acted on; meanwhile, genetic counselors are starting to advocate for automatic referrals for patients to be sent to them.

#### **Conversations Between Nurses and Patients About Testing Are Becoming More Common as Testing Becomes More Common**

- Nurses play a key role in “reassuring the patient” – a common phrase heard in most conversations. They need to explain testing in a simplified way and get clear with the patient on whether they understand “why we want to wait”
- There’s no typical conversation about testing as every patient and caregiver is different
- Nurses need to be able to address the difference between a somatic and germline mutation – whether it’s specific to the disease or something that can be passed onto the family.
- Most patients, when they learn they can “take a pill” are willing to wait for the results of biomarker testing.
- Academic hospital nurses deal with more challenging conversations with patients who are referred there from community hospitals. Sometimes no or limited testing occurred requiring the patient to endure more waiting for more panels to be run and/or another biopsy for more tissue.

#### **Genetic Counselors Aren’t Active with Lung Cancer Patients - Yet**

- Genetic Counselors (GCs) aren’t meeting with lung cancer patients about germline mutations, but this could change. A 2018 study presented at ASCO showed that 5% of lung cancer patients have hereditary traits.
- GCs cite breast, colon, and endometrial patients as top candidates for referral conversations from the oncologist/surgeon. GCs talk to patients about types of testing – liquid, germline, tissue, etc.
- GCs do some education of nurses/PAs regarding risk assessment for testing and how to talk to patients about genetic testing.