LUNGEVITY

Voices from the HER2 community

Understanding unmet needs of people living with HER2-positive non-small cell lung cancer

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Overview:

HER2 (ERBB2) alterations, including mutations, amplifications, and overexpression, occur in approximately 2%–4% of NSCLC cases (Yu, Ji, & Su, 2022). Despite recent approvals of targeted agents, this population remains underrepresented in research, advocacy, and peer support. Patients are frequently misidentified using breast cancer HER2 frameworks, delaying recognition of their distinct clinical and community needs.

LUNGevity Foundation's Patient-Focused Research team conducted two structured listening sessions with people living with HER2-mutated NSCLC to deepen understanding of their lived experiences and inform the Foundation's advocacy, education, and community-building priorities.

This report synthesizes firsthand participant accounts into actionable recommendations for LUNGevity Foundation, pharma partners, and the clinical community. Participant voices are preserved throughout.

Purpose

The listening sessions were designed to:

- Understand the diagnostic journey, including biomarker testing experiences.
- Identify systemic barriers to accessing appropriate targeted therapy.
- Explore the personal and emotional impact of a HER2-positive lung cancer diagnosis.
- Understand community engagement patterns and unmet support needs.
- Identify educational gaps and opportunities for LUNGevity to action upon.
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Methodology

Two 90-minute moderated listening sessions were conducted in Spring 2026 with a combined total of 12 patients living with HER2-mutated NSCLC. Each session followed a structured discussion guide covering five domains: diagnostic pathways, barriers to care, impact of diagnosis, community, and educational needs.

- Session 1: In-person at the LUNGevity HOPE Summit, May 1, 2026 (n=8 participants)
- Session 2: Virtual, May 20, 2026 (n=4 participants)

Prior to each listening session, participants received a pre-session survey that captured key demographics. This report was developed by analyzing full session transcripts from both sessions. Direct participant quotes are included throughout are de-identified.

Participant characteristics:

Twelve patients with HER2-mutated NSCLC participated across the sessions. The group represented diverse disease journeys, stages, and treatment histories. Key demographics and clinical characteristics from the pre-session survey are summarized below and presented in Appendix Tables 1 & 2.

- Fifty percent of the participants were under the age of 50. The sample was predominantly female and White/Caucasian (11/12), with one Black/African American participant. No participants identified as Hispanic or Latino.

- Most participants were diagnosed at an advanced stage. Two-thirds (8/12) were diagnosed at stage IV/advanced/metastatic disease, with an additional three diagnosed at stage III. Only one participant was diagnosed at stage I, underscoring the late-stage presentation common in HER2-mutated NSCLC.

- HER2 identification was often delayed relative to initial diagnosis. Only two learned of their cancer's HER2-positive status at the time of cancer diagnosis. The majority found out before (5/12) or after (3/12) their first treatment, and one-third (4/12) experienced a delay in biomarker testing. The findings are consistent with the barriers to timely diagnosis and molecular testing described throughout the listening sessions.

- HER2 biomarker subtype varied across the group. As expected, Exon 20 insertions were the most common subtype (4/12) (Yu et al., 2022). There was confusion around the specific type of HER2 mutation, pointing to a need for clearer biomarker education at the time of diagnosis. Despite the groups' relatively young average age, only three were employed full- or part-time. A quarter were on disability, and others were unemployed (2/12), retired (2/12), or unable to work due to illness (1/12). This reflects the significant work-life impact that participants described throughout both listening sessions.

Session findings:

Theme 1: Diagnostic pathways – A long road to the right answer

No two participants shared the same diagnostic path. What united them were the delays they experienced, difficulties communicating with their provider, their reliance on self-advocacy, and other barriers to their care.

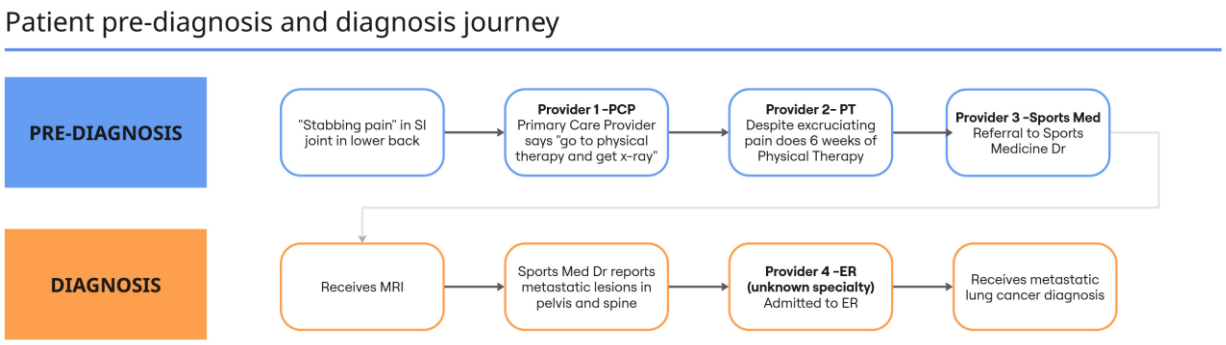
Delays in diagnosis

The most common delays participants experienced were misattributed, sometimes for months, before a lung cancer diagnosis was considered. Examples were progressive symptoms dismissed by multiple providers, withheld imaging, and eventual diagnosis only after significant disease progression. Breathlessness was attributed to asthma or deconditioning. Severe, progressive bone pain was diagnosed as sacroiliac (SI) joint dysfunction or a bulging disc. A persistent cough was treated as allergies. In multiple cases, imaging that could have detected the cancer earlier was withheld pending completion of physical therapy, or simply not offered.

> *"I didn't realize at that point that MRIs are very specific…They found a bulging disc in my neck…And so I literally did weeks of physical therapy… and then I started to develop a cough and, um, I went to see an allergist because that's what my primary care said to do, go see an allergist… "This cough is because of the seasonal allergies that you have." There was no discussion of [an] MRI: "Let's check to see what's going on with your lungs" None of that."*

Several participants described being diagnosed in emergency or acute care settings after their health deteriorated. Participants also experienced delays in getting comprehensive biomarker testing and discovery of their HER2 diagnosis, citing insurance and financial barriers and push back from their providers. **Figure 1** illustrates one participant's journey diagnosis highlighting the number of providers consulted, and challenges encountered, before receiving their diagnosis in the Emergency Room.

Figure 1



Communication with Providers

During both focus groups, insufficient communication between the participants and their providers was a recurring topic. Participants noted that there were instances where details about their diagnosis, prognosis, and condition were not communicated to them, or they found out on their own by reviewing their medical records. One participant described finding "ERBB2" in her chart and not recognizing it as HER2, spending hours in distress searching online, ultimately having a breakdown in her driveway. When the doctor called, his response offered little comfort, "Yes, not what we were expecting, but I guess it's targetable." In instances where providers informed participants of their diagnosis, they may not have discussed biomarker results, used jargon, and/or did not explain the implications of the diagnosis.

> *" My oncologist at the time, he didn't even tell me I had HER2. He just said, "Oh, we're gonna do chemo and immunotherapy." He said, "There's not a targeted therapy, um, for your mutation." So, I basically learned everything by printing out the Caris report, my pathology report, and trying to figure out what it said myself."*

A minority of participants mentioned providers that had long appointments where they were allowed to ask questions, provided video or audio recordings of their appointments for them to reference, and provided outlines of options and details on the progression of treatment.

> *" By the time I met with him, he was amazing and said, 'You have a HER2 mutation. This is what it is. Yes, it's rare.' He talked me off the ledge and explained what we were going to do and then said, 'We're going to get you on Enhertu. It's typically a second-line drug, but I think I can get you approved for first-line."*

Self-Advocacy

Often because of insufficient communication with their providers or difficulties with their insurance providers, participants resorted to advocating for their own testing and treatment. As mentioned in the section on delays, participants had to push for MRIs, CTs, and biomarker testing. Some participants reported "*begging her for an MRI*" or that they "*report pushed [their] doctors to consider some different types of therapy.*" Self-advocacy usually occurred alongside delays in diagnosis and patients seeking education and information about their diagnosis.

Barriers to Care

Almost all participants experienced at least one barrier to care, including difficulties in obtaining diagnostic imaging, or biomarker testing, and resistance from providers or health insurance providers. Many of these barriers affected diagnostics and treatment access and were discussed in the previous

sections. Participants also described ongoing insurance barriers; for example, changing insurance providers sometimes required using lower-cost medications or delivery methods. Sometimes they were not allowed to receive treatment until their healthcare team received prior authorization. Though, participants noted that their healthcare teams will handle communication with their insurance to ensure authorization is obtained.

> *"I've literally shown up for treatment, other things, and they're like, "Oh, sorry, your insurance...I've literally shown up and they're like, "We can't do the test." I'm like, "Well, I'm here. I just drove two and a half hours, so you better figure it out."*

Step therapy, the insurance requirement to try and have a less expensive treatment fail before accessing the preferred targeted agent, was not uncommon. Multiple participants reported they were required to undergo chemotherapy before Fam-trastuzumab deruxtecan could be authorized, and Fam-trastuzumab deruxtecan before zongertinib, even when the targeted therapy was the oncologist's preferred first-line choice. One participant described a stark contrast between two oncologists – one at a major university center who said he could not prescribe zongertinib without two prior lines of therapy and could not guarantee the insurance company would approve it after these two treatments had failed, and her own oncologist who was able to successfully prescribe it as first-line because it was clinically the right decision. It is important to note that zongertinib was first approved in August 2025 followed by a first-line approval in February 2026. This may explain why it may not have been the preferred choice in some of the instances described by the participants.

Theme 2: Community, Support and Impacts

Participants from the in-person listening session appreciated the opportunity to meet fellow HER2 community members in person.

> *" This is the first time I've been in a room with other people who actually understand what HER2 lung cancer means. I didn't even know this community existed"*

Overall, participants were well-connected to existing support groups or platforms with participants relying heavily upon these groups for community and informational needs. Participants mentioned using the following community support groups or forums: LUNGevity's virtual rare-mutation support group, HER2 specific Facebook groups, Young Lung Cancer Initiative, general lung cancer support groups in their geographic or hospital community, GO2 organization's living room and phone buddy program, and ICAN's Exon 20 group. Participants explained that some groups or forums were merely a platform to gather information on other's treatment experiences rather than a place for community. All participants that had participated in LUNGevity's virtual support group praised the group for being a well-run community space where reliable information was shared clearly with guardrails clearly outlined to prevent misinformation.

> *" I think LUNGevity does a phenomenal job moderating the [zoom] call. It gives people the opportunity to talk about what's on their mind. Sometimes the calls are very long, but it's hard to be able to give everybody the opportunity to speak at once too. To me, that's what helps people feel like they belong in community."*

HER2 Community Needs & Solutions

Participants identified two key community needs and potential solutions: 1) Stronger HER2-specific support through a HER2-specific group or one-to-one support that connect patients with long-term

HER2 survivors and provide hope for long-term survivorship, and 2) greater access to HER2 experts who can share up-to-date information and guidance.

Participants agreed that they lacked a community space for HER2 specifically or even a space to connect with another person living with HER2. Several participants noted that, due to its rarity, a HER2 diagnosis is particularly isolating even within the lung cancer community. While they identified some HER2-specific forums they were largely used for drug treatment or side effect sharing rather than community support. Along these lines, several participants suggested a process of speaking with someone upon first contact with an advocacy organization to meet their informational needs. With one individual explaining, *"I think one of the things that would have been helpful at the time [soon after diagnosis], was somewhere prominent [on the LUNGevity website], like you could speak to someone. I think it's really helpful to talk to someone."*

The most recurring need discussed was greater access to HER2 experts. Participants lamented the lack of an expert to ask questions of, as they have observed in other onco-gene driven lung cancers such as EGFR. An added advantage to having an expert run group is that it would help to prevent the spread of misinformation, as an individual noted is sometimes a problem in HER2 meet-ups they have attended.

> *"I feel like what I'm missing, maybe from a HER2-specific group, is being able to talk with someone…have someone that's a part of that group that's knowledgeable about HER2. Some expert in the field to moderate a group, instead of just hearing the same questions that we're all asking, and not really having an answer…"*

Lastly, a need that was spontaneously articulated by one individual was providing a space to cope with grief and survivor's guilt. The individual suggested that it would be beneficial to hold space for those lost explaining that *"in terms of the loss, and it kind of sounds contrary to HOPE Summit, but that there could be a place for us to even have a vigil or something for the people we've lost or, you know, some place."*

Impacts of diagnosis and disease

When asked about impacts of their lung cancer diagnosis, participants spontaneously discussed impacts relating to their family life, social life, work life, and mental health.

Social and Family Life Impacts

Living with lung cancer profoundly affected participants' sense of self, social independence, and ability to plan for their future, including both financial and logistical considerations. While the specific impacts varied based on individuals' lives prior to diagnosis, participants across both focus groups consistently described significant effects on their social relationships and family lives.

Four participants mentioned loss of independence to be a particularly difficult impact to navigate. In one case physical symptoms necessitated the individual to sell their home and move in with their family. Another's loss of independence was predicated on *"feeling handcuffed"* to their diagnosis, which made decision-making about how to lead their life difficult. Similarly, an individual lamented their loss of spontaneity and another the loss of being able to participate in hobbies with their family that they previously enjoyed.

There is considerable burden that may be experienced by care partners of those living with HER2 driven lung cancer. Participants occasionally described the impact of lung cancer on their families in terms of burden, though more often they spoke about the support and assistance they received from

family and substantially changing plans for their family life. One participant noted that her dedicated care partner was *"burnt out."*

Four participants described the challenges of being single and having lung cancer with several expressing feelings of loneliness and noting that navigating dating after a lung cancer diagnosis can feel nearly impossible.

> *" It's just really a complicated thing to try to figure out how to navigate all of it. And then being a single person, I mean, I pretty much threw dating out the window because [chuckles] you have stage 4 cancer, you know? How are you supposed to meet somebody with a diagnosis like that."*

Lastly several participants discussed difficulties navigating friendships while living with lung cancer with individuals explaining that they lost some friendships after their cancer diagnosis. Participants highlighted that, *"friends sort of like initially were checking up, and then they just kind of disappear."*

Work-Life Impacts

Issues related to work that participants spontaneously reported included: challenges with retirement and career planning following diagnosis, difficulty taking time away from work for medical appointments, financial strain due to inability to work, and a lack of employer understanding regarding the nature and implications of their diagnosis.

Work life Concept	*Explanatory Quote*
Retirement and Career planning	*I actually want to work. It's not enough to actually cover all of my expenses and you can make a certain amount. It's just kind of a complicated thing...I don't want that to mess up the benefits that I have. Not so much because of the monthly payment, because I would be making money obviously working full time, but because that can take me into Medicare...I don't want to have my insurance that like based on employment that maybe if I get sick I can't have any more.* *It's actually impacted because I've always thought I'll wait until 67 before I retire with full social security, full federal retirement paycheck. When all this happened, I'm like, "Screw that. I'm retiring at 62," which is next. I could be dead right after that.*
Employer understanding diagnosis	*But the fact maybe that HER2 is so rare, nobody really understands how bad it could actually be. Because even my employer, he asked me the other day, he's like, "Are you in remission yet?" I don't want to tell him like that's not really a thing because then I'd be afraid he wouldn't want me to work at all, because right now I'm doing well, thankfully. But it's questions like that that's a little triggering, and it's like, "Ugh," like, "I can't tell you the truth," but like I'm like, "Well, no, but I'm doing well right now."*

Mental Health Impacts

Six participants spontaneously mentioned feelings of loneliness, alienation, or social isolation, making it the most frequently expressed mental health impact. Participants explained that many factors may lead to feelings of loneliness from coping with the physical limitations of their diagnosis to being diagnosed with a rare onco-gene mutation that does not yet have a support system in place to meet their evolving needs.

> *"Honestly, feeling like an alien. I'm going to cry…It's so alienating to get a diagnosis of lung cancer. Then on top of that, you're told you have an ultra-rare mutation. On top of that, not having the resources or support that you believe you should have, regardless of having that mutation or not. It's really isolating. I love these meetups. They make me emotional, because it's like, we're all in this together. We all get it. We all do the same drugs. There's something very special about that. I wish we could do it more."*

Additional mental health impacts participants discussed were: 1) stigma of lung cancer diagnosis, 2) difficulty accessing mental health therapist, 3) general feelings of distress, restlessness, and anxiety associated with both receiving their diagnosis and living with a rare oncogene-driven lung cancer.

Theme 3: Education & Information Needs

The theme of education and information needs was woven throughout most of the focus group discussions. Participants' need for timely information and education is implied in themes of diagnostic pathway and community, support, and impact above. During their diagnostic journey, participants recounted wanting more information about their diagnosis and treatment options. Specifically, one participant shared that *"[their] hospital gave [them] nothing at all. They were like, you have cancer, here's the PDF."* Participants either received no information on their treatment or biomarkers or were given long and dense text from the National Comprehensive Cancer Network (NCCN). Due to difficulties in communication with their healthcare teams, they felt the need to become "Google warriors" and seek their own information online or in support groups. Without the proper expert advice this opened them up to the risks of misinformation and/or confusion.

> *"When I'm out there on Google and looking for it, you have to hunt it all down. Then you hunt it down, and it's all in PhD talk. I did not study that long, I don't know as if you guys. It's just very not user-friendly. It's like, okay, but then I'm having to Google, what does this mean, and how does this describe, and break it down for me, or put it in ChatGPT. I don't want to do that, because it's like the game telephone. You're losing something each time."*

In both focus groups, participants shared that it would be helpful to have a repository of information that they could access when they were less overwhelmed on their own time. They desire educational materials in laymen's terms, with information about their HER2 biomarker and treatment options and clinical trials available for each stage of their disease.

A critical and underappreciated education barrier is the conflation of HER2 in lung cancer with HER2 in breast cancer. Virtually all self-directed searches on HER2 return resources related to breast cancer, a disease with a different prognosis, different treatment landscape, and a different patient community. This is a source of significant confusion. Participants explicitly requested HER2 lung cancer-specific content that clearly distinguishes their experience from the breast cancer context.

> *"I can't find anybody on the web even talking about HER2 unless you have breast cancer. That's how I eventually found a HER2 specialist. He has some reported talks that he's done on HER2 lung cancer specifically."*

From voices to action – A shared agenda for the HER2 community

The following recommendations are grounded in the specific gaps participants identified.

What LUNGevity can do: Participants were explicit about what they want from LUNGevity as a patient advocacy organization. LUNGevity can support:

- Facilitation of one-on-one support mechanisms (buddy systems etc.) and more frequent HER2 specific community support groups
- Hosting in-person meeting opportunities for the HER2 community such as a HER2 Live at a future HOPE Summit
- Hosting webinars and/or Q&As with experts in HER2
- Provide resources and space for patients to grieve and remember friends
- Develop a dedicated HER2 lung cancer hub on the LUNGevity website with a clear guide for newly diagnosed patients, clearly differentiated from breast cancer HER2 content
- Advocate for elimination of step therapy requirements for biomarker-directed NSCLC therapies and for standardized coverage of comprehensive biomarker testing at diagnosis and progression (this is already part of LUNGevity's broader policy initiatives)

What pharma partners can do: Pharmaceutical companies developing and commercializing HER2-directed therapies in NSCLC have both an opportunity and a responsibility to support the patient community described in these sessions. Pharma partners can:

- Sponsor HER2-focused webinars and educational events about treatment methods available
- Support HER2 peer-to-peer support groups and networks
- Ensure robust and navigable copay assistance and patient support programs for approved HER2-targeted therapies and actively communicate these to community-based oncology practices
- Engage with payers to advocate against step therapy requirements for HER2-targeted first-line treatment in appropriate patients, citing clinical evidence and patient experience data
- Ensure HER2-specific clinical trials are listed in plain language on patient-facing platforms

What healthcare teams can do: The clinical represents the most significant single-point opportunity for change. Participants described transformative experiences with oncologists who were knowledgeable, communicative, and advocacy-minded, and starkly different experiences with those who were not. Healthcare teams can:

- Provide approachable, patient-centered materials patients can reference at any time during their diagnostic and treatment pathway
- Offer resources and appropriate referrals for mental health support, therapy, etc.
- Refer patients to social work services to help navigate supportive healthcare, financial planning, and safety net planning and services
- Proactively advocate with insurers for first-line targeted therapy for eligible HER2-mutated NSCLC patients rather than defaulting to chemotherapy to avoid prior authorization friction
- Connect HER2-community members with patient advocacy groups at the time of diagnosis

The community voices in these two listening sessions paint an urgent picture. People living with HER2-mutated NSCLC are navigating a rapidly evolving treatment landscape with fragmented diagnostic pathways, significant access barriers, inadequate education, and almost no community infrastructure built for their specific experience. LUNGevity has the relationships, credibility, and infrastructure to accelerate that process – by building the community infrastructure these patients need, filling the educational gaps they have identified, and translating their experiences into systemic change through policy advocacy and clinical practice improvement.

References

Yu, X., Ji, X., & Su, C. (2022). HER2-Altered Non-Small Cell Lung Cancer: Biology, Clinicopathologic Features, and Emerging Therapies. Front Oncol, 12, 860313. doi:10.3389/fonc.2022.860313

Appendix

Table 1. Demographic Characteristics of HER2 Listening Session Participants (n=12)

Characteristics	n	%
Age		
21-29	0	0%
30-39	3	25%
40-49	3	25%
50-59	0	0%
60-69	5	42%
70-79	1	8%
80-89	0	0%
Gender		
Female	11	92%
Male	1	8%
Other	0	
Race		
AIAN	0	0%
Asian	0	0%
Black/AA	1	8%
Middle Easter/North African	0	0%
White/Caucasian	11	92%
Other	0	0%
Hispanic origin		
Yes	0	0%
No	12	100%
Employment		
Employed (FT)	2	17%
Employed (PT)	1	8%
Unemployed	2	17%
Unable to work due to illness	1	8%
On disability	3	25%
Retired	2	17%
Student	0	0%
Stay-at-home spouse/partner	1	8%

Table 2. Diagnostic Characteristics of HER2 Listening Session Participants

Characteristics		
Years since diagnosis (mean ± SD); range	2.92 ± 2.23	1 to 7
	n	%
Stage at diagnosis		
Stage I	1	8%
Stage II	0	0%
Stage III	3	25%
Stage IV/advanced-stage/metastatic	8	67%
Time of HER2-positive diagnosis		
At diagnosis	2	17%
Before 1st treatment	5	42%
After 1st treatment	3	25%
Other	2	17%
Delay in biomarker testing		
Yes	4	33%
No	8	67%
Treatments		
Chemotherapy	9	75%
Immunotherapy	5	42%
Zongertinib (Hernexeos®)	7	58%
fam-trastuzumab deruxtecan-nxki (Enhertu)	6	50%
Radiation therapy	7	58%
Surgery	4	33%
Clinical Trial	5	42%
Other	3	25%
Treatment changes		
Still on 1st treatment	1	8%
One change, on 2nd treatment	3	25%
Two changes, on 3rd treatment	5	42%
Changed treatment 3 times or more	3	25%
HER2 biomarker type		
A775_G776insYVMA	2	17%
Exon 20 insertion	4	33%
HER2 over-expression	1	8%
I do not know	2	17%
Other	3	25%