



Image is not of an actual patient.

HEAR MY VOICE:

What People With
Non-Small Cell Lung Cancer
Want You to Know

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Contents

- 2-4 Lung Cancer
- 4 NSCLC
- 5 Exon 20 Insertion Mutations
- 5-12 Take Action
- 12 Moving Forward
- 13-15 Helpful Resources and Support
- 16 Survey Objectives
- 16 Survey Methodology
- 17-23 Survey Details
- 24-25 Acknowledgments
- 26 Glossary
- 26-27 References

Getting a diagnosis of non-small cell lung cancer (NSCLC) can be overwhelming. There are big emotions to work through, appointments to make, heavy choices to weigh, and new vocabulary to learn. It is a disease that often occurs without warning.

Joanne said she was in “complete shock” when she was diagnosed with NSCLC in 2021. “I had never been sick or hospitalized for anything other than giving birth.”

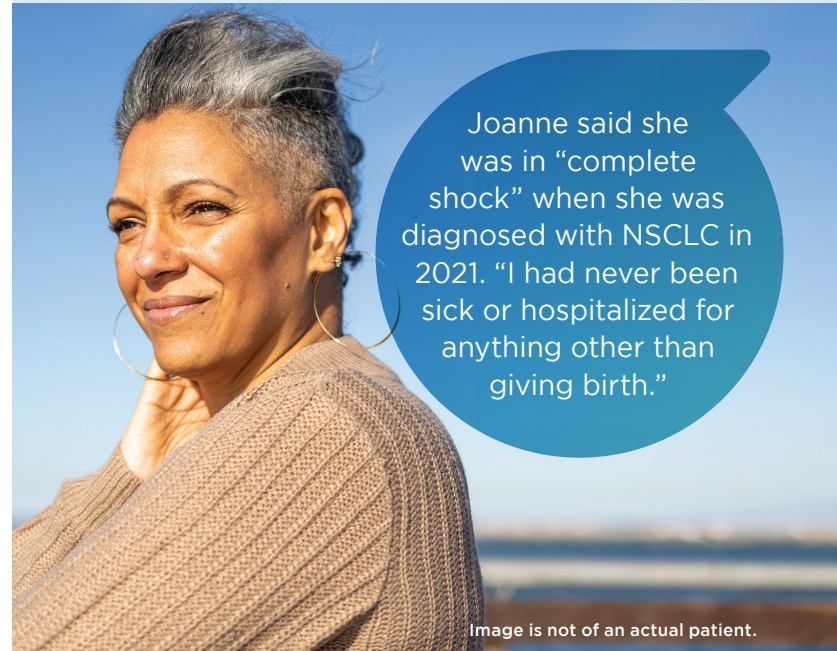
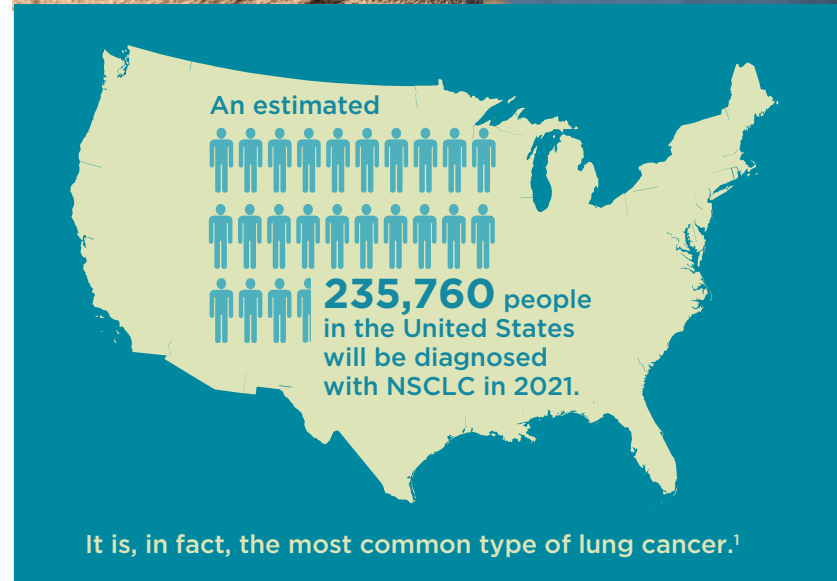


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Along with nearly 60 other people with a very specific and rare type of NSCLC, Joanne took part in a survey sponsored by Takeda in the summer of 2021 to glean insights from patients, for patients. (The names of survey participants have been changed to protect their privacy.)

SURVEY PARTICIPANTS

More than half between 55 and 69 years old

Nearly three-quarters female

Nearly all living in an urban or suburban setting

More than three-quarters white

More than half earning \$100,000+ per year

Most insured through their own or their spouse’s employer or through Medicare

The survey collected important insights, highlighting patients’ challenges, needs, and expectations. While every survey participant had a very specific type of NSCLC involving something called an epidermal growth factor receptor (EGFR) gene with the Exon 20 insertion mutation, these insights are valuable for all people with NSCLC.

The findings show that having NSCLC does not have to mean facing challenges alone and that, despite the fear, sadness, and discomfort the condition can bring, there is reason for hope.

Another common theme: the need for information. A total of 40% of survey participants said they did not receive enough information at their initial doctor visits after diagnosis with NSCLC to make good decisions about what to do next.

“I did not feel there was adequate time spent with us to be sure we were comfortable with our options,” said Emma, who was diagnosed in 2018. “I felt rushed and was not comfortable with the lack of information.”

Like many people who were surveyed, Joanne said she wished she had a comprehensive information source sheet for patients and caregivers.

With this report, we hope to fulfill that wish by providing valuable information and learnings from people who share this diagnosis.



LUNG CANCER: Symptoms vary

Lung cancer starts when cells in the lungs change, becoming abnormal and then growing out of control.² The illness can spread, or metastasize, to other areas of the body, such as the bones, liver, brain, lymph nodes, or adrenal glands.³ Symptoms can range from those you might expect, such as shortness of breath, coughing, fatigue and weight loss, to those you might not instinctively associate with lung cancer. Joanne’s only symptom at the time of diagnosis was a few months of back pain.

What were your initial symptoms that led to your diagnosis of non-small cell lung cancer (NSCLC)? (Check all appropriate)

Respiratory symptoms such as excessive coughing or difficulty breathing	31.6%
General feeling of being unwell	21.7%
No symptoms or illnesses—was initially diagnosed as part of a scheduled medical exam	20.0%
Fatigue	15.0%
Weight loss	11.7%
Others (please provide answer[s] in space provided)	50.0%

A total of 33 responses noted other symptoms, including hoarseness, pneumonia, a loss of balance, and diarrhea.

Greg, who was diagnosed with NSCLC by his primary care physician in 2020, said he hadn’t been feeling well for several months. In addition to respiratory symptoms, Greg also had bone pain and fatigue. A range of symptoms was common in those surveyed. Some, like Emma, had none at all.

Emma said she was in disbelief when she got the diagnosis. She lived an active life, enjoying regular walks and her weekly yoga class. “I thought they mixed up my scans,” she said. “I felt perfectly normal.”

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BICYCLING
WALKING SPORTS
SWIMMING EXERCISE
ACTIVITIES
WALKING
GOLF

The survey showed participants were often active, engaging in a range of activities.



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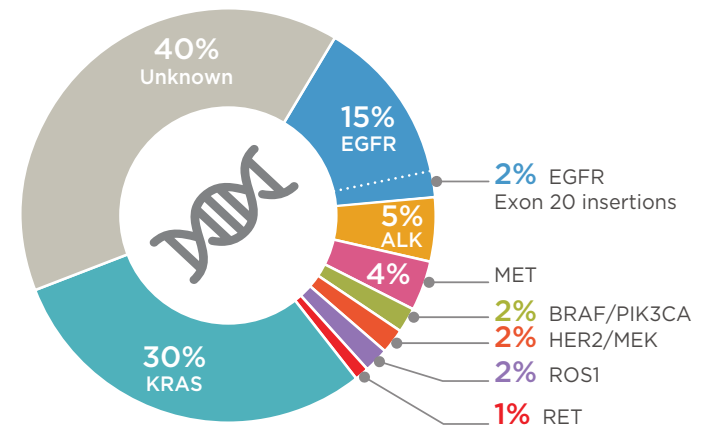
Many lung cancers develop in connection with smoking; however, approximately 10% to 20% of patients who are diagnosed with the disease have never smoked or used any form of tobacco.⁴

“I was a nonsmoker with no family history of cancer,” Joanne said.

NSCLC: A cancer with many possible paths

Like all lung cancers, NSCLCs happen because of mutations, or mistakes, that develop in genes⁵ with unwieldy names, such as epidermal growth factor receptor (*EGFR*), anaplastic lymphoma kinase (*ALK*), and c-ros oncogene 1 (*ROS1*).⁶ Finding out which change—or biomarker—is responsible for the growth of your lung cancer is recommended by leading medical and advocacy organizations, such as the American Cancer Society⁷ and LUNGevery.org,⁸ because the information can affect decisions about care. The test involves a tissue sample or blood draw to investigate possible mutations.⁹

Driver mutations in NSCLC adenocarcinomas¹⁰⁻¹²



For some NSCLC patients, the answer is found on a gene called EGFR. This gene has the instructions for making a protein with the same name.¹³ But there’s more than one way this gene can mutate, and knowing the type of mutation can make a big difference in finding the ideal treatment.¹⁴

EXON 20 INSERTION MUTATIONS: A rare and emerging priority

One genetic mutation—the kind that Joanne, Emma, and Greg all have—is the EGFR Exon 20 insertion mutation. They are called insertion mutations because they involve extra bits of DNA inserted into the gene, much like an extra word in a sentence that confuses its meaning.^{14,15} Exon 20 insertion mutations only occur in approximately 2% of patients with an NSCLC diagnosis and approximately 10% of all cancers with a documented EGFR mutation, making them rare.¹⁰⁻¹²

Unfortunately, NSCLC patients with an Exon 20 insertion mutation usually have a worse prognosis than those with other EGFR mutations.^{11,16,17} The Exon 20 insertion mutation changes the shape of EGFR protein in a way that makes it hard for some of the older treatments to work.^{11,16,17} Thankfully, some treatments specifically designed for patients with Exon 20 insertion mutations are now available.^{18,19}

TAKE ACTION: Ask for comprehensive biomarker testing

Your healthcare provider may not routinely offer biomarker testing. In fact, only 39% of those surveyed said that biomarker testing was recommended as a next step after their NSCLC diagnosis. Talk to your doctor about the latest tests available and how they might influence treatment. It’s important to be proactive about testing.⁸

If your healthcare provider doesn’t suggest biomarker testing, consider raising the topic yourself. Without those test results, your treatment may not be adequate for your cancer.⁹ In fact, many patients surveyed described receiving treatment with drugs or regimens unlikely to be effective for their subtype of lung cancer.

In our survey, more than 12% of patients waited longer than 2 months—some over a year—after diagnosis before receiving a recommendation that they undergo biomarker testing. That may represent a significant delay in treatment, especially when results can take a few weeks to get back after the blood is drawn or tissue collected. The majority of those surveyed said it took between 2 weeks and a month to get their test results back. You are not alone in feeling anxious during this period, but ultimately it can lead to important answers.



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If anxiety lingers, consider focusing on a well-defined task, such as writing 5 questions for the next time you meet with your healthcare team, or reaching out to 2 or 3 people you’d like to enlist as care partners.

There are different kinds of biomarker tests, including polymerase chain reaction (PCR)²⁰ and next-generation sequencing (NGS). NGS is one of the most comprehensive methods because it can assess thousands of mutations simultaneously.²¹

Kathleen Phan, a project manager for the clinical trials office at City of Hope Comprehensive Cancer Center in Long Beach, California, said that in her experience, “most of the time, the doctors would prefer NGS testing because it’s just more comprehensive.”^{22,23}

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Marcia Horn is the Executive Director of the Exon 20 Group and the President and CEO of the International Cancer Advocacy Network (ICAN). “PCR is missing a good 50% of all EGFR Exon 20 insertion mutations, which can be disastrous for a patient,” she said. “Fortunately, NGS will pick up the 50% that PCR fails to identify.”^{22,23}

Dr. Andre Liem is a medical oncologist and hematologist who is also affiliated with City of Hope Comprehensive Cancer Center. He said he also prefers NGS biomarker testing.

“With the NGS, you’ll get the most information at once so you don’t have to go back each time to get follow-up testing,” said Dr. Liem.



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Biomarker tests are often covered by health insurance, though this varies from one provider to the next. Some still consider such testing for NSCLC experimental, despite the fact several professional organizations have developed guidelines for biomarker testing and treatment.²⁴ Remember that this testing is important for identifying the best treatment for you.⁹ If your insurance provider is not willing to cover the test, work with your healthcare provider to try and get the testing you need.



TAKE ACTION: Consider a lung cancer specialist as part of your medical team

Most of those surveyed got their initial diagnosis from someone who did not specialize in lung cancer, such as a primary care physician, pulmonologist, or general oncologist. A lung cancer specialist may be an important part of your medical team.

“See an oncologist specializing in lung cancer and willing to research your particular mutation,” suggested Felicity, who was diagnosed with NSCLC in 2018. “Find a doctor who [will] guide you in making decisions but presents you with all your options and allows you to have a say in your treatment.”

If there isn’t a lung cancer specialist near where you live, many may be open to reviewing your case while most of the care is done near you. They can act as a second opinion, making sure your care is complete.

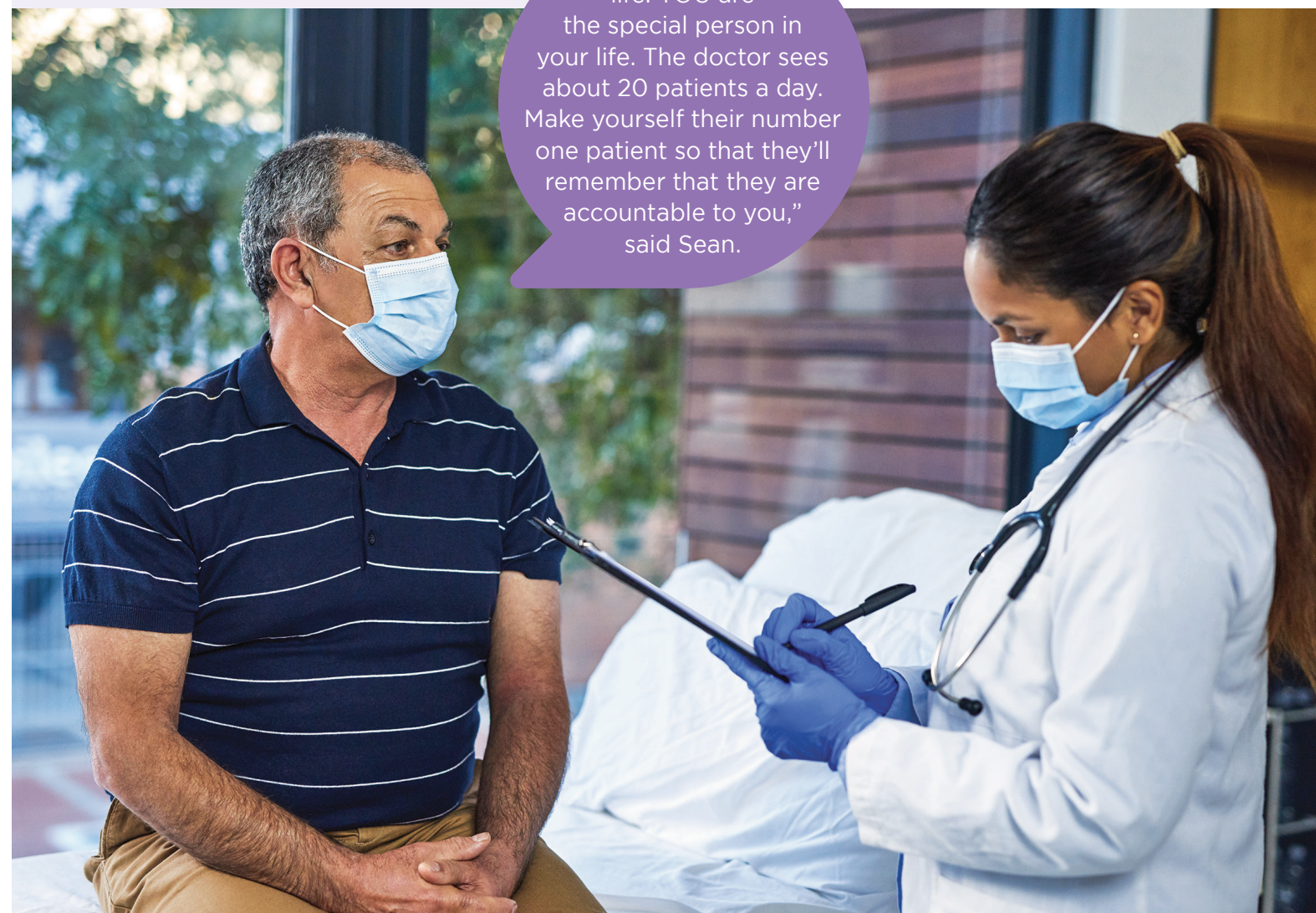
Who first suggested the idea that you should receive the testing that led to the identification of your EGFR Exon 20 insertion mutation?

The oncologist that first diagnosed my non-small cell lung cancer (NSCLC)	41.0%
The specialist in the diagnosis and treatment of non-small cell lung cancer (NSCLC) to whom I was referred	21.5%
Other (please specify)	16.0%
The specialist in the diagnosis and treatment of non-small cell lung cancer (NSCLC) that I accessed through my own research	14.3%
My primary care doctor	3.6%
The specialist in the diagnosis and treatment of non-small cell lung cancer (NSCLC) that was identified through patient support groups/advocacy organizations	3.6%
Care partner	0.0%
Myself	0.0%

TAKE ACTION: Be open to a second opinion

Emma notes that you don’t have to stick with the first doctor you meet. “I had a couple of second opinions and found an oncologist I was comfortable with,” she said.

Lily had a similar experience when she was diagnosed with NSCLC in 2019. “The information I was given by the assigned doctor at the hospital I was admitted to was generic, statistic-based, and fatalistic in nature,” she said. After talking to a lung cancer specialist—her second-opinion doctor—she felt she had “a much clearer understanding of my mutation and the treatment options.”



“It’s your life. YOU are the special person in your life. The doctor sees about 20 patients a day. Make yourself their number one patient so that they’ll remember that they are accountable to you,” said Sean.

Image is not of an actual patient.

TAKE ACTION: Come to each appointment with a list of questions

It may be helpful to do your own research to supplement the information that you receive from your healthcare team. The majority of respondents said most of the information and education that they received regarding their initial diagnosis of NSCLC came from their own research, not from the healthcare team.

Diagnosed with NSCLC in 2018, Sean suggests being proactive and assertive. “Don’t be bashful holding any doctor accountable. You are ultimately in charge of your health,” he said. “It’s your life. YOU are the special person in your life. The doctor sees about 20 patients a day. Make yourself their number one patient so that they’ll remember that they are accountable to you.”

TAKE ACTION:
Recognize your emotional needs

Finding out you have a hard-to-treat mutation, such as an Exon 20 insertion mutation, can be an emotional moment. In fact, the majority of those surveyed said their attitude or emotions changed when they first learned that their cancer was driven by an EGFR Exon 20 insertion mutation.

HOPEFUL
suffer
GUILT
WORRIED
UNHAPPY
HOPELESS
ACCEPTANCE
CONCERNED

ENIGMA
upset
FRUSTRATION
ANXIETY
devastated
fear
calmer
GRIEF
denial
WALKING

Worried about your diagnosis? You are not alone! When asked how getting a diagnosis of NSCLC with an Exon 20 insertion mutation made them feel, participants typically expressed negative emotions.

On the other end of the emotional spectrum is Greg. Greg said news that he had an Exon 20 insertion mutation made him “hopeful because there seem to be so many new treatment options on the horizon.”

Indeed, there are treatments designed to slow the growth of this uncommon type of NSCLC. Some of these treatment options have been approved by the US Food and Drug Administration (FDA) for patient use, and others are being tested in clinical trials.^{18,19,25}

“The Exon 20 field has made such tremendous strides over the past several years,” said Horn. “We have two drugs now in the standard arsenal, clinical trials, and ongoing expanded access.”



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TAKE ACTION:
Get copies of your test results

It will be up to you and your care team to decide on the best course of action for your specific type of NSCLC. If you’re finding this challenging, know that you are not alone! More than 40% of those surveyed who have an EGFR Exon 20 insertion mutation say they didn’t get enough information about their mutation to make good decisions about their treatment plan.

“Read, research, dig!” suggested Carolyn, who was first diagnosed with NSCLC in 2015. She only found out she had an Exon 20 insertion mutation the following year, after reviewing her medical records. “My original surgery has pathology results that showed the EGFR mutation! That got filed away and never saw the light of day until months later,” she said. “If I hadn’t found it, I would have had a totally different treatment plan and probably not be alive today.” Be sure to ask for copies of test results so you know what questions to ask.

Your oncologist might not fully discuss your mutation initially, but don’t be afraid to ask them questions. If you have a copy of the report, then you can offer it to other members of your care team and folks handling intake for groups who specialize in your mutation.

“We are so grateful when they have a copy of the report in hand for our first intake phone call with them,” said Horn. “We might spot something on the report that indicates a question that should be asked because something has been overlooked. We prompt the patient to discuss that issue with the oncologist. For example, a finding on the report that leads to a different clinical trial or a combination therapy that needs to be discussed with the oncology team.”



Image is not of actual patients.

TAKE ACTION:
Consider a care partner

While it is certainly possible to journey through lung cancer solo, be open to finding a care partner relationship and leaning into that relationship. According to the survey, many people diagnosed with NSCLC enlist a care partner to act as a second set of eyes and ears on their journey. Friends and relatives can help in a myriad of ways—no medical training required!

“Using the network of family and friends can be very helpful for patients to take some pressure off, have someone to discuss things with, and make sure that they are not missing any vital information,” said Horn. “If a patient does not have that network, then the Exon 20 Group’s Angel Buddies can fill at least part of that gap. This peer-to-peer support network of fellow patients and care partners is very helpful in providing hands-on moral support and battle-hardened tips for the patient and family.”

“If a patient does not have that network, then the Exon 20 Group’s Angel Buddies can fill at least part of that gap. This peer-to-peer support network of fellow patients and care partners is very helpful in providing hands-on moral support and battle-hardened tips for the patient and family,” said Horn.

It’s not a matter of being a burden. Take people at their word when they say they want to help and be clear with folks about what specifically you hope they can do. Many people enjoy helping others, especially when their role is clear.

Phan said sometimes the patient is so “overwhelmed” with the diagnosis that they focus on certain aspects of their treatment and response while omitting others. “With the caregiver there, they’re able to see the whole picture,” she said.

Dr. Liem said the role of the care partner is very important. “I think [patients] do much better if they have somebody who advocates for them,” Dr. Liem said. “Part of the taking care of patients is to give reassurance and address their well-being.”

WHAT KINDS OF SUPPORT WOULD HELP YOU MOST?

Practical Support

- Share health updates with family and friends
- Shop
- Pick up prescriptions
- Make meals
- Babysit

Informational Support

- Research your disease and treatments
- Brainstorm questions for upcoming appointments

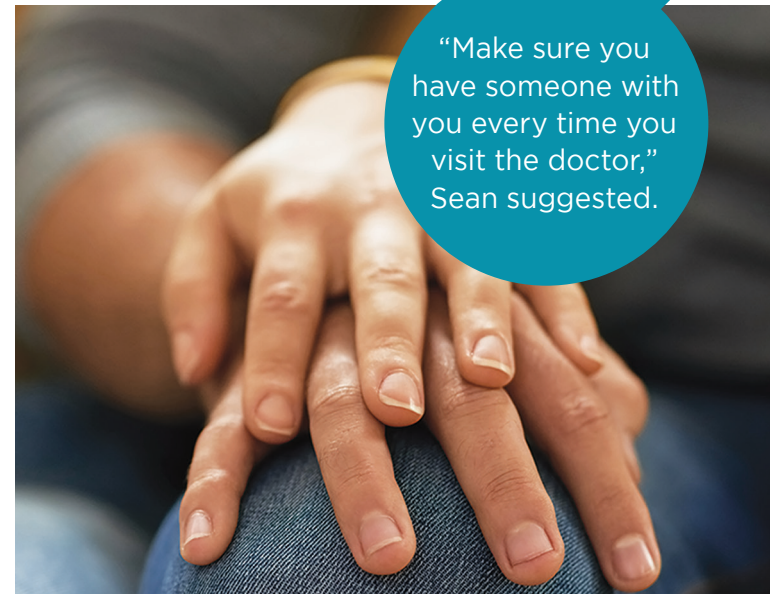
Emotional Support

- Accompany you to appointments
- Listen to your thoughts and feelings

According to the patients surveyed, care partners helped in a variety of ways. While most of those surveyed said a spouse acted as a care partner, others recruited adult children, friends, and siblings. There are many ways a care partner can help, including emotional support, research assistance, asking questions to healthcare professionals, and sharing updates with family and friends.

“Make sure you have someone with you every time you visit the doctor,” Sean suggested.

Care partners can help get you to and from appointments, even if they can't stay. If that's not an option and you are having trouble affording transportation, reach out to [CancerCare.org](https://www.cancer.org/cancer/cancer-care/support) or other organizations listed in the resources on page 13.



“Make sure you have someone with you every time you visit the doctor,” Sean suggested.

Some care partners help get their loved one into a clinical trial. Clinical trials are research studies designed to see whether a particular treatment is safe and effective in people. Most of those surveyed who were involved in a clinical trial said the support they received as a part of the trial was positive. A clinical trial might be part of your journey, too. Some patient organizations and advocacy groups, such as the Exon 20 Group or the Cancer Support Community, can also help in your hunt for clinical trials. The website for the Lung Cancer Foundation of America offers lots of background information about clinical trials. It is important to note that clinical trials are not appropriate for everyone. Many people do not meet inclusion criteria for clinical trials. Your doctor is the best source of information if you are interested in learning more about potential clinical trials.

TAKE ACTION: Participate in patient advocacy and social media groups specific to your mutation

An important part of dealing with your disease is connecting with other folks on the same journey. Social networking sites and patient advocacy groups can help with this. [CancerCare.org](https://www.cancer.org/cancer/cancer-care/support) offers counseling with social workers who specialize in cancer of all sorts. Additionally, the group hosts support groups online, over the phone, and in person at sites across America. (For a list of such groups, turn to the Resource Toolbox in this publication.)

Patient advocacy groups are often organized around a specific disease or a subset of folks with that disease. They connect patients to each other, provide outreach, and publish materials in an effort to raise awareness and create a sense of community. For example, those impacted by an Exon 20 insertion mutation can join the online community at [Exon20group.org](https://www.exon20group.org). The site [SmartPatients.com](https://www.smartpatients.com) offers discussion boards for a variety of types of lung cancer, including ROS1-positive and KRAS-positive patients. People with ALK-positive lung cancer, which involves the fusing together of two genes,²⁶ can find a community for their needs at [AlkPositive.org](https://www.alkpositive.org). Search Twitter and Facebook for the name of your mutations, too. You'll be surprised by the specificity of groups geared toward patients!

“I was completely lost until a fellow patient informed me about the patient advocacy group,” said Greg. “Everything changed for my wife and me once we connected and became educated. We became familiar with the vernacular associated with my diagnosis.”

While participants reported receiving a lot of information from their healthcare teams, those who connected early on with advocacy groups and other patients reported experiencing more clarity and confidence along the cancer journey. This suggests that it can be helpful for patients to start by talking

to their doctors and then reach out to these additional sources.

“These sites helped me significantly with skin and gastrointestinal side effects of the targeted meds and how to deal with them!” said Carolyn in regard to the information she received.

Such groups may be beneficial even if you have a skilled medical team. While nearly 70% of respondents believe that they receive adequate information and guidance about how to manage side effects from the medication they take for NSCLC with an EGFR Exon 20 insertion mutation, many still reached out to others to get information on side effects and management. Many said they wanted to hear about side effects from other patients who had experienced them.

“Find a cancer support group—online or in person. This has been a game changer for me!” said Lily, who takes part in multiple groups focused on Exon 20 insertion mutations. “[They] give me practical, personalized information to make informed decisions about what's next.”

“These sites helped me significantly with skin and gastrointestinal side effects of the targeted meds and how to deal with them!” said Carolyn.



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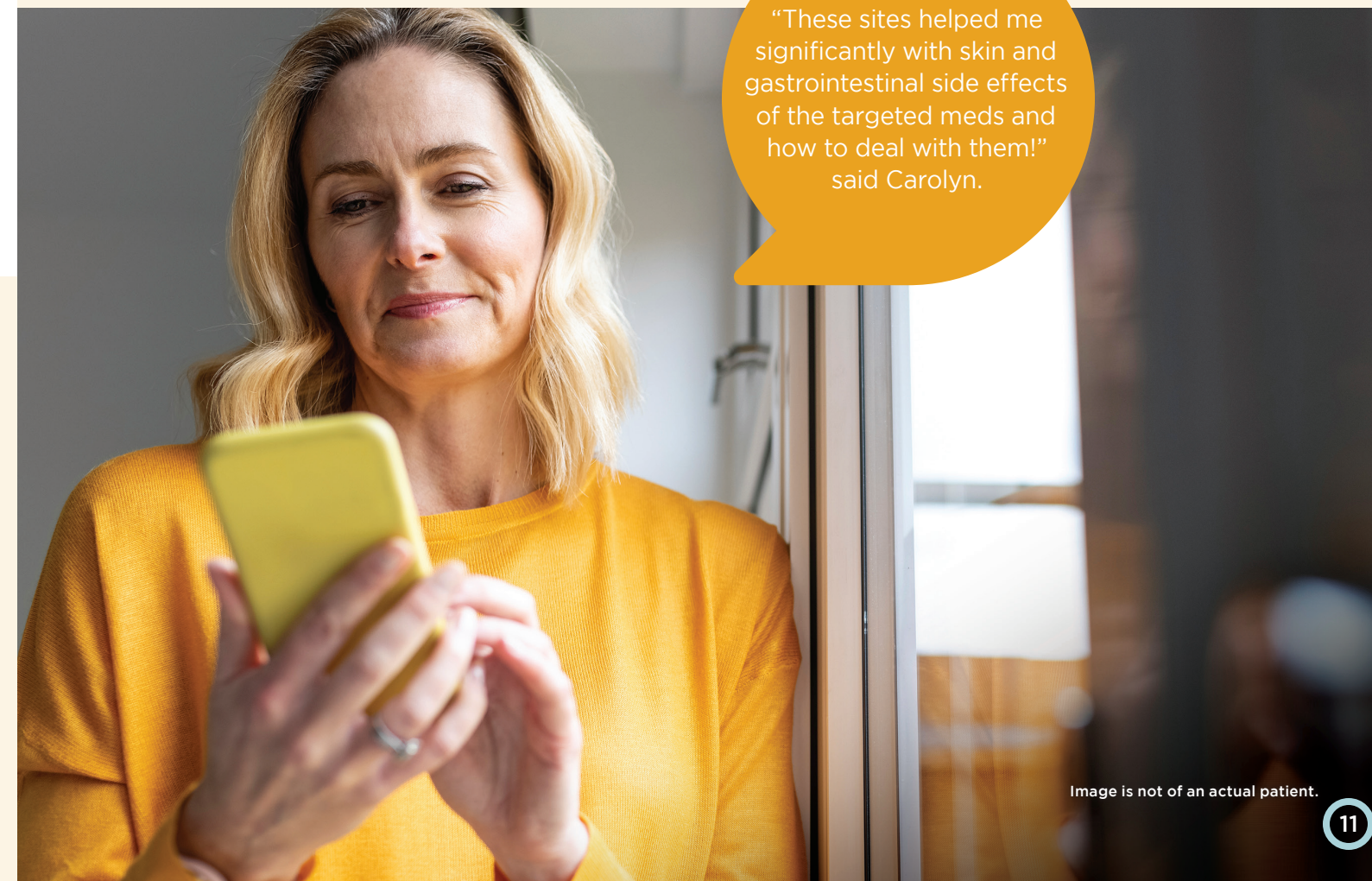


Image is not of an actual patient.

What were the sources for information that you received about your non-small cell lung cancer (NSCLC) with the EGFR Exon 20 insertion mutation? (please check all appropriate answers)

My doctor(s)	72.9%
Information that I found online by using Google and/or other search engines	71.2%
Patient advocacy organizations/support groups that provide information/support specifically for non-small cell lung cancer (NSCLC)	52.5%
Other patients with non-small cell lung cancer (NSCLC) in online support groups or social media (such as Facebook)	49.2%
Online social media groups sponsored by patient advocacy organizations that provide information/support specifically for non-small cell lung cancer (NSCLC) with EGFR Exon 20 insertion mutation	47.5%
Nurse practitioner, nurse, or other medical professional working with my doctor(s)	32.2%
Patient advocacy organizations/support groups that provide information/support for multiple kinds of cancer	11.9%
Other (please provide answer[s] in space provided)	6.8%

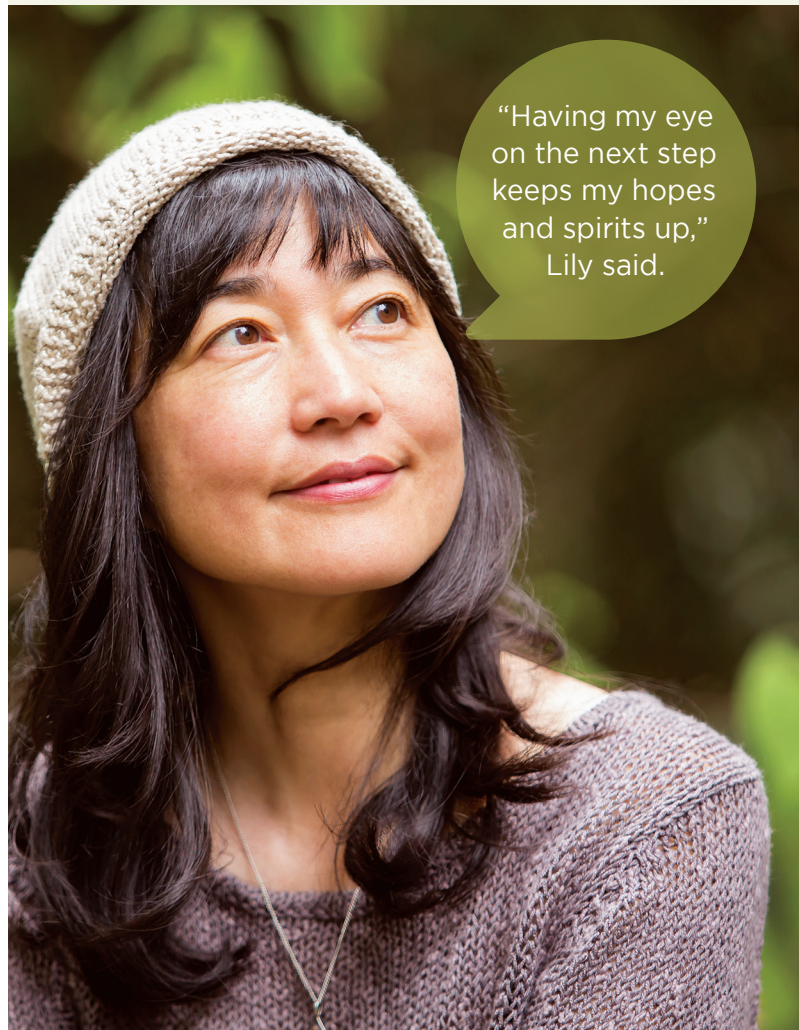


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Moving forward with hope and empowerment

Getting a diagnosis of NSCLC can, of course, be daunting. But there are ways to make it easier. What kept coming up in the survey findings, again and again, was having hope. Many found hope through online communities, noting that joining a social media group or patient advocacy group provided them with emotional support. For some, this came with knowing they were not alone. For others, the information they received helped ease their thoughts. Knowledge, after all, isn't just power. For some, knowledge can be very calming.

"Having my eye on the next step keeps my hopes and spirits up," Lily said.

»» TAKE ACTION ««

- Ask for comprehensive biomarker testing
- Consider a lung cancer specialist as part of your medical team
- Be open to a second opinion
- Come to each appointment with a list of questions
- Recognize your emotional needs
- Get copies of your test results
- Enlist a care partner
- Participate in patient advocacy and social media groups specific to your mutation

Helpful Resources and Support

American Cancer Society

800-227-2345 helpline;
<https://www.cancer.org/>;
<https://www.facebook.com/AmericanCancerSociety>;
<https://twitter.com/americancancer>

This national organization is on a mission to free the world from cancer by funding and conducting research, sharing expert information, supporting patients, and spreading the word about prevention. It offers a wide variety of information and services to patients and their families.

American Lung Association

1-800-LUNG-USA;
<https://www.lung.org/>;
<https://www.facebook.com/lungusa/>;
<https://twitter.com/LungAssociation>

The American Lung Association's mission is to save lives by improving lung health and preventing lung disease. We do this through education, advocacy, and research.

ALK Positive

<https://www.alkpositive.org/>;
<https://www.facebook.com/alklungcancer>;
<https://twitter.com/ALKLungCancer>

A support community where ALK-positive lung cancer patients and caregivers could share their personal experience with this condition.

American Society of Clinical Oncology (ASCO)

<https://www.cancer.net/>;
<https://www.facebook.com/CancerDotNet>;
<https://twitter.com/cancerdotnet>

Trusted, compassionate information for people with cancer and their families and caregivers from the organization considered the voice of the world's cancer physicians and oncology professionals.

CancerCare

800-813-4673;
info@cancercare.org;
<https://www.cancercare.org/>;
<https://www.facebook.com/cancercare>;
<https://twitter.com/cancercare>

A national organization that provides free, professional support services and information designed to help those with cancer manage its emotional, practical, and financial challenges.

Cancer Support Community

<https://www.cancersupportcommunity.org/>;
<https://www.facebook.com/CancerSupportCommunity>;
<https://twitter.com/CancerSupportHQ>;
<https://www.CancerSupportCommunity.org/non-small-cell-lung-cancer>;
<https://www.CancerSupportCommunity.org/BiomarkerTool>

A global nonprofit network of 175 locations, delivering more than \$50 million in free support and navigation services to patients and families. In addition, the Cancer Support Community administers a toll-free helpline and produces award-winning educational and digital resources. The network also conducts cutting-edge research on the emotional, psychological, and financial journey of cancer patients and advocate at all levels of government for policies to help individuals whose lives have been disrupted by cancer.

CaringBridge

<https://www.caringbridge.org/>

For nearly 25 years, CaringBridge has made it simple and safe to offer or ask for support. More than 300,000 people use the free, private, secure, and ad-free online platform every day to share health updates and rally family and friends around a loved one's health journey.

EGFR Resisters

<https://egfrcancer.org/>;
<https://www.facebook.com/groups/EGFRResisters/>;
<https://twitter.com/EGFRResisters>

A grassroots, patient-driven community dedicated to changing EGFR-mutated lung cancer into a manageable chronic disease. Specifically, the group focuses on driving research aimed at finding treatments for patients with EGFR-mutated lung cancer that has become resistant to treatment.

European Society for Medical Oncology (ESMO)

<https://www.esmo.org/>;
<https://www.esmo.org/for-patients/patient-guides>;
<https://www.facebook.com/esmo.org>;
<https://twitter.com/myesmo>

Improving the quality of cancer care, from prevention and diagnosis to palliative care and patient follow-up, is the core mission of ESMO. The organization seeks to educate doctors, patients, and the public about best practices and the latest advances in oncology, as well as to promote equal access to optimal cancer care for all patients. Among the information this organization offers is a collection of patient guides that can be found online.

Takeda Oncology is not affiliated with these organizations. By listing these resources, Takeda Oncology is not endorsing any particular service or group and we are not responsible for the services provided. They are provided here for informational purposes and are not meant to replace your healthcare provider's medical advice.

Helpful Resources and Support (Continued)

Exon 20 Group

602-618-0183; exon20@exon20group.org;
Exon20group.org

An international multi-stakeholder organization of patients, care partners, thoracic/medical oncologists, NGS labs, and pharmaceutical/biotech partners, co-founded with EGFR Exon 20 patient Kevin M. Hanlon and his brother Robert T. Hanlon, PhD, dedicated to turning EGFR Exon 20 insertions and HER2 Exon 20 insertions into chronic diseases through providing advocacy, funding research, and accelerating drug development through its Exon 20 International Research Consortium. Patients and their care partners can receive case navigation, second opinion referrals, oncology nursing services, assignment of an "Angel Buddy" mentor, strategies for managing side effects, clinical trials matching services, comprehensive biomarker testing matching services, and invitations to participate in conferences and online support groups, including Facebook (<https://www.facebook.com/groups/136311127056022/>) and Inspire (<https://www.inspire.com/groups/exon-20/>).

Family Reach

<https://familyreach.org/ftp/>;
<https://www.facebook.com/familyreach/>;
<https://twitter.com/familyreach>;
<https://www.instagram.com/familyreach>

Family Reach is a national nonprofit organization that helps families manage the many costs of cancer. Services include financial education, financial coaching, and resource navigation to patients and caregivers facing a cancer diagnosis.

GO2 Foundation for Lung Cancer

800-298-2436 helpline;
202-463-2080 general questions;
info@go2foundation.org; go2foundation.org;
<https://www.facebook.com/GO2Foundation/>;
<https://twitter.com/go2foundation>

Founded by patients and survivors, the aim of GO2 Foundation is to transform survivorship through work devoted to saving, extending, and improving the lives of people who are vulnerable to, at risk for, or diagnosed with lung cancer. The organization's goals include ending stigma, increasing public and private funding for research, and ensuring access to care.

Imerman Angels

<https://imermanangels.org/>;
<https://twitter.com/imermanangels>;
<https://www.facebook.com/ImermanAngels>

Imerman Angels partners anyone, any age, any gender, anywhere and any cancer type seeking support with someone just like them – a "Mentor Angel." A Mentor Angel is a cancer survivor or caregiver who most importantly has faced the same type of cancer.

Inheritance of Hope

<https://inheritanceofhope.org/>;
<https://www.facebook.com/InheritanceOfHope/>;
<https://twitter.com/caringbridge>

Inheritance of Hope inspires hope in young families facing the loss of a parent. The 501(c)(3) charity offers on-site Legacy Retreats®, online Hope@Home™ weekends, and monthly groups for all ages – all with other families who "get it."

International Association for the Study of Lung Cancer (IASLC)

<https://www.iaslc.org/>;
<https://www.facebook.com/IASLC/>;
<https://twitter.com/IASLC>

Incorporating the involvement of cancer specialists, patients, and caregivers, this organization is the only global network dedicated to the study and eradication of lung cancer and other thoracic malignancies. By hosting global conferences, funding science, and informing the healthcare and patient communities, it strives to improve care through research, clinical practice, care delivery, and advocacy. Its website offers a variety of informational resources, including current news in the lung cancer arena.

Living With EGFR Exon 20 Insertion Takeda webpage

<https://www.livingwithexon20.com/>

This page offers information on, and tips for living with, the disease and lists resources for patient support.

Lung Cancer Foundation of America

<https://lcfamerica.org/>;
<https://facebook.com/lungcancerfoundation>;
<https://twitter.com/LCFAmerica>

LCFA's mission is the improvement in survivorship of lung cancer patients through the funding of transformative science. While raising funds to support lung cancer research, LCFA will raise the public's awareness and serve as a resource for patients or anyone seeking answers, hope, and access to updated treatment information, scientific investigation, and clinical trials.

Lung Cancer Research Foundation

Patient Support: (844) 835-4325;
<https://www.lcrf.org/support>;
<https://www.facebook.com/LungCancerResearchFoundation>;
https://twitter.com/lcrf_org

The mission of the Lung Cancer Research Foundation (LCRF) is to improve lung cancer outcomes by funding research for the prevention, diagnosis, treatment, and cure of lung cancer. LCRF offers free patient and caregiver educational materials as well as a toll-free lung cancer support line.

LUNgevity

844-360-5864 HELpline;
312-407-6100;
<https://www.lungevity.org>;
<https://www.facebook.com/lungevity/>;
<https://twitter.com/LUNgevity>;
<https://www.lungevity.org/noonemissed>

Provides support, community, and information to people affected by lung cancer. The organization also sponsors a Facebook group for people with NSCLC that has the EGFR Exon 20 insertion mutation, as well as an online support group for people with EGFR-mutated NSCLC. The No One Missed website (<https://www.lungevity.org/noonemissed>) highlights the importance of comprehensive biomarker testing in NSCLC.

Patient Advocacy Foundation

<https://www.patientadvocate.org/>;
<https://www.facebook.com/patientadvocatefoundation>

Patient Advocate Foundation (PAF) is a national 501 (c)(3) non-profit organization that provides case management services and support services to people living with cancer and other chronic, life-threatening and debilitating illnesses. These services include helping patients, families and caregivers navigate the healthcare system and identifying local, regional, and national resources to solve access and affordability issues.

Smart Patients

<https://www.smartpatients.com>;
<https://www.facebook.com/smartpatientscommunity/>;
https://twitter.com/smart_patients

Smart Patients is an online community for patients and families affected by a variety of illnesses. Here, you can learn at your own level about scientific developments related to your condition, share your questions and concerns with other members, and use what you learn in the context of your own life.

Triage Cancer

<https://trriagecancer.org/>;
<https://www.facebook.com/TriageCancer/>;
<https://twitter.com/TriageCancer>

Triage Cancer is a national, nonprofit organization that provides free education on the practical, insurance, employment, and financial issues that may impact individuals diagnosed with cancer and their caregivers, through events, materials, and resources.

Takeda Oncology is not affiliated with these organizations. By listing these resources, Takeda Oncology is not endorsing any particular service or group and we are not responsible for the services provided. They are provided here for informational purposes and are not meant to replace your healthcare provider's medical advice.



With comprehensive biomarker testing, you'll know all about your cancer. Make sure all of your healthcare professionals know the details, too! Fill out your own Cancer Information Sheet and keep a copy in your wallet or purse so you'll have it with you for all of your appointments.

Fold here →

My cancer information

Hi! My name is _____

I have non-small cell lung cancer. I was diagnosed:

day month year
[] [] [] [] [] [] [] [] [] [] [] []

my biomarkers:

Name of Mutation 1: _____

Location: _____

Name of Mutation 2: _____

Location: _____

my treatments:

My Current Treatment Regimen: _____

My Past Treatments: _____

Takeda Oncology is not affiliated with these organizations. By listing these resources, Takeda Oncology is not endorsing any particular service or group and we are not responsible for the services provided. They are provided here for informational purposes and are not meant to replace your healthcare provider's medical advice.

Survey Objectives

For nearly two and a half centuries, Takeda's mission has been to improve people's health, and we have built upon that heritage by developing and delivering life-changing treatments to patients—for example, those who have NSCLC involving rare *ALK* gene mutation. Today, our commitment to science, collaboration, and innovation fuels our continued dedication to creating care options for people affected by cancer, including those with NSCLC involving the EGFR Exon 20 insertion mutation.

To more fully meet the needs of the patients and care partners we serve, we also consider it essential to provide meaningful quality of life support. As a patient committed to becoming your own best advocate or as someone who supports that journey, you may be seeking guidance about how to best conduct online fact-finding, get emotional support, and select and work with doctors who are experts in both lung cancer and the use of biomarker testing, which is important because it can help diagnose and track your disease and guide its care.

The bottom line is that you may appreciate information that can help empower you in that search. That's why we worked with the Exon 20 Group to conduct this survey and share its results.

Like Takeda, the Exon 20 Group is devoted to supporting those affected by NSCLC with the EGFR Exon 20 insertion mutation. The Exon 20 Group has pledged to advance the discovery and approval of promising Exon 20-targeted drugs, help patients and their families thrive through treatment, and connect clinicians and other stakeholders with the community of people affected by NSCLC that have the EGFR Exon 20 insertion mutation.

Through this partnership, we're excited to be able to extend a hand to you. We're also thrilled that the findings of this study will expand the wisdom and hope we helped develop within the lung cancer community over the past decade.

Survey Methodology

The "Rare, But Not Alone" survey was designed by Takeda with the help of a roundtable of experts who collaborated to design a set of 86 questions that addressed the issues most relevant to those affected by NSCLC with the EGFR Exon 20 insertion mutation.

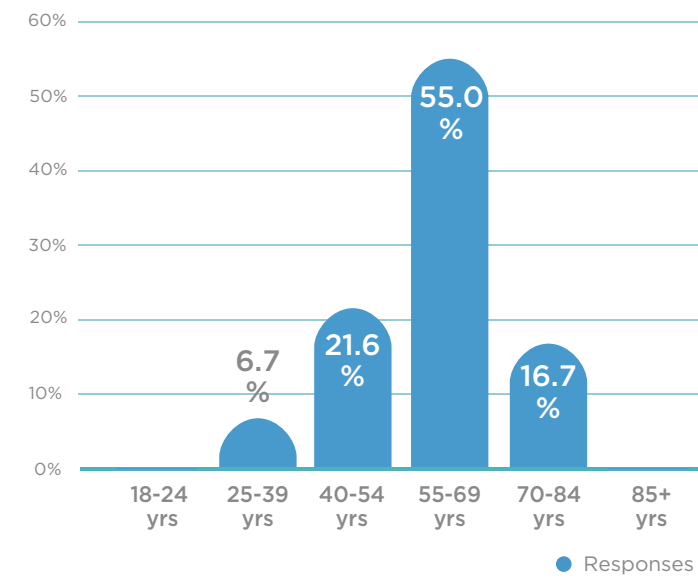
Administered online, the survey was conducted from June 17, 2021, to July 31, 2021, by leaders of the Exon 20 Group and the EGFR Resisters organization among their members, including some outside the United States. The survey was presented in English.

Within the population that initially agreed to take part in the survey, participants were self-selected. Some 79 people started the survey but 19 dropped out after the first question, regarding whether or not they had the Exon 20 insertion mutation. Aside from the answer to that question, the results shown here represent the remaining 60 people. Some participants opted not to answer one or more questions.

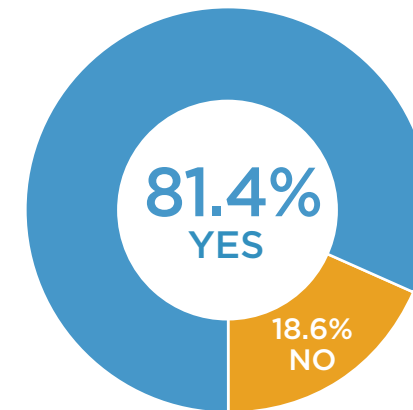
Because most were connected with advocacy organizations before they took the survey, participants may have demonstrated a higher level of understanding about their disease, along with its diagnosis and treatments, compared with the overall population of people with NSCLC that have the EGFR Exon 20 insertion mutation. However, this may ultimately have been beneficial, as participants were able to share considerable expertise about the resources they found most helpful, as well as advice about how to connect with them.

Survey Details

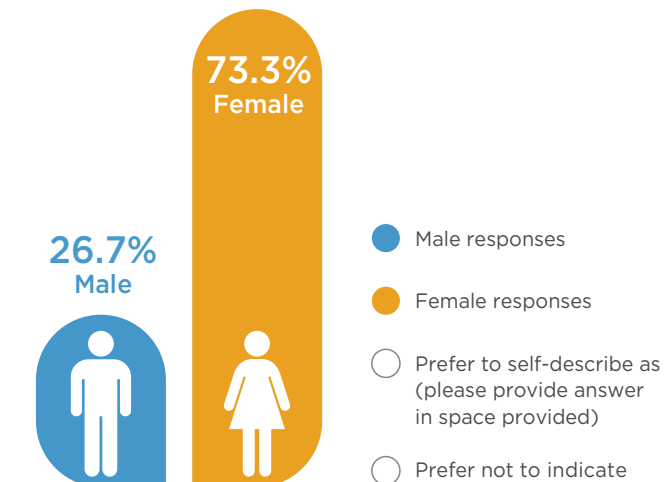
What is your age?



Have you been diagnosed with non-small cell lung cancer (NSCLC) with the EGFR Exon 20 insertion mutation? (please check one)



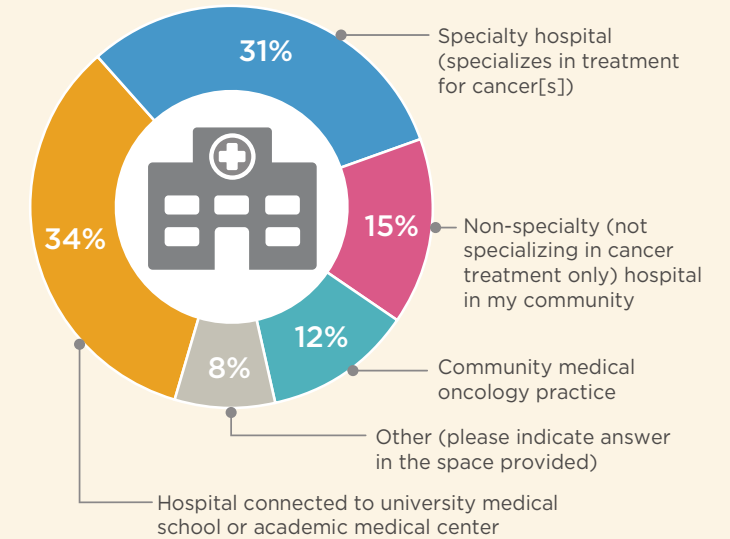
What is your gender?



Which of the following best represents your racial or ethnic heritage? (please check one)

Non-Hispanic, White/Caucasian, or Euro-American	86.6%
East Asian or Asian-American	5.0%
Hispanic or LatinX	3.3%
Black, Afro-Caribbean, or African-American	1.7%
Middle Eastern or Arab-American	1.7%
Native American or Alaskan Native	1.7%
South Asian or Indian-American	0.0%
Other	0.0%

Where (what type of hospital or medical practice) were you first treated?

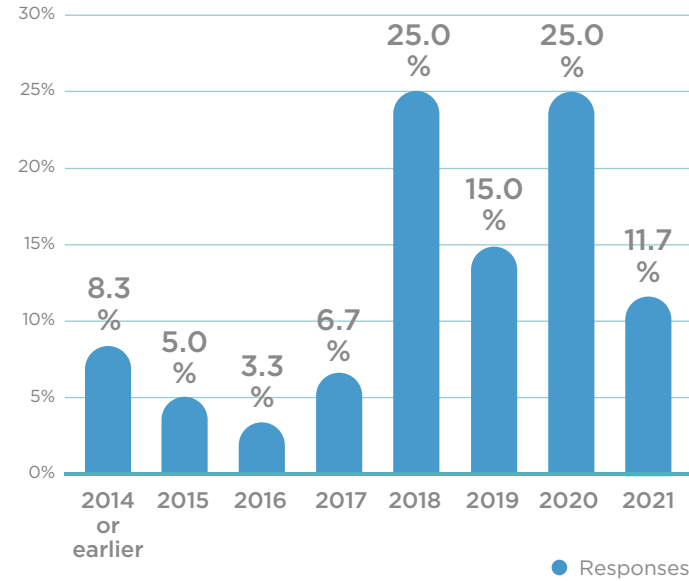


my Oncologist's name: _____

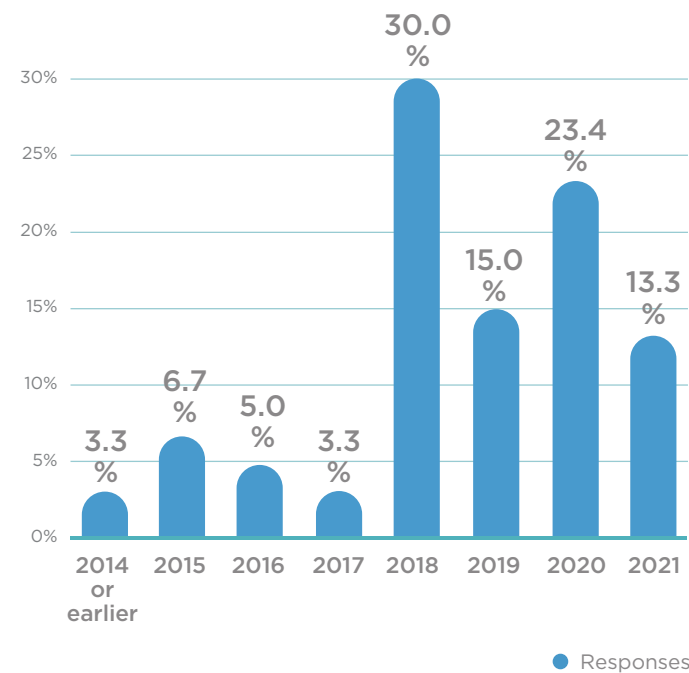
my notes: _____

Survey Details (Continued)

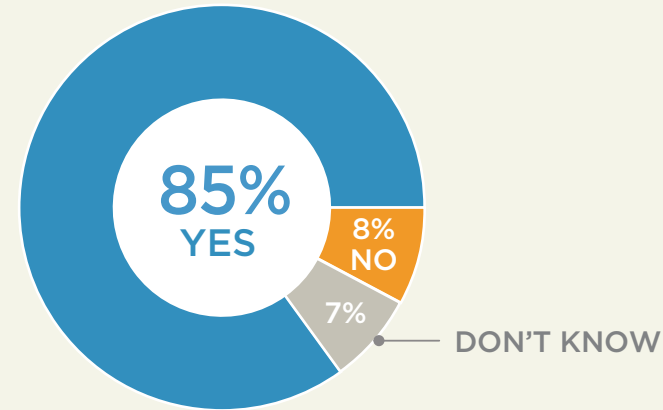
What year were you initially diagnosed with non-small cell lung cancer (NSCLC)?



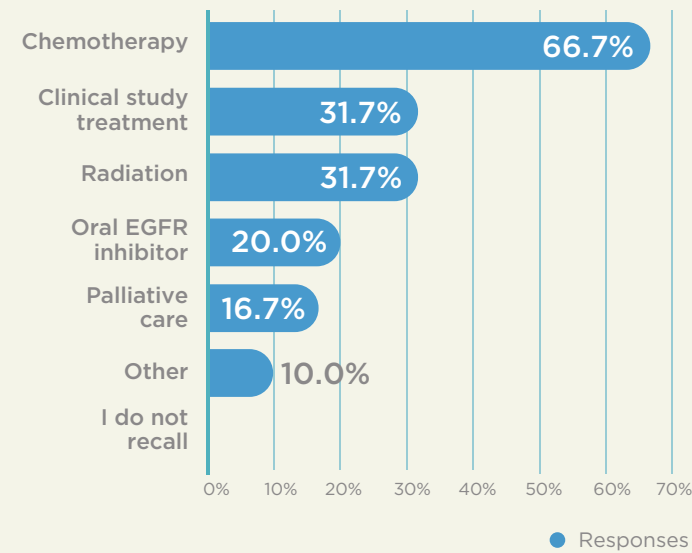
What year was the EGFR Exon 20 insertion mutation identified as the specific type of non-small cell lung cancer (NSCLC) you have?



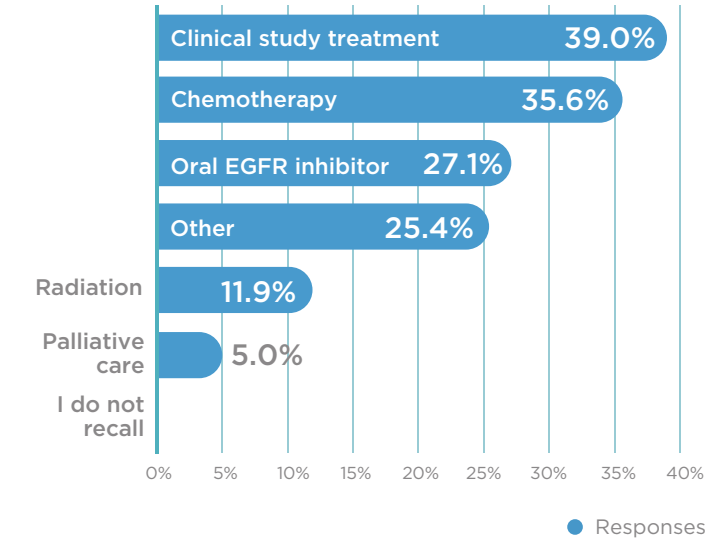
Does your current oncologist treating your non-small cell lung cancer (NSCLC) with the EGFR Exon 20 insertion mutation specialize in lung cancer?



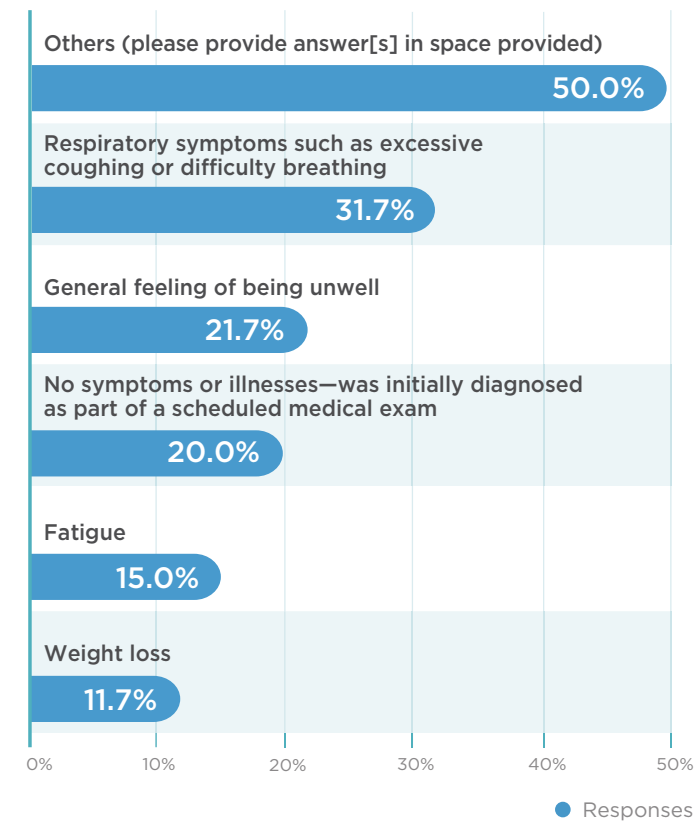
What were the anti-cancer treatments (if anti-cancer drug[s]) that you were first prescribed for the treatment of non-small cell lung cancer (NSCLC)? (please select all that apply)



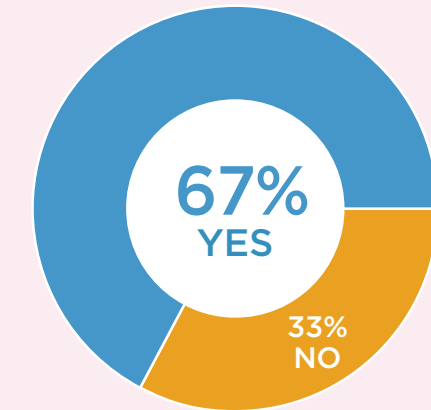
What anti-cancer treatments (if anti-cancer drug[s]) are you taking now as single drug or in a combination of drugs for the treatment of your non-small cell lung cancer (NSCLC) with the EGFR Exon 20 insertion mutation? (please select all that apply)



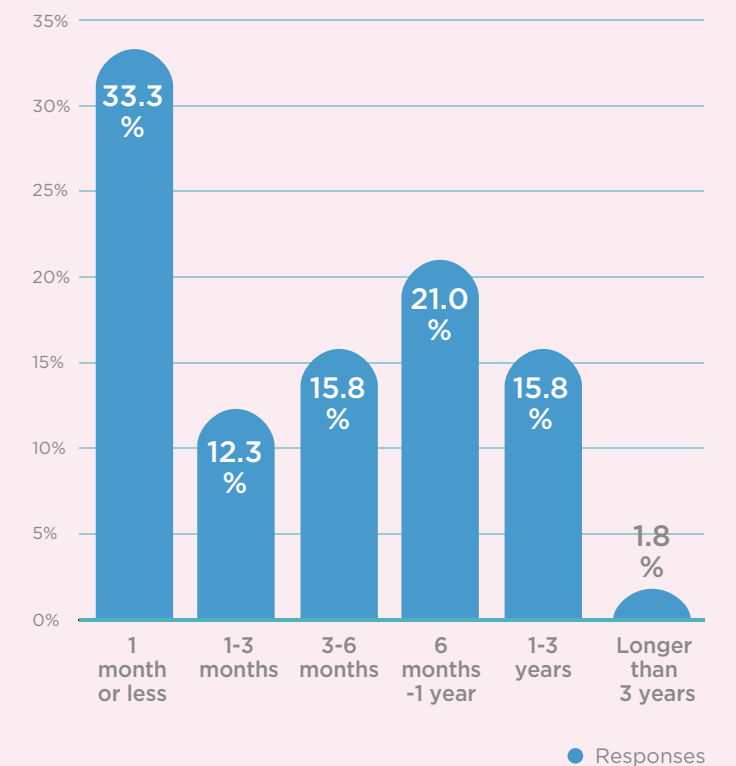
What were your initial symptoms that led to your diagnosis of non-small cell lung cancer (NSCLC)? (Check all appropriate)



Do you engage in sports and/or physical activity/exercise?

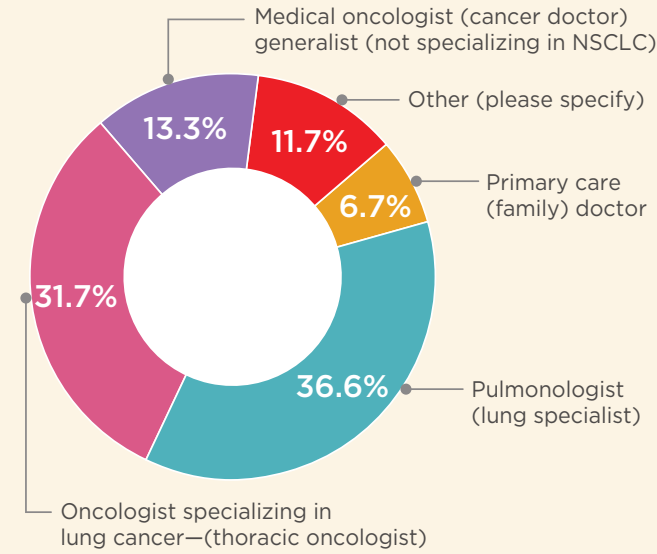


How much time passed between the time you first experienced symptoms that eventually led to your diagnosis of non-small cell lung cancer (NSCLC) to the time you actually received your diagnosis of NSCLC?

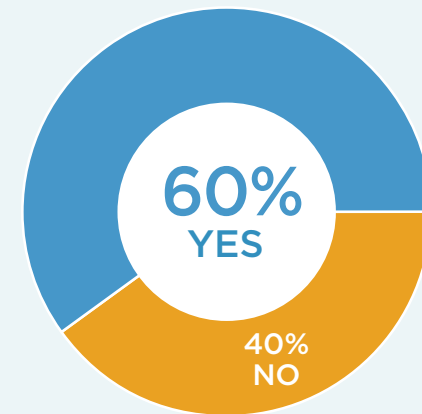


Survey Details (Continued)

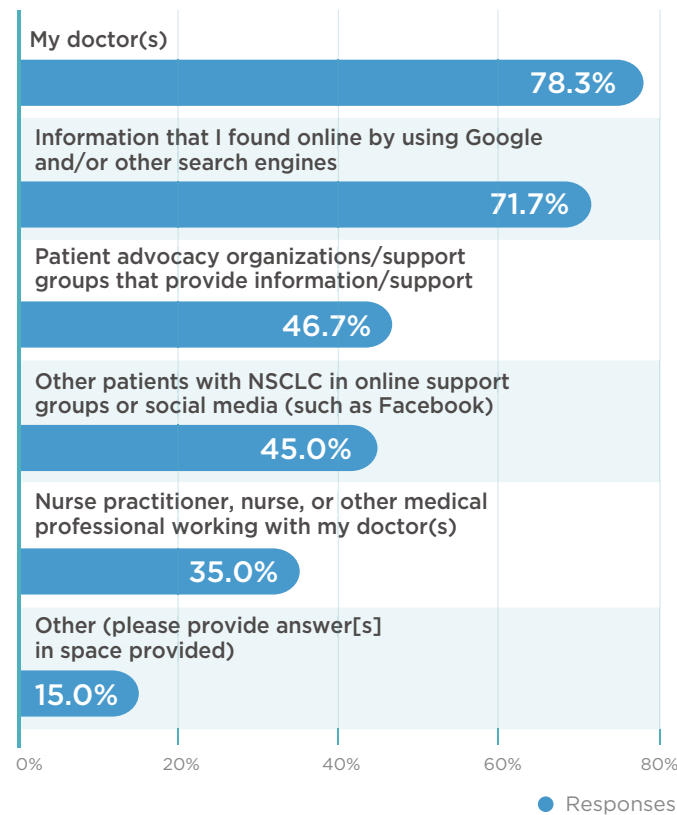
What type of doctor first diagnosed your non-small cell lung cancer (NSCLC)? (please check one)



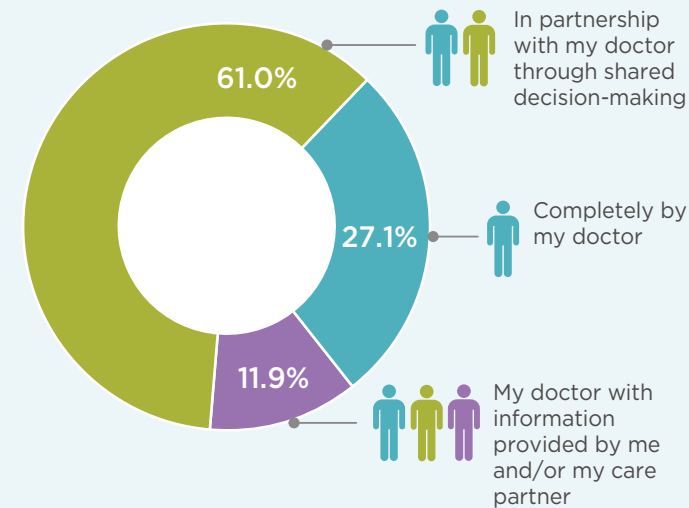
Do you believe that you received enough information at your initial doctor visits after your diagnosis of non-small cell lung cancer (NSCLC) to make good decisions about what to do next?



What were the sources for information that you received about your non-small cell lung cancer (NSCLC)? (please check all appropriate answers)



Who made the treatment decisions after your diagnosis of non-small cell lung cancer (NSCLC)? (please check one)



At approximately what time after diagnosis with non-small cell lung cancer (NSCLC) did you begin to do your own research on your condition?

Directly after diagnosis (within 1 week)	75.0%
2-4 weeks after diagnosis	18.3%
1-3 months after diagnosis	5.0%
3-6 months after diagnosis	1.7%
6 months-1 year after diagnosis	0.0%
More than 1 year after diagnosis	0.0%

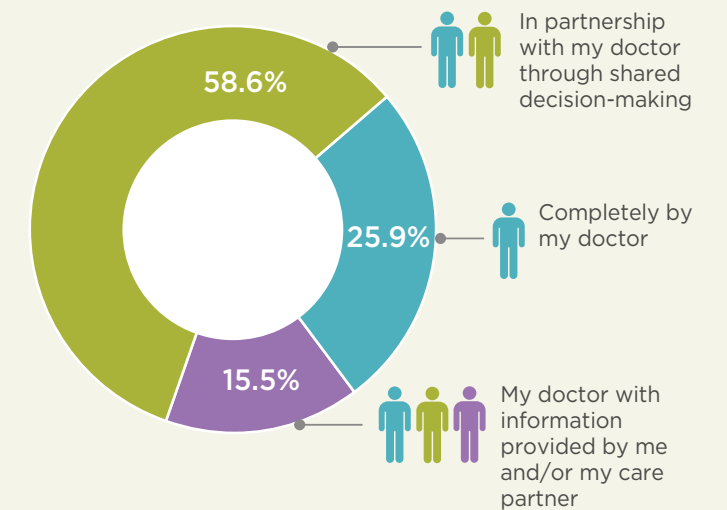
In what ways has your treatment for non-small cell lung cancer (NSCLC) with the EGFR Exon 20 insertion mutation impacted your quality of life? (please select all that apply)

Management of side effects causes a physical burden	59.3%
I feel that many people in my life do not understand how difficult management of my cancer is	39.0%
The drug regimens have challenged my ability to see friends and family	23.7%
Management of side effects causes a financial burden of unexpected additional expenses	17.0%
My treatment for NSCLC does not impact my quality of life	16.0%
Management of my cancer causes a financial burden	15.2%
Other (please specify)	15.2%
The side effects of my current treatment compromise my ability to care for children and/or other loved ones	11.9%

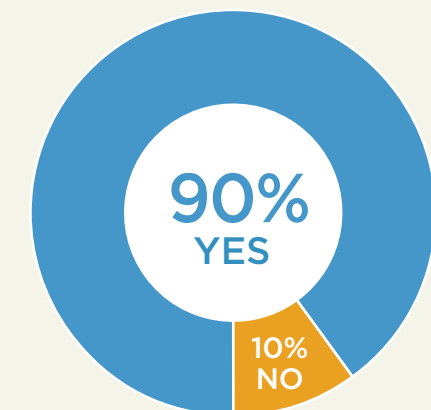
On a scale of 1 to 5 (WHERE 1=COMPLETELY DISAGREE AND 5=COMPLETELY AGREE), to what extent do you agree with the following statement? "Most of the information and education that I received regarding my initial diagnosis of non-small cell lung cancer (NSCLC) came from my own research, not from the healthcare team."

Agree	43.3%
Completely Agree	21.7%
Neutral	16.7%
Disagree	13.3%
Completely Disagree	5.0%

Who made the treatment decisions after your diagnosis of non-small cell lung cancer (NSCLC) with EGFR Exon 20 insertion mutation? (please select one)



Did your doctor and/or healthcare team discuss the potential side effects of your anticancer drugs and how to treat those side effects?



Survey Details (Continued)

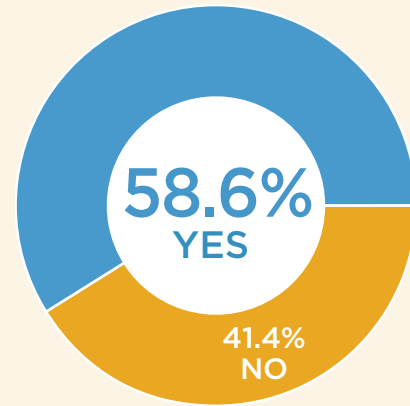
What were the next steps recommended to you after diagnosis of non-small cell lung cancer (NSCLC)? (please check all appropriate)

Treatment was discussed and I began my first drug regimen for NSCLC	47.5%
Additional testing, such as comprehensive biomarker testing, was discussed or recommended	38.9%
Referral to a hospital that is part of a university medical school or academic medical center	18.6%
Referral to an National Cancer Institute (NCI)-designated comprehensive cancer center that specializes in cancer treatment	13.5%

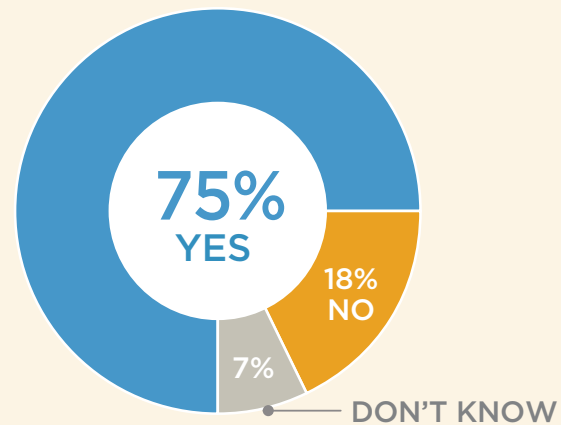
What were the next steps recommended to you after diagnosis of EGFR Exon 20 insertion mutation non-small cell lung cancer (NSCLC)? (please check all appropriate)

Treatment was discussed and I began my first drug regimen for EGFR Exon 20 insertion mutation NSCLC	44.0%
I was referred to a clinical trial	32.2%
Follow-up visit(s) were scheduled to discuss next steps	23.7%
Referral to an National Cancer Institute (NCI)-designated comprehensive cancer center that specializes in cancer treatment	22.0%
Other (please specify)	15.2%

Have you had to change/switch medications/treatment for your non-small cell lung cancer (NSCLC)? (please check one)



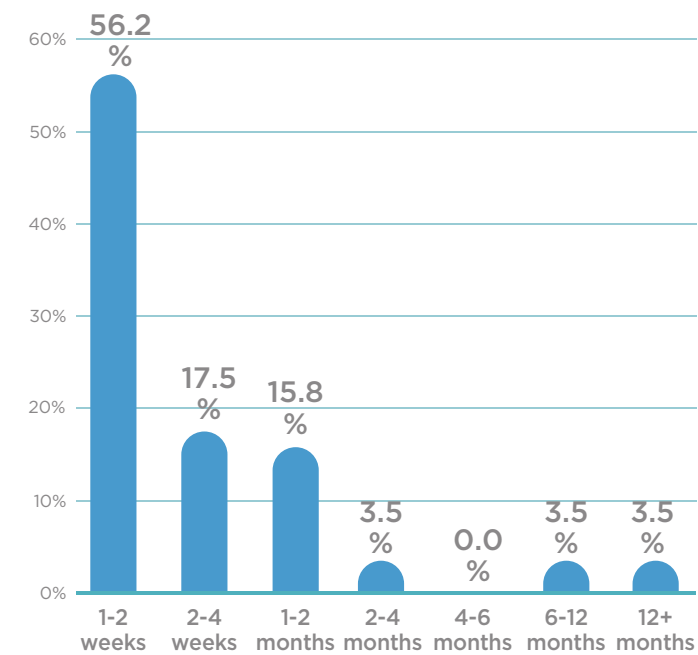
Was testing of your tissue or blood to look for genetic mutations (changes in your genes that may help identify the specific kind of non-small cell lung cancer [NSCLC] you have) discussed at the initial oncology appointments that you had for your NSCLC diagnosis?



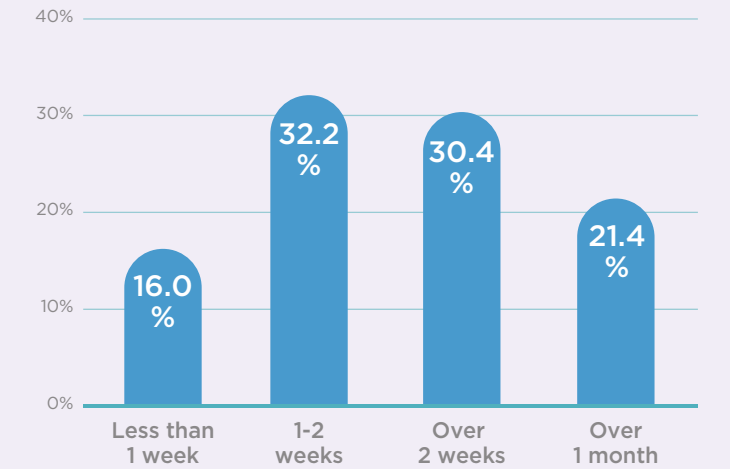
If you underwent testing for genetic mutations (changes in your genes that may help identify the specific kind of non-small cell lung cancer [NSCLC]), which doctor ordered the test?

Oncologist specializing in lung cancer—cancer doctor that specializes in NSCLC	42.9%
Medical oncologist/oncologist—generalist (cancer doctor not specializing in NSCLC)	37.5%
Pulmonologist (lung specialist)	8.9%
Other	7.1%
Primary care (family) doctor	1.8%
Not applicable	1.8%

How much time passed from the time you were first diagnosed with non-small cell lung cancer (NSCLC) and the time it was recommended that genetic mutation testing (changes in your genes that may help identify the specific kind of NSCLC you have) should be performed? (please check one)



How much time passed from the time testing for genetic mutations (changes in your genes that may help identify the specific kind of non-small cell lung cancer [NSCLC] you have) was ordered to the time you received the results of the test(s)?



Where did you receive information about clinical trials? (please select all that apply)

My healthcare team (physician, nurse practitioner, physician's assistant, nurse)	49.1%
Patient advocacy organizations	38.6%
Internet search	36.8%
Other (please specify)	28.0%
Social media groups sponsored by patient advocacy organizations	26.3%

Acknowledgments

“Rare, But Not Alone” Survey Participants

This publication would not have been possible without the contributions of the dozens of people who participated in the online survey. We thank you for your time, your insights, and your honesty.



Takeda Pharmaceutical Company sponsored this report. Conducted by Takeda in collaboration with the Exon 20 Group, it discusses the results of a global survey of patients with NSCLC that have the EGFR Exon 20 insertion mutation.

Takeda Pharmaceutical Company is a global biopharmaceutical company focused on research and development that, for two-and-a-half centuries, has been developing life-changing potential treatments for groups of people who face a high level of need. Through its commitment to science and innovation and its passion for improving lives, the company is dedicated to delivering new kinds of care to patients across the world, including those who have hard-to-treat cancers.

In addition to its deep in-house expertise, Takeda has established a network of partnerships with other organizations with a goal of unlocking the most promising science while providing meaningful quality of life support to the communities it serves.

Learn more about Takeda at [takeda.com](https://www.takeda.com).

Some of the uses described in this publication have not been approved by the FDA.

This article is for informational purposes only and is not intended to provide medical advice. Marcia K. Horn, Dr. Andre Liem, and Kathleen Phan received compensation from Takeda for their participation in this publication.



The Exon 20 Group, a nonprofit organization founded in 2017, is dedicated to turning EGFR Exon 20 insertion-mutated NSCLC and similar conditions into diseases that can be medically managed long-term by funding research and providing emotional and informational support. This international organization includes key stakeholders from more than 50 countries: patients and their care partners, oncologists who specialize in these cancers, oncology nurses, laboratory researchers, health regulatory experts, and pharmaceutical companies.

While drawing clinicians into the effort to speed up the discovery and quick approval of promising treatments, the Exon 20 Group is committed to helping patients and their loved ones thrive through the journey with NSCLC that has the EGFR Exon 20 insertion mutation. Through this group, patients and their care partners can receive case navigation, referrals for second opinions, assignment of an “Angel Buddy” mentor, strategies for managing side effects, help finding appropriate clinical trials, and invitations to participate in conferences and online support groups.

The Exon 20 Group makes a simple but powerful pledge to each of its members: “We will never give up on you, and we will never leave you stranded.”

Learn more about this support organization at [exon20group.org](https://www.exon20group.org).

The Patient Survey Roundtable included 3 experts who helped shape the questions asked of participants. Using their experience across a variety of rare lung cancers, the roundtable members were asked to ensure that the survey addressed the issues that matter to those facing NSCLC with the EGFR Exon 20 insertion mutation.



Marcia K. Horn, JD, of Phoenix, Arizona, has been president and CEO of the International Cancer Advocacy Network (ICAN) since 1997 and executive director of the Exon 20 Group since 2017.

Named a top-rated health nonprofit by [GreatNonprofits.org](https://www.GreatNonprofits.org), ICAN has navigated complex cases of stage IV cancer for more than 15,000 patients, families, and caregivers worldwide, with a goal of increasing survival while providing the highest possible quality of life. Within ICAN, the Exon 20 Group is a working group and international coalition dedicated to increasing treatment options for patients who have either of 2 unusual genetic mutations that contribute to cancer’s growth, including the EGFR Exon 20 insertion mutation.

Ms. Horn’s additional involvement across the cancer community includes membership in the SWOG Cancer Research Network’s Early Therapeutics and Rare Cancers Committee, an advocacy role for the Stand Up 2 Cancer Lung Cancer Interception Dream Team, and service as a research advocate for the National Cancer Institute’s Lung Specialized Program of Research at the University of Texas Southwestern and as an ambassador to the Patient-Centered Outcomes Research Institute. In her home state, she spearheaded a lobbying effort that resulted in the Arizona legislature providing \$10 million to fund the Arizona Anticancer Drug Discovery and Development Act of 1998.



Andre Kiem D. Liem, MD, is a medical oncologist and hematologist with City of Hope Comprehensive Cancer Center in Long Beach Elm, Long Beach Worsham, and Torrance. Dr. Liem also works as an assistant Clinical Professor in the Department of Medical Oncology & Therapeutics Research at City of Hope. He had been affiliated with Pacific Shores Medical Group in Long Beach, California, since 1999. There, he was director of the clinical research program, serving as an investigator in numerous clinical trials, including those testing anticancer treatments designed for patients with NSCLC driven by the EGFR Exon 20 insertion mutation.



Kathleen Phan is a project manager for the clinical trials office at City of Hope Comprehensive Cancer Center in Long Beach, California. She is skilled in all aspects of clinical trial coordination across studies in various medical areas, including oncology, hematology, and urology. Phan has worked with City of Hope, formerly, Pacific Shores Medical Group, since 2017, first as a patient coordinator, then as a clinical research coordinator, and now as a senior clinical research coordinator. In that role, she serves as lead clinical research coordinator and a sub-investigator on phase I to IV clinical trials at 7 clinic sites that provide 14 medical experts to participate as investigators. The trials she has supported include several with recently published results that tested anticancer treatments designed for patients with NSCLC driven by the EGFR Exon 20 insertion mutation.



We offer special thanks to the **EGFR Resisters** for also fielding this survey among its members. EGFR Resisters is an organization for people living with lung cancer that is sparked by an EGFR gene mutation and has become resistant to targeted treatment—drugs designed specially to fight a specific type of cancer. The group’s aim is to drive important research questions and fund new science and clinical trials.

Glossary

ALK gene:

The anaplastic lymphoma kinase gene, which contributes to cell growth and division. Mutations to the ALK gene can contribute to the development of cancer.²⁷

Biomarker testing:

Tissue or fluid testing for mutations that were not inherited. The results of these tests can help identify the best type of treatment for your cancer.⁹

Chronic disease:

A disease that continues for at least 1 year and requires ongoing medical attention, limits daily activities, or both.²⁸

Clinical trial:

A research study that includes human patients who receive medical treatment with the goal of determining the health outcomes of the therapy.²⁹

DNA:

Deoxyribonucleic acid is a chemical sequence found in cells that acts as instructions information for building and maintaining an organism.³⁰

Driver mutation:

A mistake in a gene that contributes to the development of cancer.³¹

EGFR Exon 20 insertion mutation:

The addition of extra genetic information in the Exon 20 section of the EGFR gene.^{13,15}

EGFR gene:

The epidermal growth factor receptor gene, which contributes to the process of cell growth and survival.¹³

FDA:

The Food and Drug Administration is a US agency that regulates clinical trials.³²

Genes: Inherited chemical sequences in the body, known as DNA, that determine a person's physical characteristics.³³

Lung cancer: A disease that starts in the lungs, cells then grow out of control.²

Mutation:

A change in DNA. It can result from copying mistakes that happen when cells divide, exposure to some chemicals, types of radiation, and viruses. Some mutations are inherited.³⁴

Next-Generation Sequencing (NGS):

A process for testing DNA samples for mutations. This method has more discovery power than another commonly used method: polymerase chain reaction (PCR).²¹

NSCLC or non-small cell lung cancer:

The most common type of lung cancer.¹

Oncologist:

A doctor who specializes in treating cancer.³⁵

Patient advocacy group:

An organization, often nonprofit, that works to inform, support, and advocate on behalf of patients.³⁶

Polymerase Chain Reaction (PCR):

A process for testing DNA samples for mutations. This kind of test is also more widely available than next-generation sequencing (NGS).²⁰

Prognosis:

The course a particular disease is likely to take.³⁷

Side effect:

An unintended and typically unwanted health effect that arises from treatment with a drug.³⁸

Support group:

A group of people who provide emotional and informational support to help each other through a challenging shared experience, sometimes led by a professional facilitator.³⁹

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