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Objectives and Methodology

Objectives

To provide Company X with an analysis of lung cancer patients' and caregivers' voice through detailed information driven by answers to specific questions relating to NGS testing, treatment side effects, treatment development research, and COVID-19 experiences

Methodology

- 30-minute survey of 100 adult patient and caregiver members from Company Y's Lung Cancer Survivors community conducted between July 23 and August 20
- Three 1-hour interviews of patients who completed the survey; interviews were conducted between August 17 and August 25

Executive Summary

Respondents see hope in the potential of NGS testing

- Sentiment around NGS is overwhelmingly positive and primarily hopeful
- Of patients who received NGS testing, 81% said the results were important when selecting their treatment plan
- While patients deeply value the information NGS brings, many of them express feelings of concern and anxiety about the cancer spreading while they wait

Patients seek treatment information specific to their lung cancer mutation

- When patients conduct research, more than 50% look for information about treatments and clinical trials for their specific mutation
- Patients are likely to discuss new treatments with their doctor, but they also rely on media resources (49%) and patient organizations (43%) for information as well

Many respondents report COVID-19 has affected appointments with their HCPs

- Most patients report their in-person appointments have been rescheduled as video or phone call appointments
- Patients who have had video appointments report having positive experiences and feel they receive high-quality care despite not being in-person
- Patients are asking their HCP about **precautions they should be taking** to reduce exposure to COVID-19 and inquired about **how their treatment plan for COVID-19 might differ** from those without lung cancer

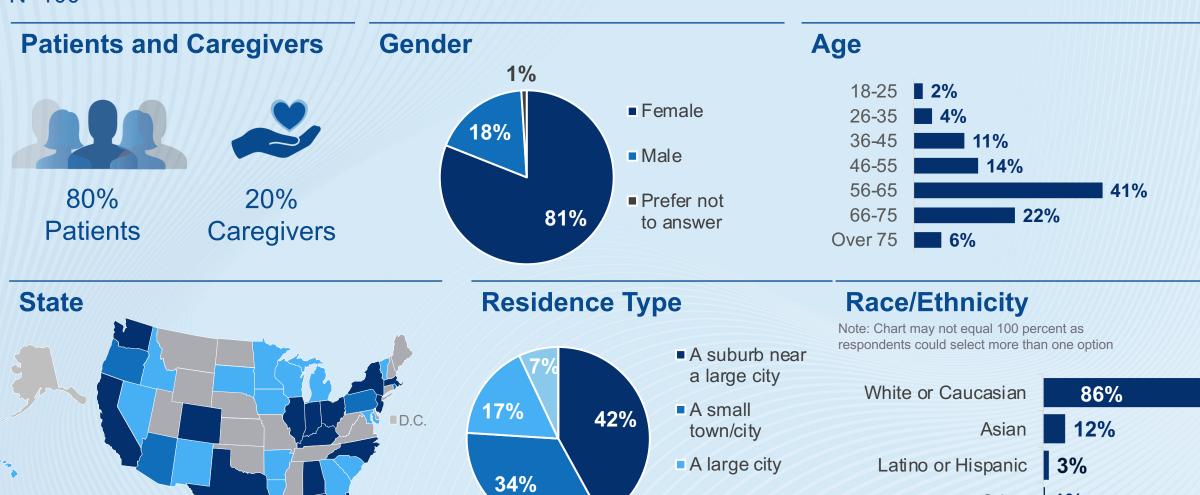
Recommendations

- Onsider creating materials about what NGS testing is, how it works, and why it is important
 - Whenever feasible, offer patients resources that explain the process of (NGS) testing and emphasize the
 importance of discussing it with their healthcare provider. Additionally, explore avenues to disseminate information
 on coping strategies for managing the stress and anxiety associated with waiting for test results.
 - Consider ways to encourage health care providers to talk about the benefits of NGS testing with patients and caregivers
- Explore ways to make treatment and clinical trial information more readily available to patients, health care providers, and patient organizations
 - Consider creating treatment informational materials that focus on specific mutations and when possible, disseminate clinical trial recruitment details to patient organizations, especially trials designed for specific types of mutations
 - Patients suffer a variety of side effects during their treatment; therefore, it is important to consider offering
 informative resources such as pamphlets, apps, or websites that provide guidance on how to effectively manage
 these side effects
- Develop informational materials addressing COVID-19 concerns and questions for patients
 - To alleviate patient concerns that the pipeline for cancer treatment has been paused, launch a social media campaign highlighting how Company X continues to be at forefront of medical progress in developing treatments even during the pandemic
 - Recognizing patients are actively seeking educational resources on the topic of lung cancer and COVID-19, it may
 be beneficial to develop a dedicated fact sheet specifically tailored to address to these concerns



Demographics

N=100



A rural area

Other

Prefer not to answer

1%

1%

Q: What is your age?

Q: Which best describes you? (gender/race)

Q: What state do you reside in?

Q: Which of the following best describes you with regards to lung cancer? Q. Which of the following best describes the type of area you currently live in?

Caregiver Details

Summary of Caregiver Demographics

N=20



Gender of Patients

50%	50%
Male	Female

Relationship to the Patient

50%	45%	5%
Spouse/Partner	Child	Parent

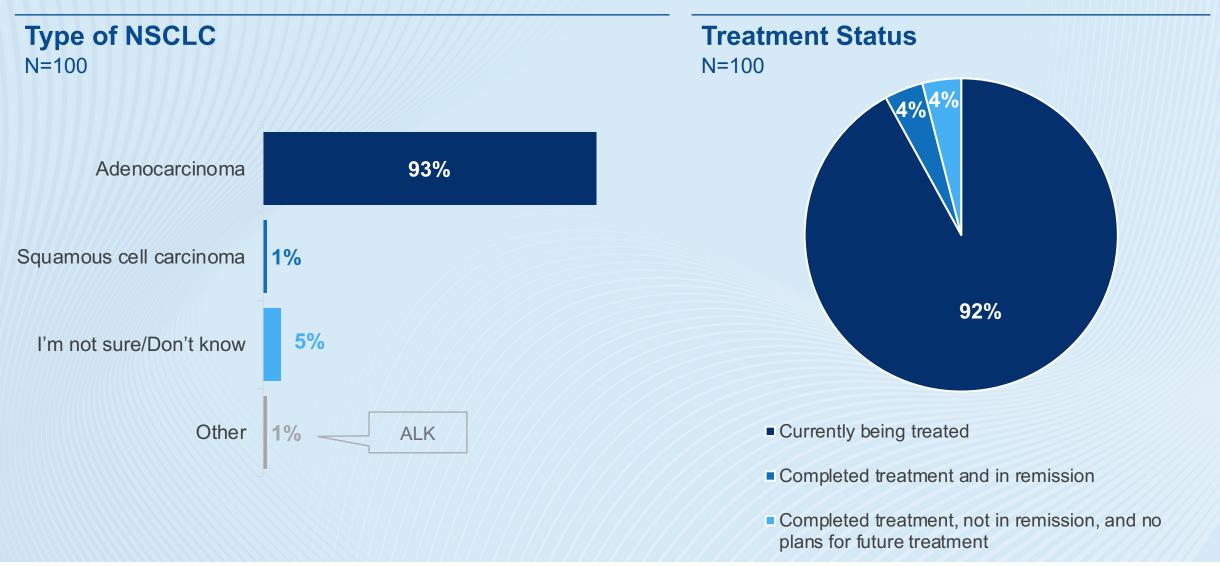
Age of Patient

15%	30%	50%	5%
46-55	56-65	66-75	Over 75

- Most of the participating caregivers were spouses/partners of patients over 66 years old
- 90% of caregivers attended a majority of the patient's health care appointments

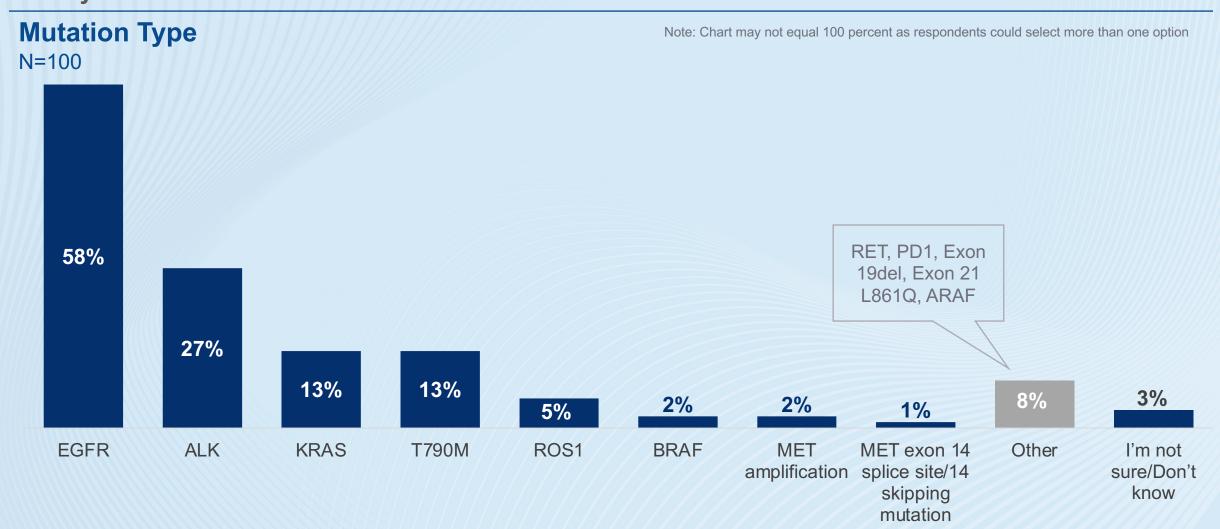
Lung Cancer Diagnosis

Nearly all patients had been diagnosed with adenocarcinoma and were undergoing treatment



Mutation Testing

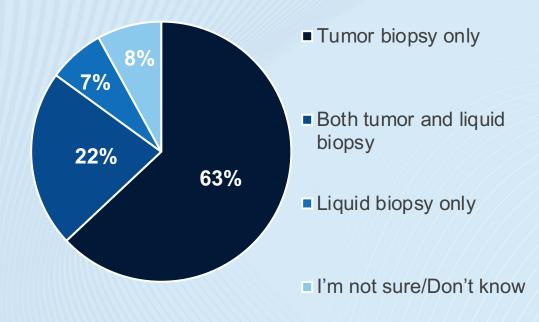
EFGR was the most prevalent mutation type patients tested positive for, appearing over twice as much as any other mutation

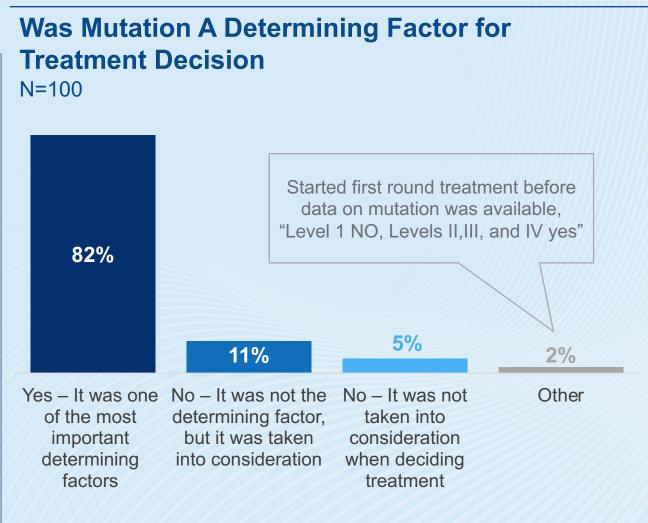


Diagnostic Screening

Tumor biopsies were far more common than liquid biopsies; most said that the mutation was one of the most important determining factors in choosing a treatment

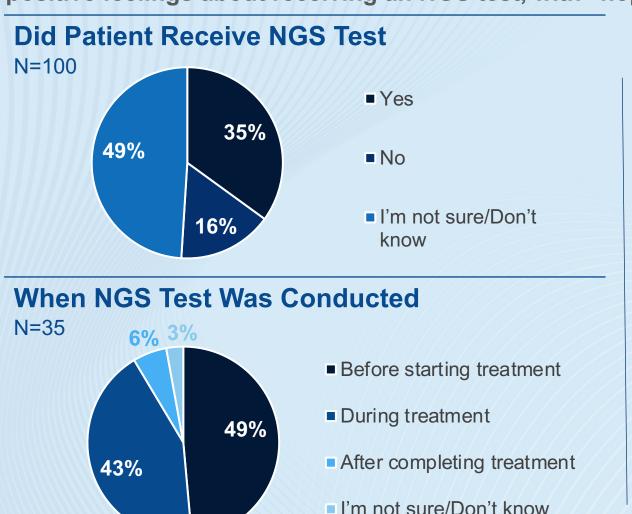






Next Generation Sequencing (NGS) Testing

Nearly half of respondents did not know if they had received an NGS test; almost all recipients had positive feelings about receiving an NGS test, with "hopeful" being the most common word used



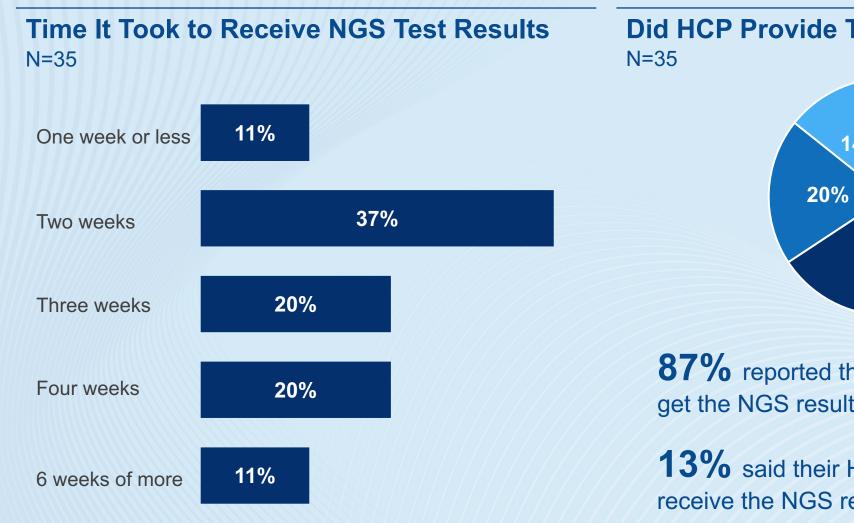




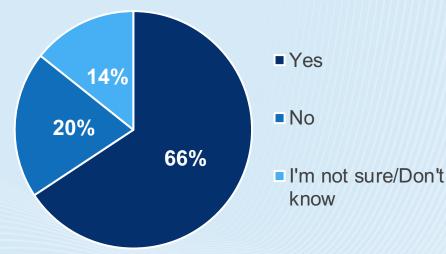
Think about ways to encourage health care providers to talk about the benefits of NGS testing with patients and caregivers

Next Generation Sequencing (NGS) Testing (cont.)

77% of patients reported receiving their NGS results within 2 - 4 weeks; this was consistent with the estimates provided by health care providers



Did HCP Provide Time Estimate to PatientN=35



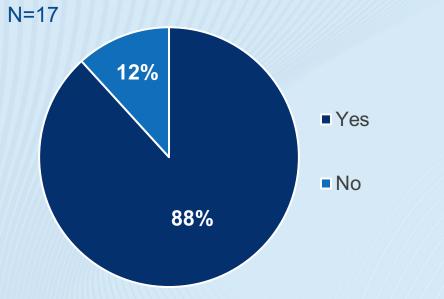
87% reported their HCP estimated they would get the NGS results in **2-4 weeks**

13% said their HCP estimated they would receive the NGS results in less than 2 weeks

NGS Testing and Patient Experience

Most respondents indicated a preference to wait for the results of their NGS test before making any treatment decisions; patients expressed optimism the results would help with treatment decisions

Did Patient Wait for NGS Results Before Making Treatment Decision

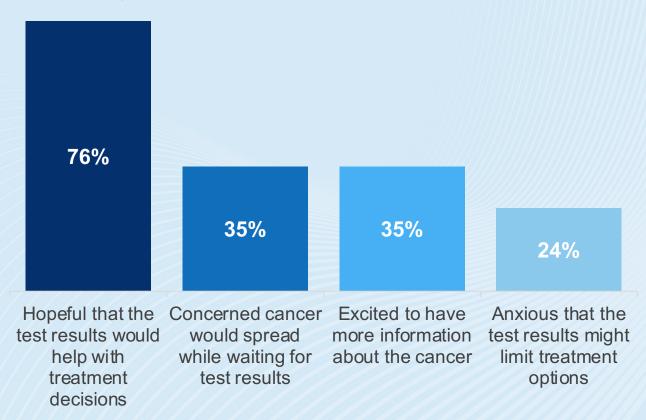


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When possible, provide resources to patients which explains how NGS testing works and why they should talk to their doctor about NGS testing and explore ways to circulate information on how to cope with the stress and anxiety that comes from waiting for results

How Patients Felt About Delaying Treatment Decision Until Results Received

N=15 Note: Chart may not equal 100 percent as respondents could select more than one option

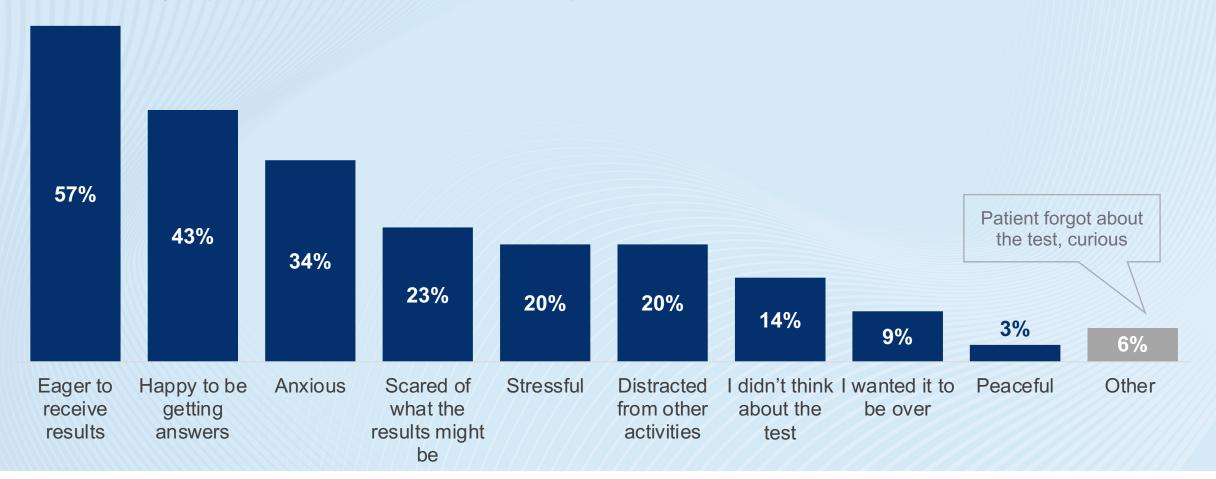


NGS Testing and Patient Experience (cont.)

Though 43% were happy to be getting answers, waiting for NGS test results caused anxiety for more than a third of the patients; 20% reported feeling unable to focus on other activities during this waiting period

How Patients Felt Waiting for NGS Test Results

N=35 Note: Chart may not equal 100 percent as respondents could select more than one option



Patient Voice: Waiting for NGS Test Results

Sentiment while waiting for tests results was mixed; patients expressed hopefulness along with anxiety and concern

How Patients Felt Waiting for Test Results N=15

- Some patients indicated having a positive attitude during the wait, feeling hopeful or thankful
- A few patients indicated feeling anxious during the wait, wanting some action to be taken
- A subset of respondents indicated feeling neutral during the wait; citing low expectations, long waits, and interest in other results as some of the reasons

"The test was done with the biopsy and I was more concerned with biopsy results."—Lung cancer patient

"Testing at diagnosis was on malignant pleural effusion and showed no mutations, so we proceeded with [Brand name] chemo combo as it had just been approved (May 2017). I had progression in fall of 2019 but tumor was not accessible for biopsy. Next progression was January 2020 and tumor was able to be biopsied. Based on my prior response to treatment, best guess was that I had a rare mutation." — Lung cancer patient

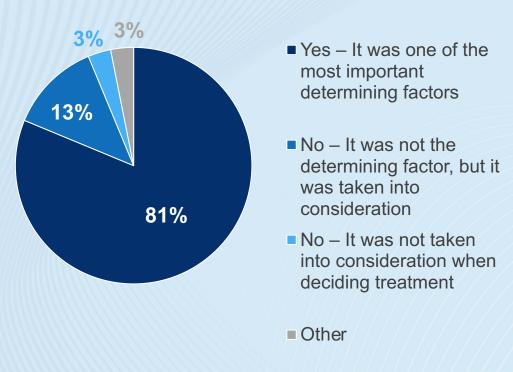
Fortunately, we discovered I am ALK Positive. We had already discussed the fact that any future chemo would be palliative. I was concerned that I might not live much longer. I have a child at home and desperately want to stay alive for her. Because of the testing I had, I know that I have a chance to live longer than I had expected. I can't describe how it feels to know there is not much medically that can be done. I didn't feel defeated, but I definitely felt that things would likely get much more complicated if my health continued to decline." -Lung Cancer Patient

Treatment Decisions

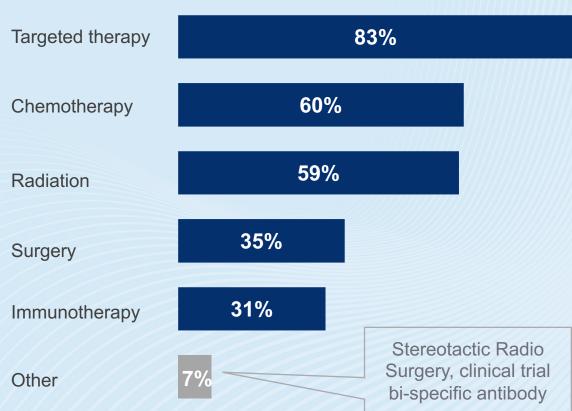
NGS results frequently dictated the type of treatment patients received; the most popular treatment given to patients was targeted therapy

Were NGS Results A Determining Factor for Treatment Decisions

N = 32



Type of Treatments Received N=100 Note: Chart may not equal 100 percent as respondents could select more than one option



Targeted Therapy Side Effects

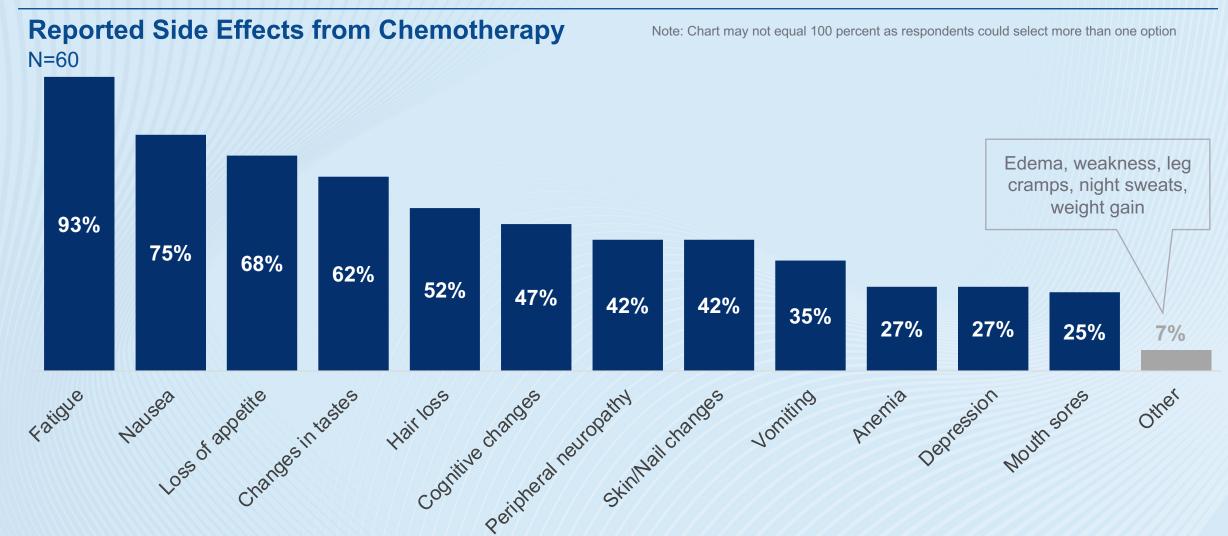
Fatigue and diarrhea were the most common side effects from receiving targeted therapy; 5% of respondents indicated that they did not experience major side effects



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Chemotherapy Side Effects

Almost all patients who received chemotherapy experienced fatigue; other frequent side effects were nausea, loss of appetite and changes in tastes

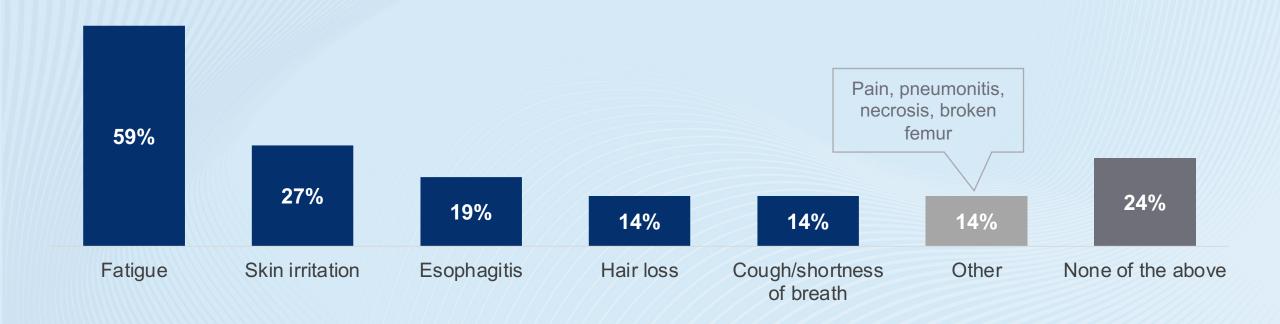


Radiation Side Effects

Almost a quarter of respondents reported that they did not experience side effects from their radiation treatment; however, more than half of patients reported experiencing fatigue



Note: Chart may not equal 100 percent as respondents could select more than one option

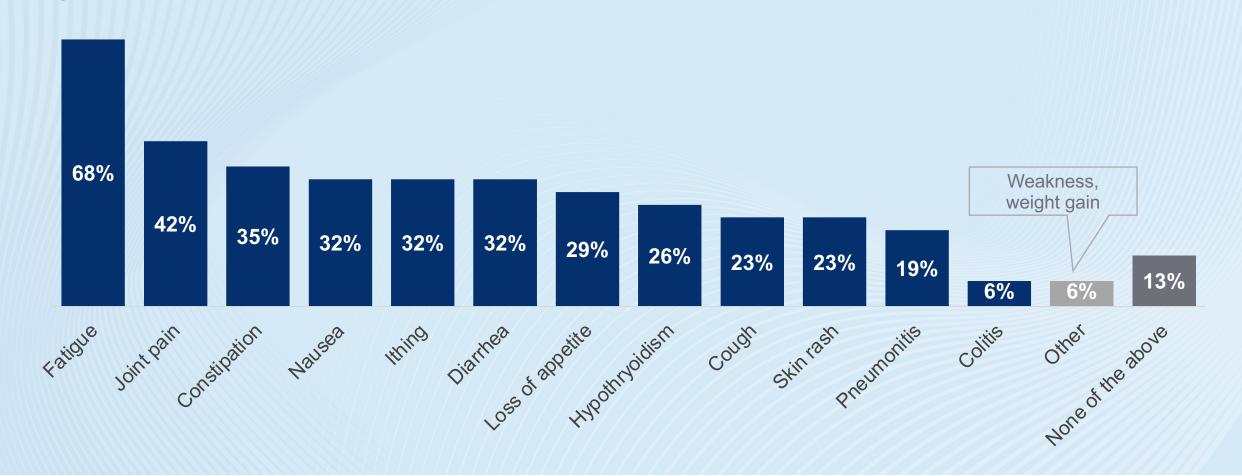


Immunotherapy/PD1 Side Effects

More than a third of respondents experienced constipation, nausea, itching, and diarrhea; the least experienced side effect was colitis

Reported Side Effects from Immunotherapy/PD1N=31

Note: Chart may not equal 100 percent as respondents could select more than one option

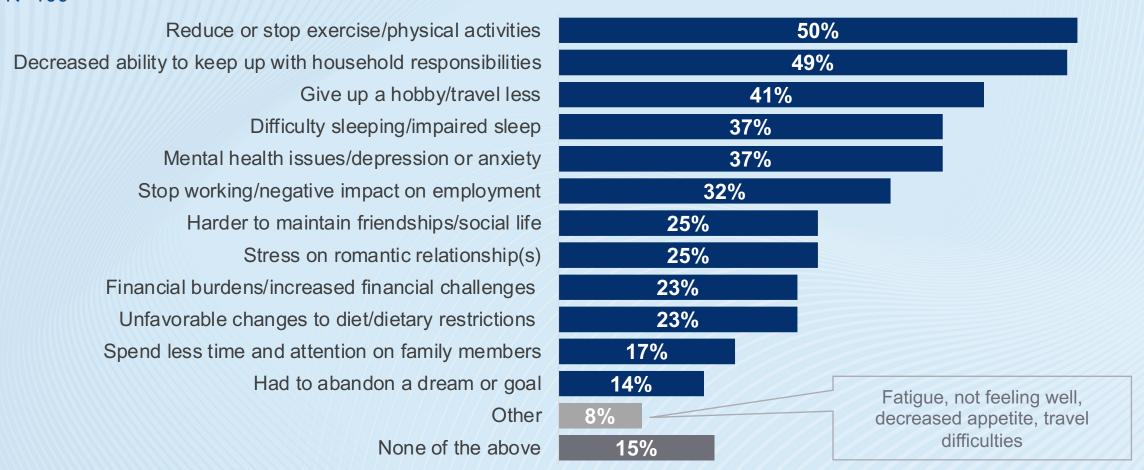


Non-Small Cell Lung Cancer Patient Experience – Quality of Life

Half said that they have had to reduce or stop physical activities and have a harder time keeping up with household responsibilities; 25% that their relationships with friends and romantic partners was affected

Impact of Non-Small Cell Lung Cancer

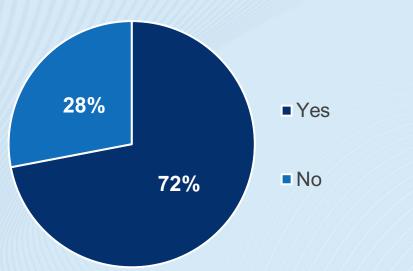
N=100 Note: Chart may not equal 100 percent as respondents could select more than one option



Treatment Knowledge

72% of patients reported that they research new treatments and clinical trials, but more than half of respondents did not recognize any of the treatments listed

Patients Who Have Looked for Information About New Treatments and Clinical trialsN=100

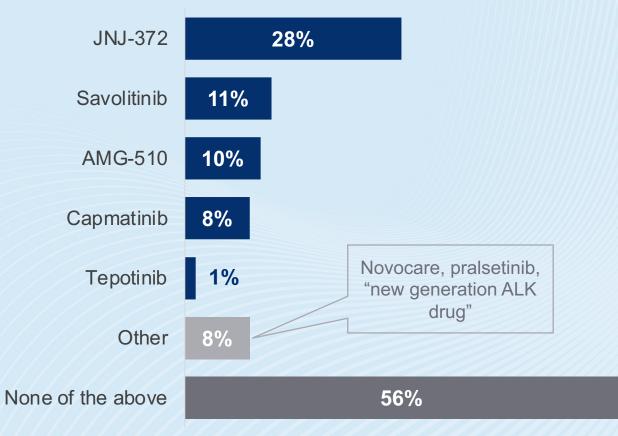




Consider creating treatment informational materials that focus on specific mutations and when possible disseminate clinical trial recruitment details to patient organizations, especially trials designed for specific types of mutations

Reported Treatments Patients Have Heard Of

N=72 Note: Chart may not equal 100 percent as respondents could select more than one option



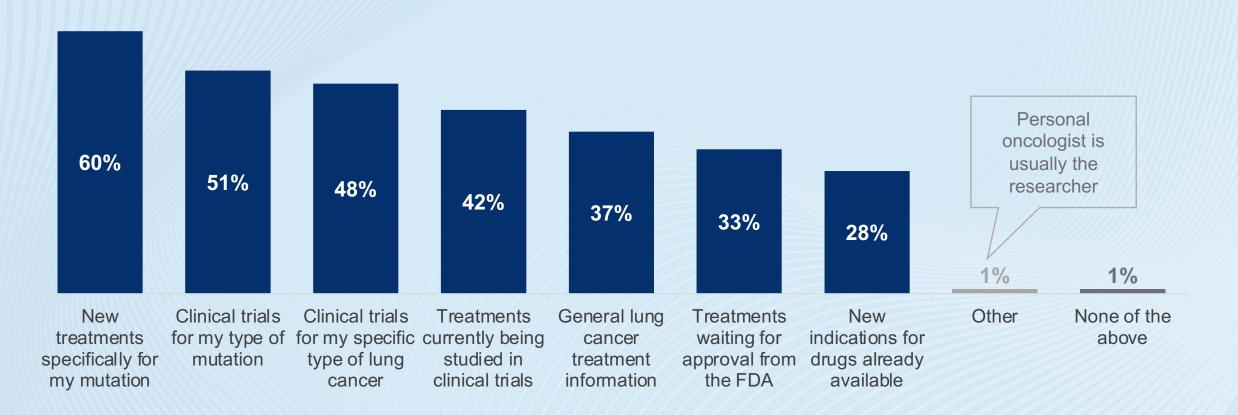
Q. Have you looked for information about new lung cancer treatments that are in development including information about clinical trials or clinical trial results. Q. What specific treatments have you heard of that are in development for lung cancer?

Information and Resources

More than half of respondents sought treatment information specifically for their mutation and clinical trials for their mutation

Treatment Information Patients Are Looking For

N=100 Note: Chart may not equal 100 percent as respondents could select more than one option



Information and Resources

Media resources were the most common source patients look to for information; drug treatment/manufacturer websites were used the least

Resources Patients Use to Find Treatment Information

N=100 Note: Chart may not equal 100 percent as respondents could select more than one option



Likeliness to Discuss New Treatments with HCP

63% of respondents were likely to discuss new treatments with health care providers; those who were unlikely to discuss new treatments reported being on an effective medication or being stable

Likeliness to Discuss New Treatments





Why Patients are Unlikely to Discuss New Treatments With Their HCP

N=8

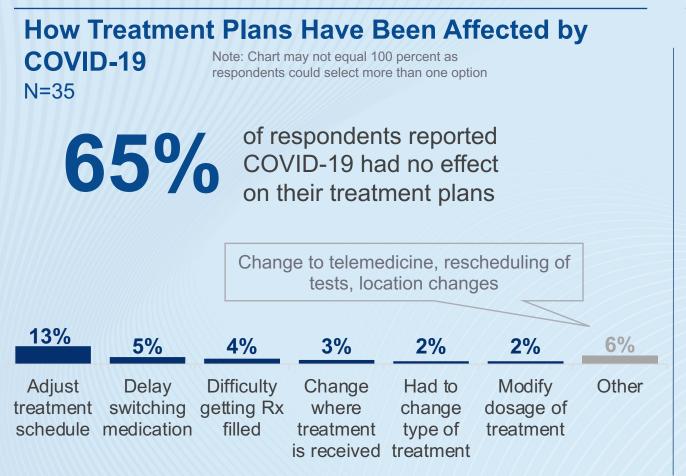
- Most patients reported their current treatment being effective
- A few respondents mentioned their disease being presently stable

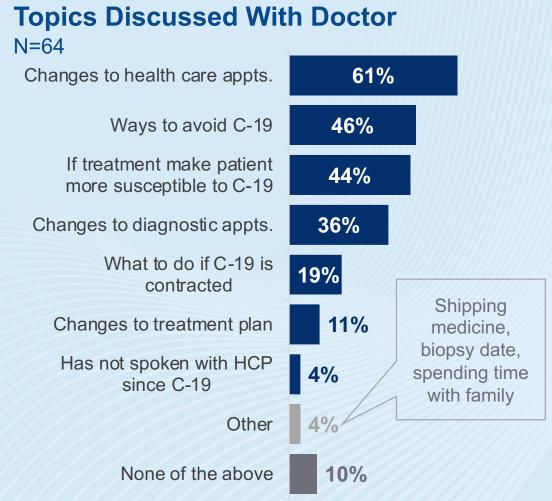


My current medication is working and [I] also feel like, it will continue to be effective.

COVID-19 – Patient Experiences

Patients mostly talked to their doctors about changes to health care appointments and ways to avoid contracting COVID-19; the pandemic had little affect on treatment plans



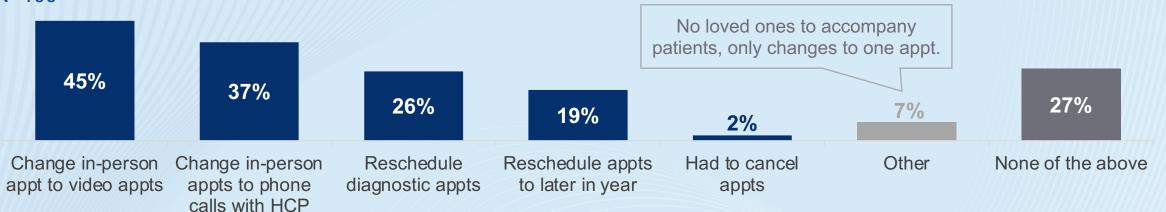


COVID-19 – Patient Experiences (cont.)

Health care providers were not canceling appointments; instead, they were conducting them via video conference or over the telephone

How Appointments Have Been Affected by COVID-19

N=100 Note: Chart may not equal 100 percent as respondents could select more than one option



Health Care Provide Advice on What to Do if Patient Contracts COVID-19

N = 31



A subset reported not receiving any instructions from their HCP

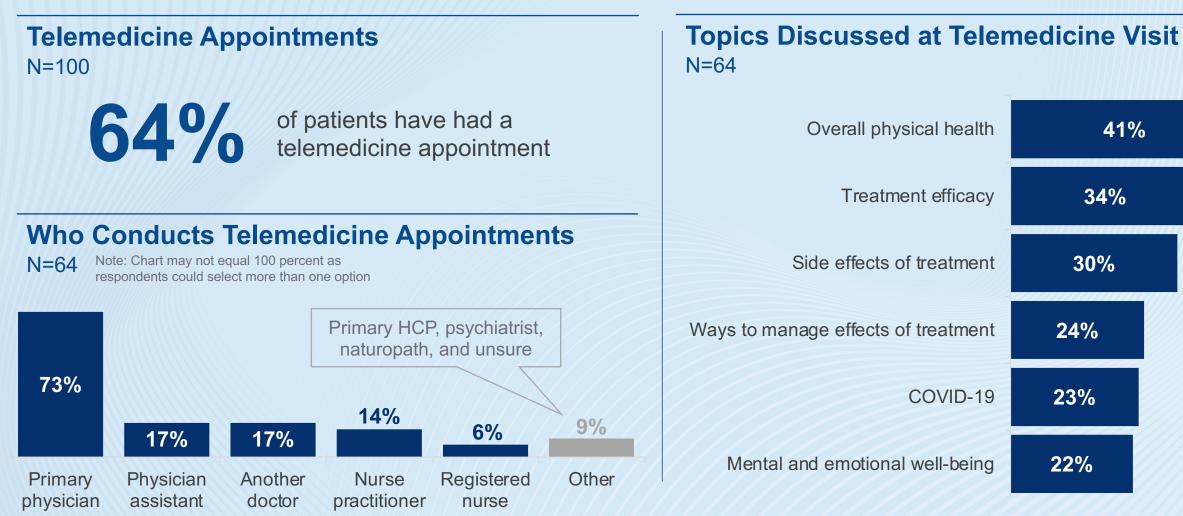


I just avoid places where Covid 19 may be. Stay home and have little personal contact with anyone. Wear masks anytime I am out at grocery store etc.

"

Telemedicine Appointments

Of the 64% of patients who have had a video appointment, three-quarters reported their primary physician conducted the meeting; overall physical health was discussed the most followed by treatment efficacy



Telemedicine Appointments (cont.)

97% of patients reported the support and level of care they received from their HCP during a telemedicine appointment as good or excellent; none of the respondents rated their care as poor

Rating of Support and Quality of Care Provided by HCP

N=64



Suggestions on How to Improve Telemedicine Appointments

N=2

- One patient suggested improving connection quality
- Another member proposed avoiding them "unless absolutely necessary"

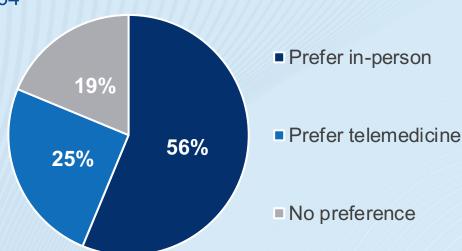
Both patients rated the support and quality of care through telemedicine appointments as neutral

Telemedicine Appointments (cont.)

Even during the pandemic, more than half of patients preferred in-person appointments; however, they did comment that telemedicine appointments are safer

Appointment Preference





66

It's a 1.5 hour trip to see the oncologist. Most of my appointments are "How are you doing? Good. Fine." If a regular scan shows progression and potentially indicate a change of treatment, I would be more likely to travel for an in-person appointment.

Prefers In-Person

N = 36

- Patients reported in-person appointments felt more personal
- Respondents often cited the various tests and treatments they needed could only be performed inperson

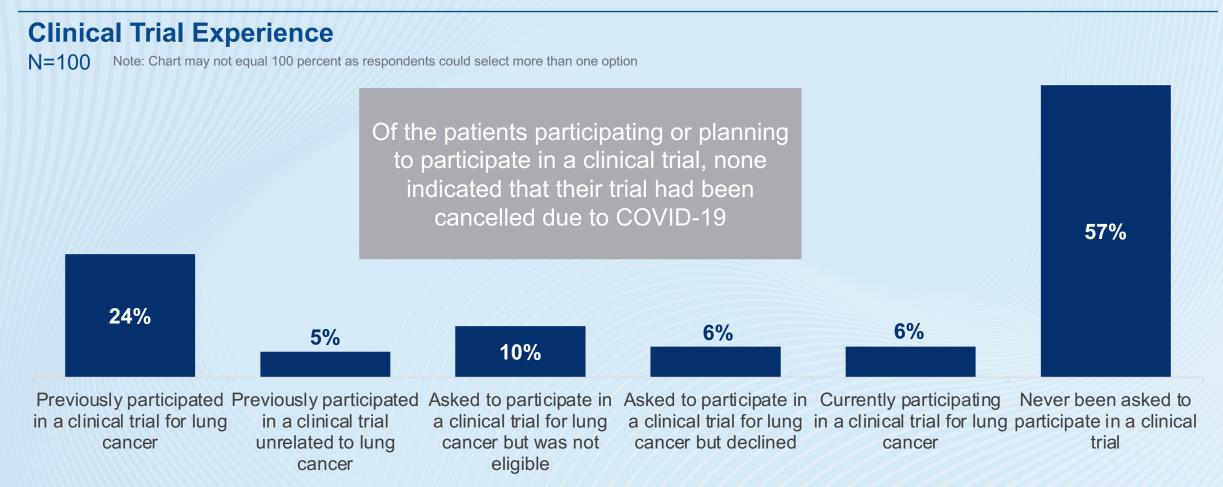
Prefers Telemedicine

N=16

- Oifficulties related to transportation were often cited by members; particularly distance to treatment center
- Additionally, patients indicated feeling safer with telemedicine appointments during the pandemic

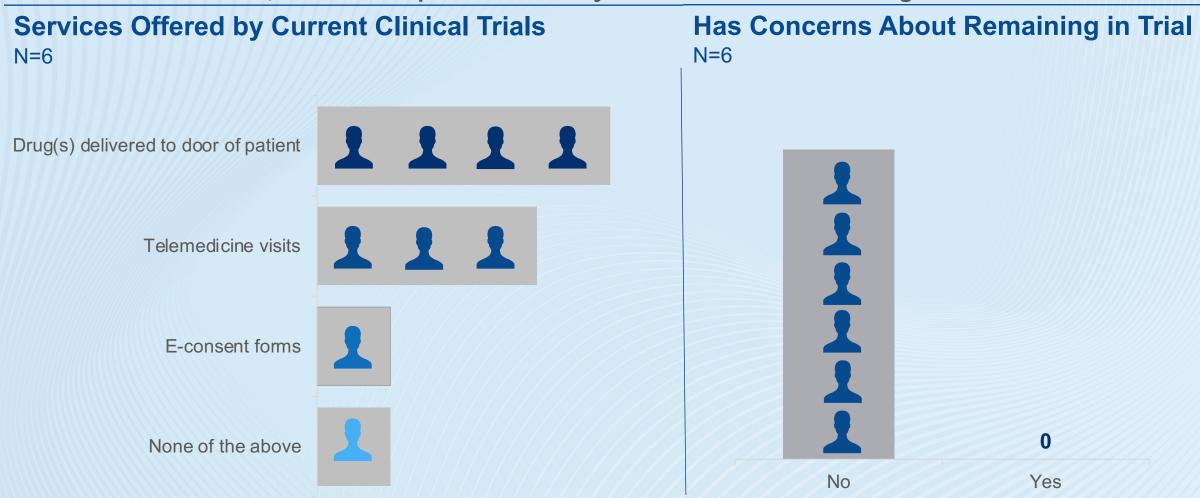
Clinical Trial Experience

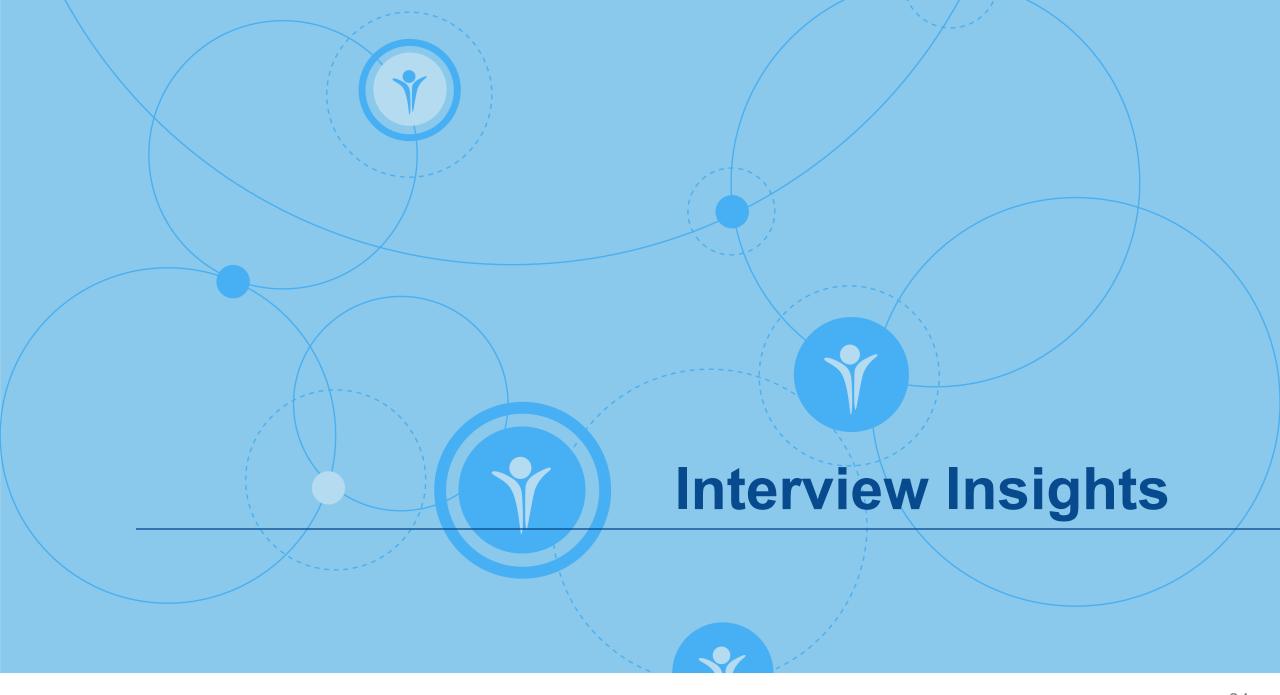
The majority of patients have never been asked to participate in a clinical trial; only six were currently participating in a clinical trial



Clinical Trial Experience (cont.)

Delivery of medications and telemedicine visits were the most common services currently being offered in clinical trials; none of the patients had any concerns about remaining in their current trial





Treatment Journey

The most important treatment factor for patients was efficacy; one patient also prioritized treatments that wouldn't inflame an autoimmune comorbidity

Treatment Decisions

- Two patients sought the "most effective" therapy with the "least number of side effects" for reducing or eliminating their tumors; both indicated that these factors had not changed in level of importance with the pandemic
- One patient chose her treatment based on which therapy would have the least impact on a comorbidity and would be effective; she would want to avoid therapies that required visiting infusion centers if she needed additional treatments



- Each of the patients discussed targeted therapy as a treatment option with their respective oncologists; two patients chose this option while the third used chemotherapy instead
- Of the two patients undergoing targeted therapy, one patient relied on surgery, chemotherapy, and radiation prior to targeted therapy while the other patient started his lung cancer treatments with targeted therapy
- The one patient who decided not to use targeted therapy expressed interest in learning more about this treatment option because of the pandemic



mutations, but I had a high ALK. I forgot what the rest – an ALK. An ALK mutation. and I know they can target some of those mutations now with different kinds of medications that are pills. I know they're working on it. I think if the doctor said, 'Hey. We really think that this medication now is in a pill, and we think it would work.' I would say, 'Yes. I'll try it.' I may not have said, 'Yes. I would try it' so much before, but now if it keeps me out of going to be around other people, definitely I would give it a try. Lung cancer patient

Concerns about Acquiring COVID

Patients expressed concerns about the risk of contracting COVID-19 due to their lung cancer diagnosis. Two patients mentioned feeling more cautious at the onset of the pandemic compared to now

Risk Assessment and Worries

- All three patients expressed concern about acquiring COVID given that they
 had lung cancer; none mentioned feeling any additional risk because of their
 treatment history (i.e., usage of chemotherapy)
- Each of the patients mentioned they were careful about wearing masks and social distancing; moreover, all of them had moved to online shopping
- Two patients stated they were more cautious at the beginning of the pandemic than now, while the third patient said she felt more cautious now because of the uptick in cases in her area
- Age was an important factor for two of the patients; in fact, one patient appeared more concerned about his age than his cancer diagnosis
- One patient mentioned that even with his age and lung cancer diagnosis, he would not be an early adopter of the vaccine
- One patient worried that acquiring COVID-19 might trigger her cancer growth



We realized that we are extremely, extremely high risks. Even like people with underlying health problems. I thought people with lung cancer like me, I felt that I may not make it. I'm paying the price with life. It's too high a price. I think that made me extremely careful about what I do. How I minimize the probability of catching it, contracting it? Again, I did go out once a while to meet some of my friends, but it was never more than two, three families. When we met, we made sure that everybody has a mask. Otherwise, we will not go. — Lung cancer patient

I'm exposed to the COVID, even if I don't come down with a full case of COVID, is that going to make you worse? Could that reactivate the cancer, or would it just be a respiratory illness in me like the regular person who has COVID? Could anything in the COVID disease trigger actively in the cancer? – Lung cancer patient

Pandemic Impact on Oncologist Visits

Two patients inquired about precautions and potential treatment plans for COVID-19 during oncology appointments; both wished their providers had been more proactive in communicating this information



Oncology Consultations

- Two patients asked their oncologists about possible procedures and treatments if they acquired COVID-19; both stated they felt more confident the disease was "beatable" after speaking with their providers
- Both patients who spoke with their oncologists about COVID-19 indicated they wished their providers had been more proactive with giving instructions about the pandemic
- Each of the patients experienced telehealth appointments as a result of the pandemic; two of the patients had video calls with their oncologists, while the third explained his visits had been phone calls
- One patient had her first in-person appointment with her oncologist in six months and a second patient planned to have an in-person appointment with his oncologist in October



I go in person yesterday and he comes in, he's happy, he's cheerful. I have the best mood and you can tell in his face, in his animations and in his voice, you can tell he has good news and he's happy to share it with you. You know and make you feel relieved. I told him, I said, 'You scared the hell out of me because we've been doing virtual appointments and then you tell me I have to come in.' He apologized for that, he said, 'I have to tell you this in person because it's good news and I need you to know it's good news.' — Lung cancer patient

So, the biggest change has been the adoption of the telehealth or virtual visits where it's now been, I think since February, that I last saw the oncologist face-to-face. I actually have a virtual visit set up for tomorrow morning and because I'm in sort of the mode of very, very luckily of how were... So, it's not like it's a big appointment in any event. If I have progression and we need to change the treatment, I might choose to go down there for a face-to-face. — Lung cancer patient

Patient Perspective of Telehealth

Although patients perceived telehealth as more convenient than in-person appointments, all three patients stated they would prefer an in-person appointment if they needed to make any significant changes to their treatment plans

Advantages of Telehealth

Disadvantages of Telehealth

- All the patients continued to meet with their oncologist through remote appointments, and none believed that their relationship with their oncologists had changed or seemed different
- Patients appreciated the convenience of telehealth appointments – that they no longer needed to drive to oncologists, wait in waiting rooms, or be around others who might be sick with COVID-19 or other contagious diseases
- All the patients indicated preferring an in-person appointment if their scans showed tumor growth or if they needed to make changes to their treatments
- Patients stated that it was challenging to get a sense of oncologists' emotions through phone or video
- Patients expressed varying levels of concern about how telehealth does not permit oncologists to physically examine them or easily observe physical changes

Pandemic Impact on Treatments

Two patients expressed concern that the pandemic may have paused or even delayed drug development for lung cancer treatments

Changes to Current Treatment

- The patient who had relied on chemotherapy at the start of the pandemic skipped two treatments in early spring because of fears of COVID-19 exposure
- One patient who was in a clinical trial received his medications through FedEx since he no longer has in-person visits to the study site
- One patient reported experiencing no changes to his lung cancer treatment as a result of the pandemic

Modifications to Treatment Plans

- Two patients described how they had been "living on the edge of medical progress" and were worried drug development for lung cancer treatments might be halted or delayed because of the pandemic
- If they needed to alter their treatment plans for lung cancer, two patients believed the pandemic would not impact their decisions and one patient said she would be more likely to try an oral medication now



Is the drug research early stage or whatever, that would've been happening, is that still happening? Are we sort of like missing out on some basically, opportunity costs here in terms of what we're – like paying attention to pandemic. Right now, I'm out of ALK inhibitors, so where is the next one? ...I don't know whether it's pandemic related or not.

I've been living on the edge of medical technology for eight years. I want to make sure that edge is continuing to move out because if it doesn't, I may not live through it. – Lung cancer patient





To relieve patient concerns that the pipeline for cancer treatment has been paused, consider a social media campaign about how Company X continues to be at the edge of medical progress for treatments during the pandemic

Pandemic Impact on Diagnostics

All three patients experienced delays in their scheduled scans, with one patient experiencing delay due to limited appointment availability resulting from the stringent safety and cleaning protocols

Diagnostic Scans

The primary concern among patients was the potential for delayed scans, as this could result in their oncologists not detecting a recurrence of their condition at an early stage

All three patients had experienced delayed scans:

- Two of the patients stated the delay was early in the pandemic before safety procedures had been established
- One of the patients stated her scan had recently been delayed because fewer appointments were available, which she believed was due to enhanced cleaning and fewer patients allowed in waiting rooms
- To minimize the risk of exposure to COVID-19, one patient made the decision to relocate his scans from a major hospital, which he perceived as a potential "COVID-19 hotspot," to a local hospital with less patients

They explain what they do with cleaning the machine and she said, 'If you're going to take longer, it's because we have to clean before each patient. We cleaned it before you came in here, but we're going to clean it now in front of you because we want you to see that we've cleaned the machine so you feel safe going through here.' That's because the scans are so – those machines are so tight. Even the through mask - the person in front of you who came before you is breathing in that machine, in that little enclosed round space. Yes, patient volume had decreased because they can't have their lobbies full with everybody sitting together. My scans were delayed, I should have had them back in July, closer

to the middle of July. – Lung cancer patient

Normally, for my treatment, every four months I'm supposed to get my scan and blood work just to make sure I have no issues with recurrence, right? For the last two and a-half years, I followed that. But since COVID-19, mostly I was not in New York. My doctor said it's okay to delay because she didn't want me to be exposed to the hospital for the X-ray. — Lung cancer patient

Emotional, Social, and Physical Impact

Emotional Impact



Patients mentioned feeling anxiety and fear about their heightened risk to COVID-19 and described their doubts about whether they could survive the disease

One patient stated the support she used to receive from cancer nonprofits has diminished, which she attributes to the pandemic (i.e., transportation to infusion centers and cartons of donated protein drinks)

Social Impact



Patients expressed the pandemic presented significant emotional challenges, particularly due to their inability to visit loved ones who were at a higher risk of exposure. This situation intensified their feelings of distress and concern

One patient expressed that going to an infusion center used to be a social experience where she could speak with other patients who were in a similar situation – she appreciated the safety protocols but recently felt isolated when receiving treatments at the infusion center

Physical Impact



One patient said he felt healthier as a result of the pandemic since he was getting more physical activity and eating at home more

After a discussion with his oncologist, one patient decided to take vitamins to improve his immune system and potentially help reduce his risk of acquiring COVID-19

Informational Sources

None of the patients had come across an educational resource about lung cancer and COVID-19, which meant they were all relying on general information intended for patients with preexisting conditions

Resources and Questions

- Patients expressed interest in an educational resource about lung cancer and COVID-19, but none had found such a resource yet
- Each of the patients explained they were relying on general information for patients with underlying preconditions to inform the precautions they were taking and to get a sense of their risk level
- Patients said they wished they knew more about how acquiring COVID-19 impacts lung cancer over the short and long term, specifically mechanisms of action, death rates, and treatment differences
- Some patients were concerned about whether they might need to adjust or pause their lung cancer treatments if they acquired COVID-19



Since some patients were actively searching for an educational resource about lung cancer and COVID-19, potentially develop a fact sheet about this topic for this patient population

I tried to find specific information about lung cancer and COVID-19. I look for it. I don't see that much information, at least, out there in spite of me trying about lung cancer and COVID. I think it's all like general. If you contract COVID or minimizing COVID-19, what should you do? I do not see if you are being a lung cancer survivor, what are the extra steps you should do. Like I said, everything they say to do for the people who have underlying problem, usually, the same as for the lung cancer survivor, but to the next level of urgency. — Lung cancer patient

So basically, I've now switched over to doing things remotely. So, instead of traveling down to the hospital for scans, lab tests and doctor visits, I now have the scans and labs done locally, and so, over — it's all part of the same health network. They're on the same ERS so it's very convenient to do that. — Lung cancer patient

