



GLOBAL LUNG CANCER  
COALITION

# COVID-19 PANDEMIC: THE IMPACT ON LUNG CANCER PATIENTS

**Insights from Canada**

2021 Patient Experience Survey

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## Introduction

At the start of 2020, the Global Lung Cancer Coalition (GLCC) and its network of patient advocacy groups ran our first ever global online survey, asking lung cancer patients around the world about their experience of their treatment and care. The survey uncovered a wealth of information and insight and was presented at the World Congress on Lung Cancer. A global report, and national reports for each participating country are available on the GLCC's website at: <https://www.lungcancercoalition.org/>

Soon after the survey closed, the COVID-19 pandemic hit.

The pandemic had – and continues to have – a profound impact on healthcare systems around the world. Systems, services and teams had to change drastically to sustain levels of support for patients. Many of the healthcare professionals who would use their respiratory expertise to support lung cancer patients were deployed to care for patients with COVID. Our member organisations had to change too, supporting lung cancer patients with questions around their risk of COVID, how they could protect themselves, and how their access to treatment might change with the pressures on services.

In this context, we wanted to understand how the care that people have received for their lung cancer has been affected by the crisis. We repeated questions that we asked before so we could look for emerging trends. But we also added in new questions about people's contact with their treatment team during the pandemic, how living with lung cancer has affected their physical and mental health, and how they would like to receive information and support.

This report sets out the **findings for Canada**. Patients from Canada took part in the first survey, so we have compared findings wherever applicable. We have also included lessons we have learned from running the survey and suggestions for areas that could be explored in future studies.

We are grateful to every patient and carer who took the time to respond to the surveys and tell us about their experience. We hope the findings will be useful to policymakers as they plan how lung cancer services can be supported to recover from the pandemic, as well as campaigners in their advocacy efforts to keep lung cancer patients' needs front of mind.

If you have any queries, please contact [glcc@roycastle.org](mailto:glcc@roycastle.org).

## Methodology

The GLCC established a multi-national steering group including patients, healthcare professionals and advocates to develop the survey questions. The survey was translated so that people could complete it in their native language. It was distributed by members' networks and promoted through social media.

The survey was sent out in 20 different countries: Argentina, Australia, Brazil, Bulgaria, Canada, Denmark, Greece, Iceland, Ireland, Israel, Italy, Mexico, the Netherlands, Portugal, South Africa, Spain, Sweden, Taiwan, the UK, and the USA. In total, 1,291 lung cancer patients or their carers completed the survey between February and April 2021.

The questions for the survey were split into the following themes:

1. **Demographics and diagnosis** – used for identifying patient populations by gender, age at diagnosis, type of lung cancer, and time since diagnosis
2. **Interventions** – to understand what testing and treatments people have had since their diagnosis
3. **Experiences** – to assess how involved people feel in decision-making about their care, whether they felt treated with dignity and respect, and how they describe themselves in the light of their experience (for example as a patient or a survivor)
4. **Emotional and physical impacts of lung cancer diagnosis** – to determine how people have been affected emotionally and physically by their diagnosis, and who they seek support from when they need help
5. **Impact of COVID-19** – to assess experiences during the pandemic, in particular its impact on mental and physical wellbeing and how people interacted with their treatment team
6. **Seeking information** – to find out how people living with lung cancer want to receive information

There were 49 respondents from Canada this year, compared to 52 last year.

Sections 1, 2, and 3 listed above were included in the first survey, and we have compared 2020 and 2021 results whenever applicable. Sections 4, 5, and 6 are new so only include 2021 data.

## 2021 Patient Experience survey and insights from 2020

### Demographics of respondents

#### Background information on respondents

Respondents were asked whether they were a patient or if they were a carer filling out the survey thinking about the experience of the person for whom they provided care. Of the 49 people who answered this question, 43 people (88%) described themselves as a patient and 6 (12%) as a carer.

Most of the respondents (63%) said they did not fill out the first patient experience survey. Just three respondents (6%) said they had completed it in 2020; 15 respondents (31%) said they were not sure.

#### Gender

This year, 40 of the respondents (82%) were women and 9 (18%) were men (Figure 1). In 2020, the gender breakdown was 77% female and 21% male with 2% preferring not to say.

Figure 1: Number and percentage of respondents, results for 2021

Female		Male		Gender neutral		Prefer not to say		None of the above, I describe myself as	
Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number
82%	40	18%	9	0%	0	0%	9	0%	0

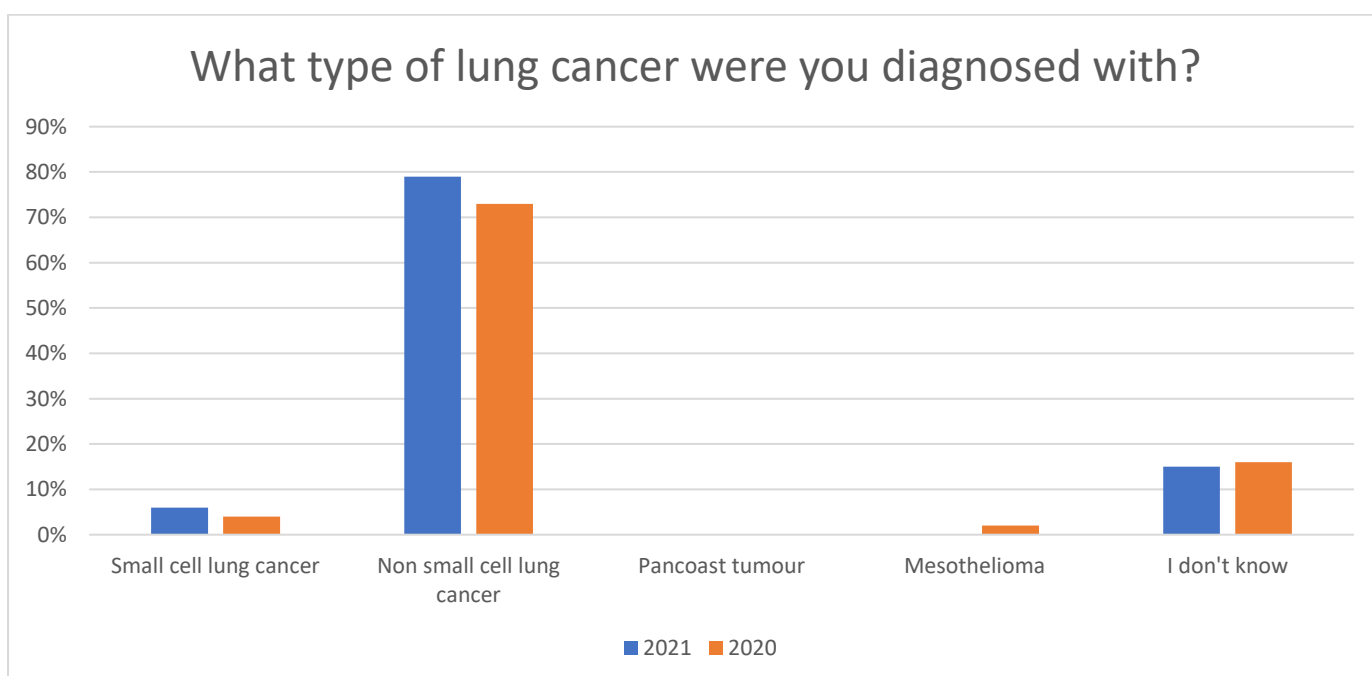
## Diagnosis

### Type of lung cancer

Respondents were asked which type of lung cancer they had (Figure 2). The survey included a list of eight different types of lung cancer as well as an 'I don't know' option. For those who did not know what type of cancer they have, this year we asked if they would like to find out.

Non-small cell lung cancer is the most common form of cancer, accounting for 80-85% of all lung cancers.<sup>i</sup> As in 2020, the largest proportion of respondents (79% in 2021 and 73% in 2020) stated they had non-small cell lung cancer.

Figure 2: Type of lung cancer among respondents, results for 2021 and 2020



Some patients do not know which type of lung cancer they had or have. In 2020, 16% respondents from Canada did not know what type of lung cancer, this year the proportion was 15% (seven people).

The type of lung cancer a patient has will affect the treatment options that are available to them. This can, in turn, can contribute to a better understanding of their treatment choices and help them feel more involved in decisions about their care. It is encouraging that the majority of Canada respondents to this year's survey know their type of lung cancer, but of concern that more than one in ten people in this survey do not.

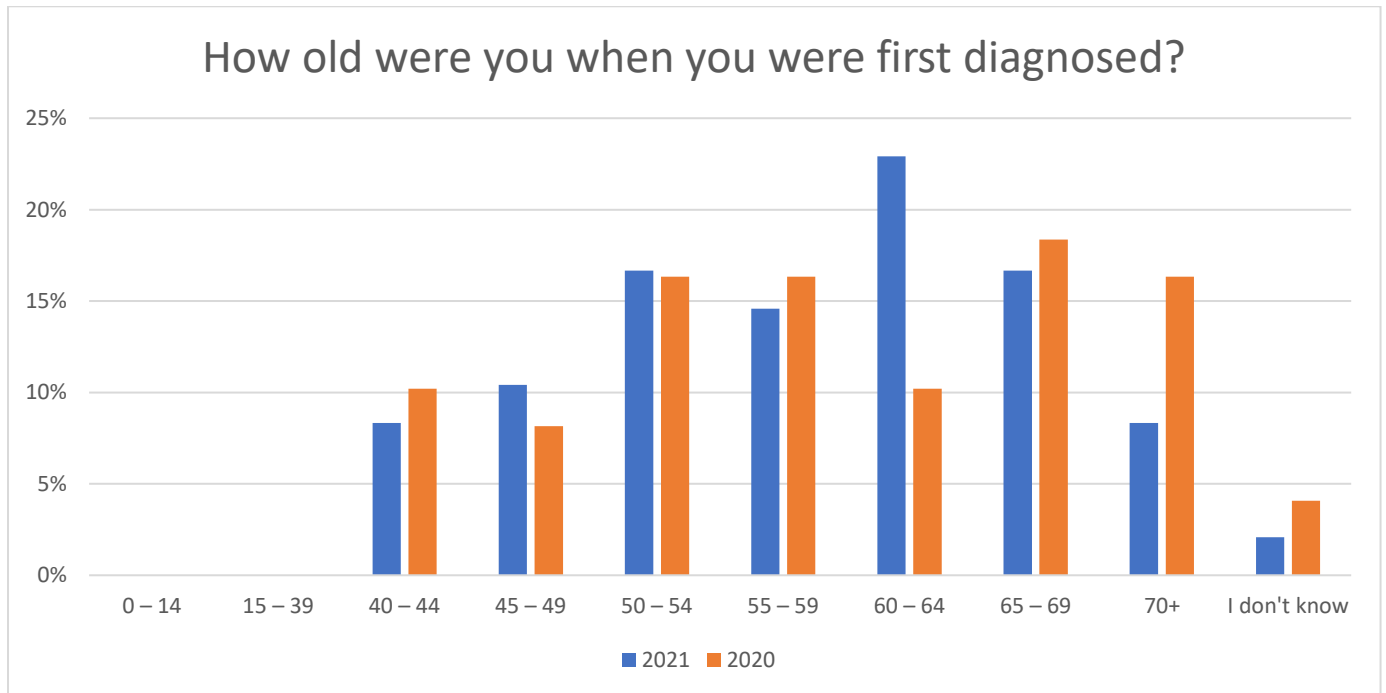
Further survey work could be conducted to determine whether the experience of the respondents reflects that of the wider lung cancer patient population in Canada (given the relatively small sample size).

## Age at diagnosis

Respondents were asked how old they were when they received their diagnosis (Figure 3).

The largest proportions of respondents said they were diagnosed at 60 – 64 years old (23%, 11 people), followed by 17% (eight people) at age 50 – 54 and 65 – 64.

Figure 3: Age profile of respondents, results for 2021 and 2020



## Year of diagnosis

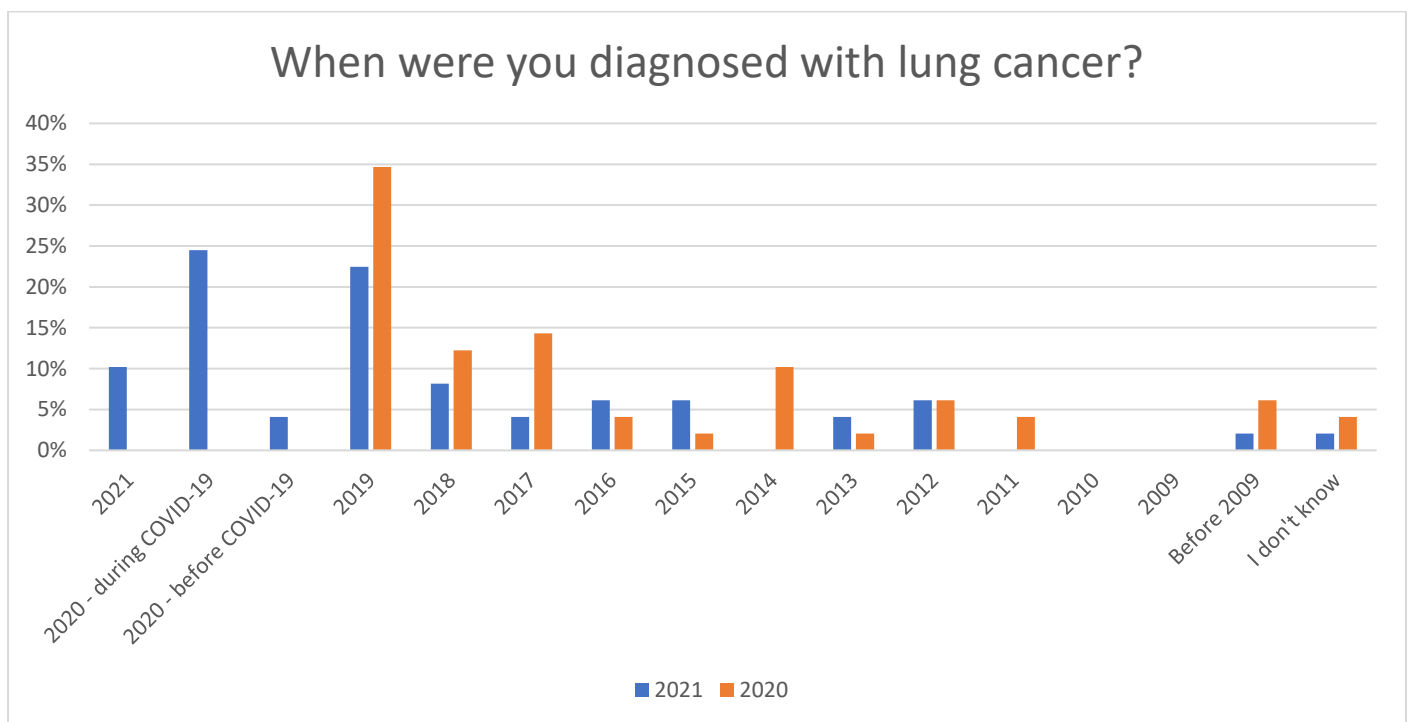
Respondents were asked in which year they were diagnosed. Knowing how recently a patient was diagnosed may help to understand differences in their diagnostic journey, especially as delays in treatment and diagnosis have been reported during the COVID-19 pandemic.<sup>ii</sup>

Around a third of respondents (35%, 17 people) had been diagnosed since the start of the pandemic. 25% (12 people) were diagnosed in 2020 during the pandemic, and a further 10% of respondents (five people) had been diagnosed in 2021.

When looking at calendar years, the largest proportion of respondents were diagnosed in 2020 (29%, 14 people). 25% (12 people) were diagnosed in 2020 during the pandemic and 4% (two people) in 2020 but before the pandemic hit.

22% of this year's survey respondents were diagnosed in 2019. Figure 4 shows the survey responses for 2021 and 2020.

Figure 4: Year of diagnosis amongst respondents, results for 2021 and 2020





## Delay in diagnosis

Earlier diagnosis is a key part of improving survival rates for people diagnosed with lung cancer. This year, people were asked if they felt that there was an unnecessary delay in getting their diagnosis. This question was added to learn about the potential impact that COVID-19 may have had on people who tried to get their symptoms checked out or were waiting for test results to come back. Participants could tick more than one option.

Figure 5: Would you say there was an unnecessary delay in getting your diagnosis? Results for 2021

Answer Choices	Percentage	Number
Yes, it took me too long to see someone to get my symptoms checked out	16%	8
Yes, it took too long to see someone to test if I had lung cancer	20%	10
Yes, it took too long to get my test results	16%	8
No, I am satisfied with the time it took to get my diagnosis	51%	25
I'm not sure	14%	7

Just 51% of respondents from Canada said they were satisfied with the time it took to get their diagnosis. 16% of respondents said it took them too long to see someone to get their symptoms checked out. 20% felt it took too long to see someone to get tested to see if they had lung cancer and 16% felt they waited too long for test results. 14% said they weren't sure.

Late diagnosis can considerably impact a patient's chances of surviving lung cancer. Healthcare professionals were working incredibly hard during the pandemic to continue to see patients and to encourage them to come forward if they had possible lung cancer symptoms. There are also challenges because some of the respiratory symptoms of COVID-19 and lung cancer are similar, and a negative swab test for COVID-19 does not mean a lung condition is not present.

While the majority of respondents from Canada were satisfied with the speed of their diagnosis, these results show a level of worry among some patients over delayed diagnosis. Future analysis using a larger sample size would help determine if these statistics are representative of the wider population and to what extent they may change as services recover from COVID-19.

## Biomarker testing

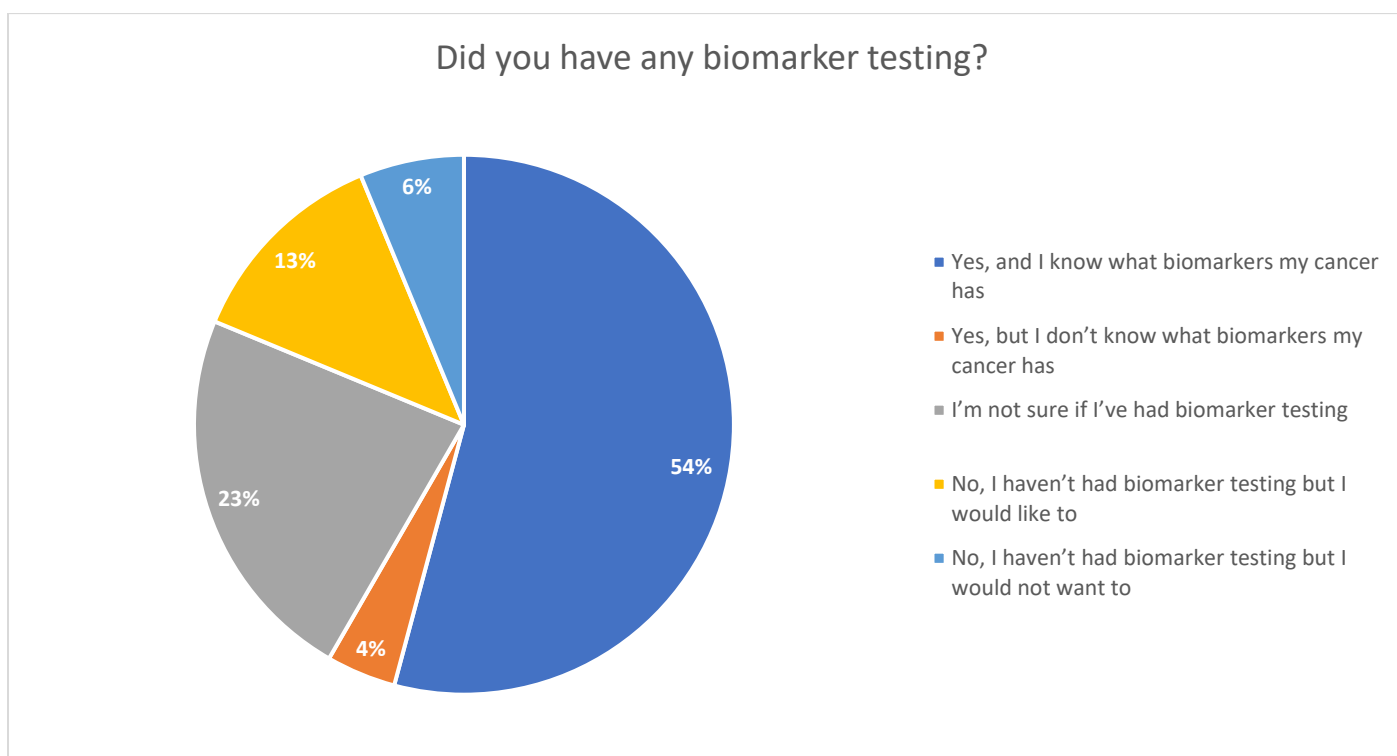
Through research, we now know that no two lung cancers are the same. The molecular characteristics of a tumour – its biomarkers – can be used to help physicians decide which treatment may work best for individual patients.

Increasing research has gone into identifying biomarkers and developing new targeted treatments over the past decade. After giving a short explanation of what a biomarker is, we asked patients if they knew if they had received a biomarker test, if they knew what biomarker their cancer has and whether they would like biomarker testing if they have not had one. One respondent skipped this question.

In the first survey in 2020, 53% of respondents from Canada said they had received a biomarker test, 19% said they hadn't received one, and 29% said they didn't know if they have had one.

The results for this year show that, overall, a higher proportion of respondents (54%) knew they had biomarker testing but, amongst those, 4% (two people) did not know what biomarkers their cancer has. 13% of respondents said they did not get a test but would like one. 23% were not sure if they'd had a biomarker test. Three people (6%) would not want to have a biomarker test.

Figure 6: Did you have any biomarker testing? Results for 2021



## Interventions

### Respondent profile

Respondents were asked where they were in their cancer journey, and could choose from five options.

Three people (6%) had just been diagnosed so were waiting for treatment to start. The majority said they were currently receiving treatment (51%), followed by 35% saying they had finished treatment.

Figure 7: Which of the following best describes you? Results for 2021

Answer Choices	Percentage	Number
I have just been diagnosed with lung cancer and haven't started treatment yet	6%	3
I am currently having treatment	51%	25
I have finished treatment	35%	17
I chose not to have treatment	2%	1
Treatment wasn't available to me	6%	3

One person said they chose not to have treatment, which is a valid personal choice to make. However, three people (6% of respondents) said that treatment was not available to them.

## Treatment

With research in lung cancer treatment advancing at a fast pace, treatment options are increasing for patients. We asked respondents to select from a list of treatments all those they had received (Figure 8). This year, to learn more about the reasons why some patients did not receive a treatment, we gave respondents additional options to choose from (Figure 9a). All respondents answered this question.

The findings are set out in the Figure 8 and summarised below:

- **Surgery:** A third (33%) of respondents had surgery compared to 40% in 2020. Surgery is still the best curative option for patients with early-stage lung cancer (stages I and II) so identifying a larger proportion of patients at an early stage, when surgery is an option for them, should be a priority
- **Radiotherapy:** Just over a third (37%) of respondents said they had received radiotherapy, a similar proportion to the 38% who had radiotherapy in 2020
- **Chemotherapy:** 43% of respondents had received chemotherapy compared to 40% in 2020
- **Immunotherapy:** over one third of respondents (35%) received immunotherapy, compared to 23% in 2020
- **Targeted therapies:** 33% of respondents this year said they had received targeted therapies, compared to 27% in 2020
- **Symptom management:** 31% of respondents said they had received treatment to help with symptom management, compared to 29% in 2020
- **No treatment:** just three respondents said they have not received any treatment: two because they had just been diagnosed and one as they chose not to

Respondents could also check an 'other' box to tell us more about their treatments. One person said that they had received home care to help them manage fluid build up on the lungs. Another used the 'other' box to say they will be starting radiotherapy shortly.

Figure 8: Types of treatment received, results for 2021 and 2020

	Surgery		Radiotherapy		Chemotherapy		Immunotherapy	
	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number
2021 survey	33%	16	37%	18	43%	21	35%	17
2020 survey	40%	19	38%	18	40%	19	23%	11

	Targeted therapies		Symptom management	
	Percentage	Number	Percentage	Number
2021 survey	33%	16	31%	15
2020 survey	27%	13	29%	14

Figure 9a: Respondents who did not receive any treatment, results for 2021

Answer options	Percentage	Number
I have not received any treatment because I have just been diagnosed	4%	2
I have not received any treatment, but I am due to start	0%	0
I have not received any treatment because COVID-19 has delayed it	0%	0
I have not received any treatment because I chose not to	2%	1
I have not received any treatment because it is not available to me	0%	0

## What support did people receive?

Patients can benefit from a range of other types of support, beyond treatment itself. This may include counselling or support with mental health, dietary and financial advice, or return to work advice for those of working age who are fit enough after treatment. In this year's survey, we added in more options around stop smoking advice, and support from peer or other support groups. We also asked about the reasons why some patients had not received additional forms of support. Respondents were also given the option to select 'other' and indicate which other forms of support they had received.

One person skipped this question. The survey results are summarised below and include comparisons with the 2020 patient experience survey:

- **Psychosocial support / counselling:** 31% of respondents to the 2021 survey said they had received psychosocial support and or counselling, compared to 23% in 2020
- **Physical therapy / pulmonary rehabilitation:** 6% of respondents said they had received physical therapy compared with 19% in 2020 (Figure 10a)
- **Occupational therapy:** No one said they had received occupational therapy (in 2020, 13% had received this type of support)
- **Dietary advice:** 25% of respondents received dietary advice, up from 23% in 2020
- **Lifestyle advice:** 8% said they had they had received lifestyle advice, compared with 26% of respondents in 2020
- **Financial advice:** 6% respondents said they had received financial advice in 2021 or 19% 2020
- **Return to work advice:** 4% said they had received advice on going back to work in 2021 or 10% 2020
- **Smoking cessation:** 2% said they had received support on how to stop smoking
- **Support group:** 52% of respondents said they had received support from peer and/or support group
- **No support:** 15 respondents had not received other forms of support: two because they had just been diagnosed; two because COVID-19 had delayed it; three chose not to and eight said it wasn't available

Figure 10a: Types of support respondents received, results for 2021 and 2020

	Psychosocial support / counselling		Physical therapy / pulmonary rehabilitation		Occupational therapy		Dietary advice	
	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number
2021 survey	31%	15	6%	3	0%	0	25%	12
2020 survey	23%	7	19%	6	13%	4	23%	7

	Lifestyle advice		Financial advice		Advice on going back to work	
	Percentage	Number	Percentage	Number	Percentage	Number
2021 survey	8%	4	6%	3	4%	2
2020 survey	26%	8	19%	6	10%	3

Figure 10b: Responses for support received, results for 2021

	Support Group		Smoking cessation	
	Percentage	Number	Percentage	Number
2021 survey	52%	25	2%	1

Figure 10c: Responses from respondents who did not receive other form of support, results for 2021

Answer options	Percentage	Number
I have not received any other support because I have just been diagnosed	4%	2
I have not received any other support, but I am due to start	0%	0
I have not received any other support because COVID-19 has delayed it	4%	2
I have not received any other support because I chose not to	6%	3
I have not received any other support because it is not available to me	17%	8

Analysis and comparisons with national datasets would be needed to understand whether the additional support received by respondents to this survey aligns with that of the wider lung cancer patient population. Further work could be undertaken to explore:

- Which services were offered and why some people (6%) chose not to take them up
- How useful people found the services they received, and if they would recommend the service to others
- Whether people who did not receive additional support because of COVID-19 were offered it at a later point
- What other types of support people would have liked to have been offered



## Respondent experiences

### Feeling involved in decisions about their treatment and care

The GLCC believes that every patient has the right to be fully informed of, and involved in, decisions about their treatment and care. This right is enshrined in the GLCC's Patient Charter. The survey findings show the extent to which patients in Canada feel sufficiently involved in making decisions about their treatment and care.

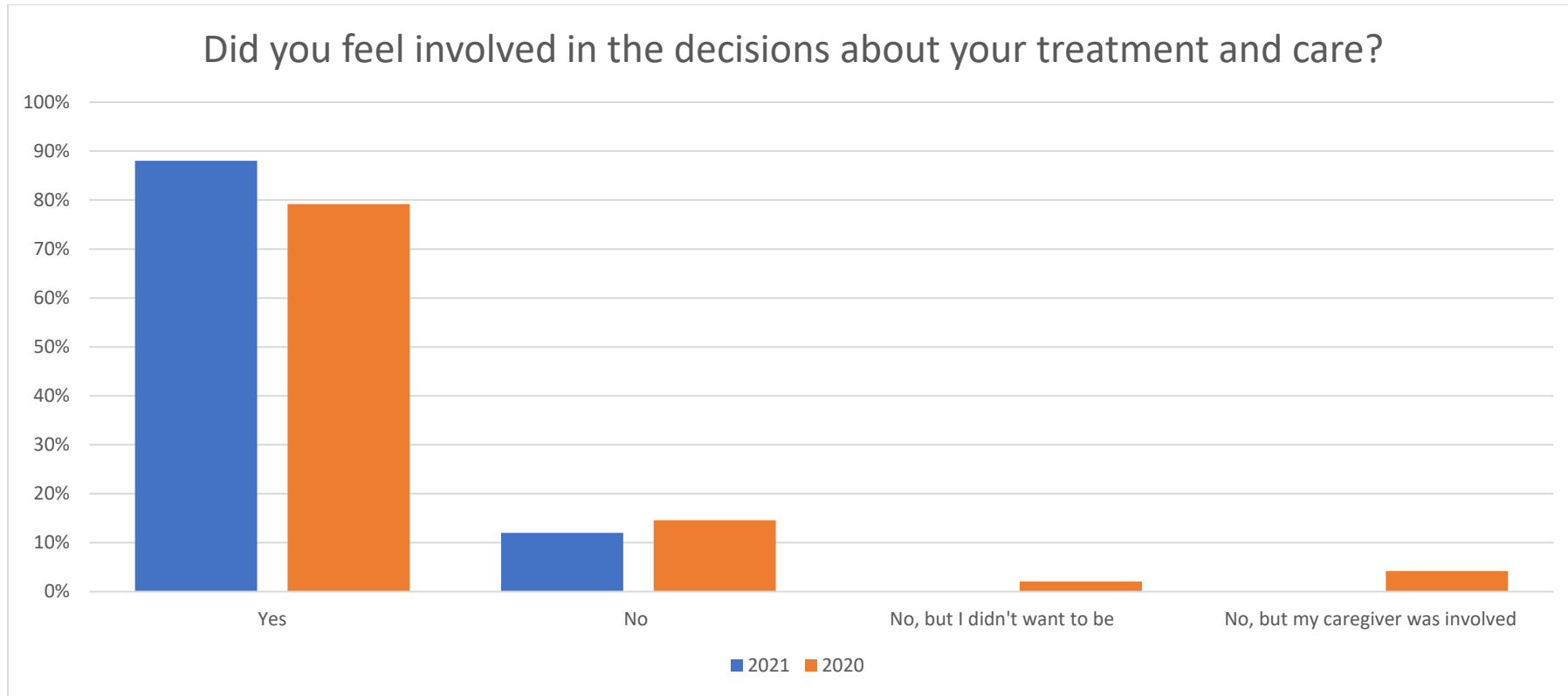
In 2020, respondents could only choose from 'Yes', 'No', 'No, but I didn't want to be involved' and 'No, but my caregiver was involved'. 79% said they felt involved in decision making about their care, while 15% said they did not feel involved. 2% of respondents said they didn't want to be involved in decision-making and 4% of respondents said their caregiver was involved in decision-making in their place.

This year, we wanted to examine this further and gave respondents additional options to choose from: 'Yes, I've been fully involved', 'Yes, I've been involved most of the time' and 'Yes, I've been involved sometimes'. Only one respondent skipped this question.

49% of respondents felt they were fully involved in decision-making, 27% felt they were involved most of the time, and 12% felt they were only sometimes involved. 12% of respondents felt they were not involved but wanted to be. No one said that they didn't want to be involved in decision-making, or that a carer was involved in their place.

Figure 11a (below) compares the responses of this year's survey to that of 2020, while Figure 11b shows the breakdown of the data for 2021.

Figure 11a: Proportion of patients feeling involved in decisions on their treatment and care, results for 2021 and 2020



*Nb: For 2021, the responses for 'Yes, I've been fully involved', 'Yes, I've been involved most of the time' and 'Yes, I've been involved sometimes' have been combined. In 2020, respondents could only choose from 'Yes', 'No', 'No, but I didn't want to be involved' and 'No, but my caregiver was involved'. For 2020, for 'No, but I would like to be involved' we used the results for 'No'*

Figure 11b: Number and proportion of respondents feeling involved in decisions on their treatment and care, results for 2021

Answer Choices	Percentage	Number
Yes, I've been fully involved	49%	24
Yes, I've been involved most of the time	27%	13
Yes, I've been involved sometimes	12%	6
No, but I would like to be involved	12%	6
No, but I didn't want to be involved	0%	0
No, but my caregiver was involved	0%	0

Future studies or surveys could explore:

- Whether this figure reflects the experience of the wider lung cancer patient population in Canada (given the relatively small sample size)
- Why respondents from Canada feel this way, and why some people were only involved sometimes when others felt fully or mostly involved
- What healthcare professionals can do to ensure people who only feel involved sometimes or not involved, are able to fully participate in decisions about their care

## Being treated with dignity and respect

Lung cancer patients can often face stigma due to lung cancer's association with smoking, although a significant proportion of lung cancers are in non-smokers. The GLCC's Patient Charter asserts the right for every patient to be treated with dignity and respect. No matter the cause of their disease, every patient should be treated respectfully.

In its first survey, the GLCC asked whether patients felt treated with dignity and respect by the team providing their treatment. Respondents were given a choice of whether they 'always', 'mostly', 'sometimes' or 'never' felt treated with dignity and respect. In light of the significant pressures the pandemic has put on healthcare systems and staff, we felt it was important to check in with patients to see if they felt they have been treated with dignity and respect.

All respondents answered this question. Compared to 2020, we found a higher proportion of respondents said they were always treated with dignity and respect (71% vs 65% in 2020). 20% of respondents said they were 'mostly' treated with dignity and respect while 6% and 2% respectively said they were only 'sometimes' or 'never' treated with dignity and respect (Figure 12b).

Figure 12a: Proportion of patients feeling treated with dignity and respect by their treatment team, results for 2021 and 2020

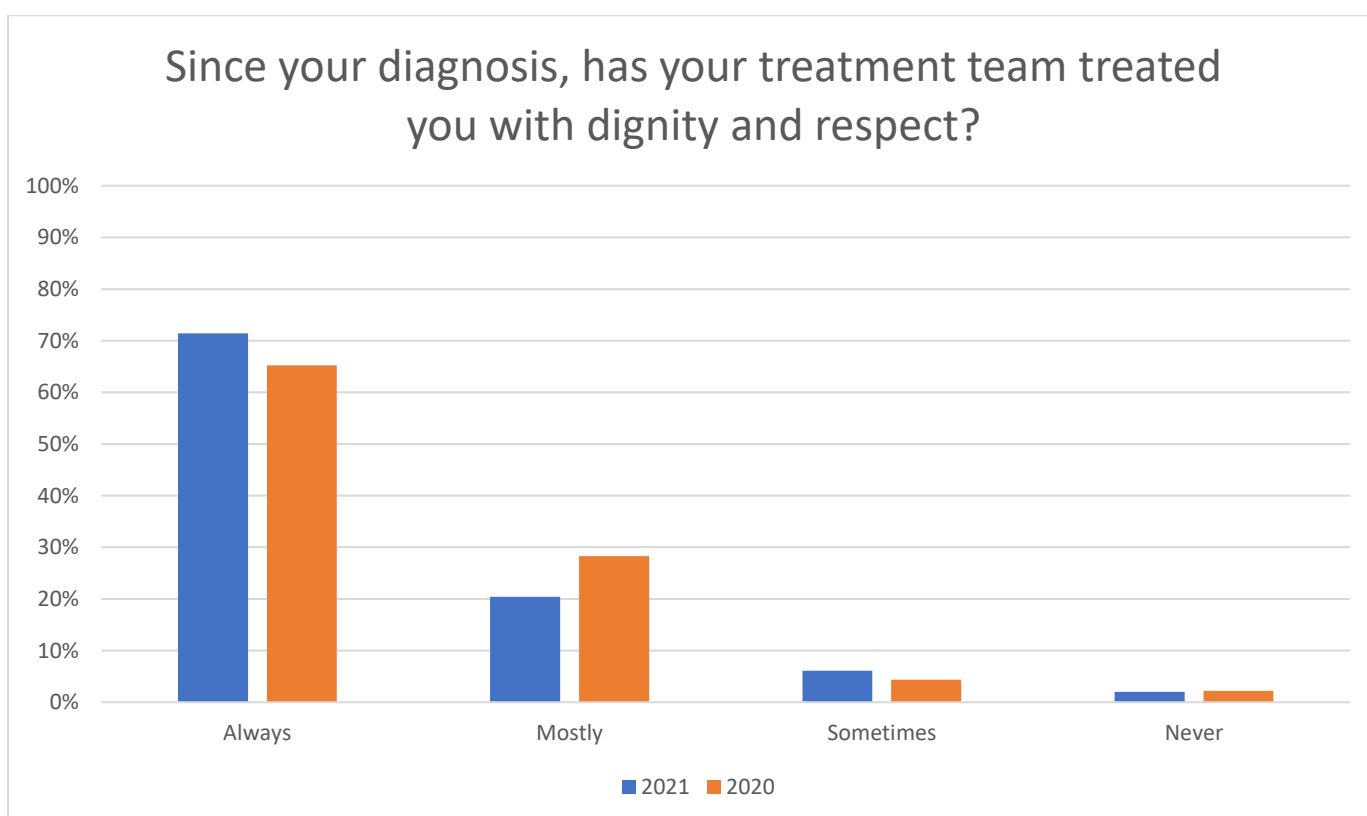


Figure 12b: Data on the number and percentage of respondents feeling treated with dignity and respect by their treatment team, results for 2021 and 2020

	Always		Mostly		Sometimes		Never	
	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number
2021 survey	71%	35	20%	10	6%	3	2%	1
2020 survey	65%	30	28%	13	4%	2	2%	1

Future studies or surveys could explore:

- Whether this figure reflects the experience of the wider lung cancer patient population by taking in a larger sample size of the population
- How the proportion of patients answering 'always' can be increased further
- Why some people only felt that they were sometimes or never treated with dignity and respect, and what could be done to address this

## How do people diagnosed with lung cancer describe themselves?

Often people with lung cancer are described simply as ‘patients’ but this may not be how people diagnosed with lung cancer think about themselves or want to be described. Some may describe themselves as ‘patients’ while having treatment, but not if their treatment stops. While there is much to be done to improve outcomes and survival from lung cancer, with earlier diagnosis and treatments improving, more people are living for longer after their diagnosis. Therefore, it is important to understand how people want to be described, and at what point do they start to identify as a ‘survivor’ for instance.

The GLCC asked people how they describe themselves and respondents were asked to tick as many of the different descriptions as they felt applied to them. One person skipped this question.

The most popular choices in this year’s survey were ‘living with lung cancer’ and ‘patient’ with 50% of respondents describing themselves this way, followed by ‘advocate’ on 29% and ‘lung cancer survivor’ and ‘fighter’ with 25%. With a higher proportion of respondents diagnosed in the last few years, and with most people being on treatment, it could be that people still feel as if they are living with lung cancer or are a patient, rather than a survivor.

Figure 13a (overleaf) shows all the responses and compares the results to those obtained in 2020. In Figure 13b, we show the results for the options that were only available this year, such as ‘fighter’ or ‘warrior’.

Figure 13a: How respondents described themselves, results for 2021 and 2020

	Living with lung cancer		Patient		Surviving with lung cancer		Lung cancer survivor		Overcomer	
	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number
2021 survey	50%	24	50%	24	21%	10	25%	12	6%	3
2020 survey	47%	21	31%	14	11%	5	27%	12	4%	2

	Survivor		Advocate		Thrifer	
	Percentage	Number	Percentage	Number	Percentage	Number
2021 survey	13%	6	29%	14	19%	9
2020 survey	22%	10	29%	13	13%	6

Figure 13b: How respondents described themselves, results for 2021

	Battling lung cancer		At war with lung cancer		Fighter		Warrior		Fighting lung cancer	
	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number
2021 survey	8%	4	2%	1	25%	12	21%	10	19%	9

Future studies could look into:

- Whether people’s experience of care impact on the way they see themselves
- If there are some descriptions that people dislike – for example, those that use ‘war’ imagery like ‘battling’ or ‘fighter’

## Insights from the 2021 patient experience survey

A cancer diagnosis can considerably affect the emotional health of a patient and that of their families and caregivers. Common feelings include distress, depression, anxiety and may involve loss of self-esteem and feelings of isolation. A 2019 study found that about one third of patients newly diagnosed with the most common form of lung cancer have moderate to severe symptoms of depression.<sup>iii</sup> It is important to recognise these changes to ensure the right emotional support is offered to people diagnosed with lung cancer.

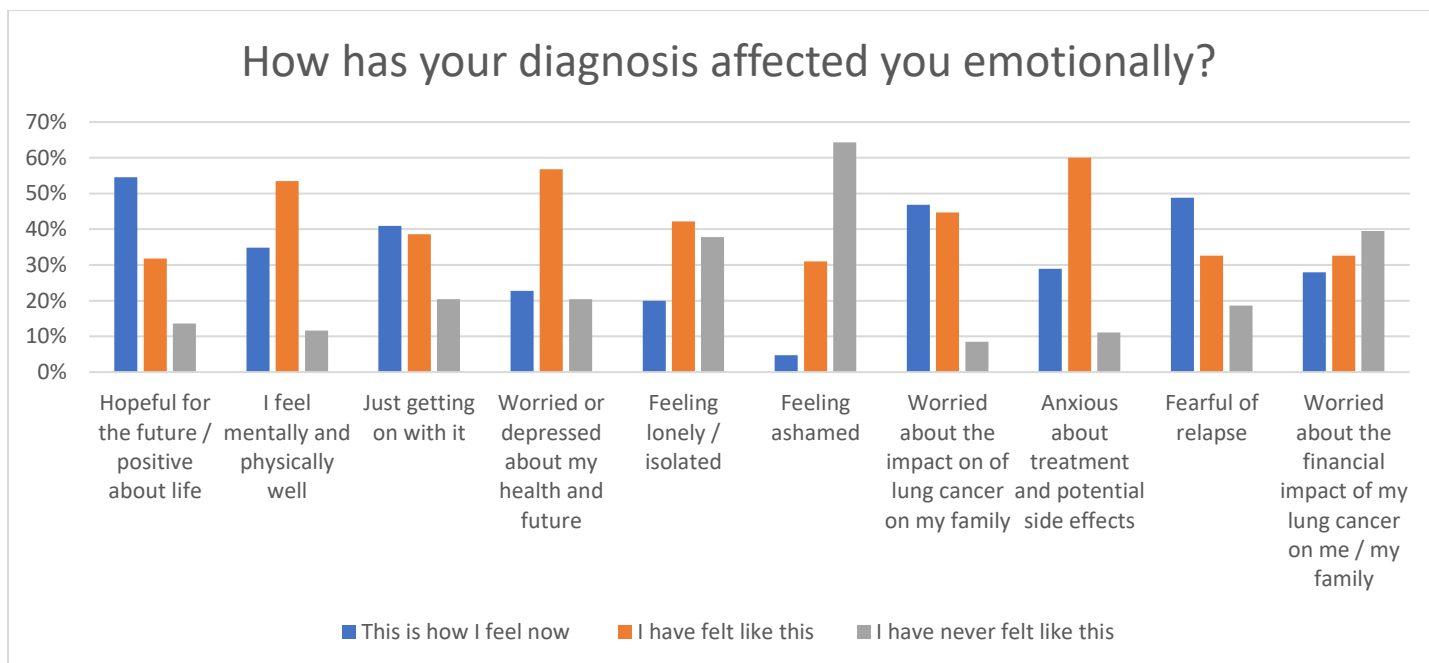
This year, the GLCC decided to ask people questions to understand how their diagnosis has affected them both emotionally and physically, and what type of support they sought.

### Emotional and physical wellbeing

#### How were people affected emotionally after a lung cancer diagnosis?

Respondents were asked how their diagnosis has affected them emotionally. The survey included a list of ten options as well as the possibility to indicate whether the statement applied to them now, in the past, or never. Only one person skipped this question. Respondents could also choose the 'other' option and indicate other forms of support they have received. Figure 15a summarises key findings.

Figure 15a: How diagnosis affected respondents emotionally, results for 2021





The results show that respondents experience a wide range of emotions.

More than half (55%) of respondents feel hopeful or positive about life and 32% used to feel this way. 41% of respondents said they were just getting on with it. However, nearly half (49%) are fearful of relapse and 47% of are worried about the impact of their condition on their family.

When it came to their mental and physical wellbeing, 35% of respondents feel well at the moment, while 53% said they previously felt well and 12% never felt well. 29% are currently anxious about treatment while 60% have felt this way. 23% of respondents said they currently feel worried or depressed about their health and future.

There is a stigma associated with lung cancer, and nearly a third of respondents (31%) told us they have felt ashamed of having lung cancer at some point, with 5% of respondents feeling ashamed at the moment.

Loneliness is another challenge, with 20% of respondents feeling lonely or isolated and a further 43% having felt this way at some point.

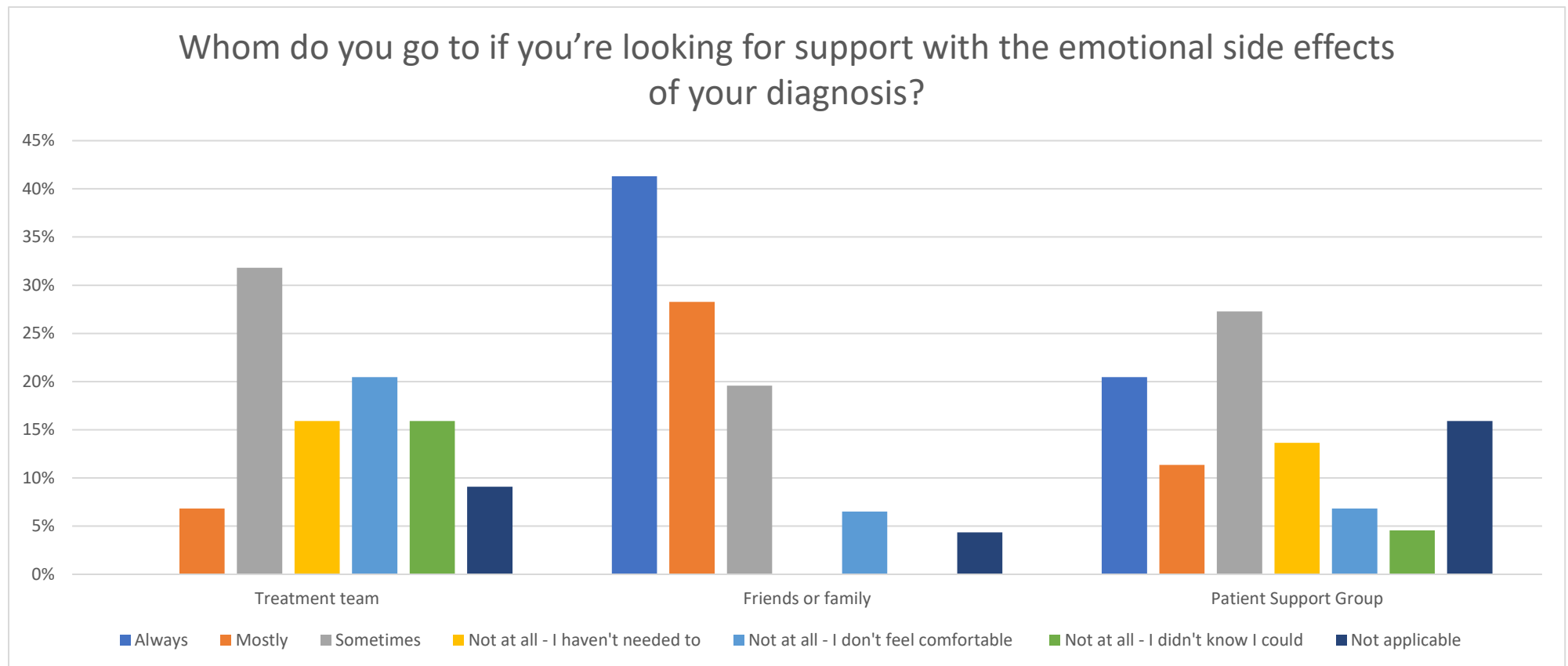
Further studies could explore:

- How experience of care and interaction with a treatment team influences the way people feel about their diagnosis as they progress through their journey
- How different forms of support and information impact people's mental and physical wellbeing, and concerns about treatment and potential impact
- What can be done to support people feeling anxious, depressed, ashamed or lonely

## Where do people turn for emotional support?

Respondents were asked about whom they go to when looking for support with the emotional impact of their diagnosis. People could choose from three options. Three people skipped this question.

Figure 16a: Where do people turn for support with the emotional impact of their diagnosis? Results for 2021



The results show that respondents primarily turned to friends and family for emotional support. 41% of respondents said they always reached out to friends and family for support, with a further 28% saying they mostly turned to friends and family and 21% saying they sometimes would. 7% of respondents wouldn't feel comfortable asking their family or friends for emotional support.

No-one said they always reached out to their treatment team for help with emotional support, with just 7% saying they mostly would, and 32% saying they sometimes would. Interestingly, 20% said they didn't feel comfortable going to their care team for emotional support and 16% said they didn't know they could.

The picture for patient groups was more mixed. A fifth of respondents (20%) said they would always go to a patient group for support, with a further 11% saying they mostly would and 28% doing so sometimes. Like friends and family, 7% of respondents said they didn't feel comfortable going to patient support groups for emotional support. A small proportion of respondents 5%, didn't know they could ask a patient group for emotional support.

Further studies could explore:

- Why people diagnosed with lung cancer do not reach out more often to their treatment team for emotional support, and why a fifth of respondents said they would not feel comfortable to do so
- Whether treatment teams offer emotional support to people diagnosed with lung cancer, and if people are aware that their treatment team can help
- What more support be offered to family members given the fact that they are often the most important source of emotional support for people affected with cancer

## What are the physical effects people have experienced due to their lung cancer and its treatment?

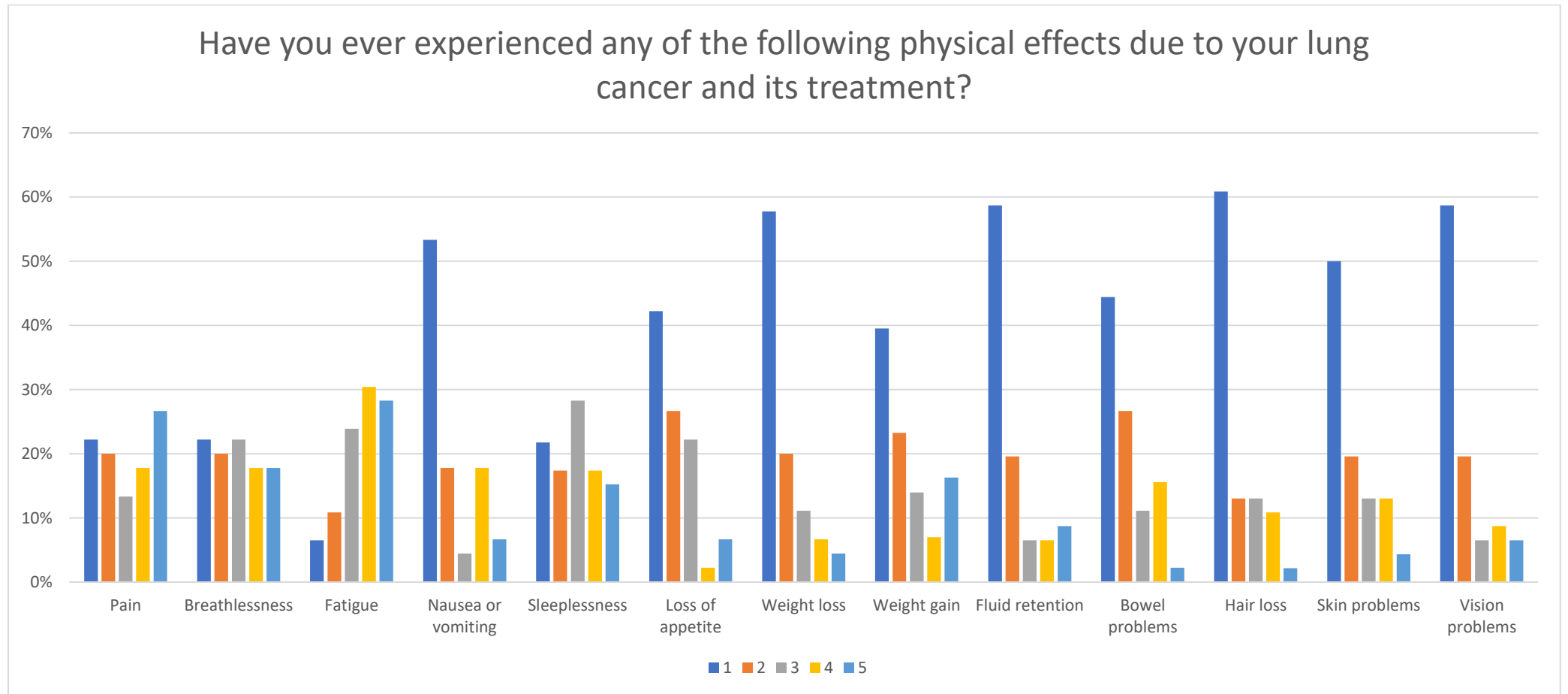
Respondents were asked about the physical effects they experienced because of their cancer and its treatment. We gave respondents 13 options and, for each option, people could select a number from 1 to 5, where 1 means this has not affected them and 5 means this has been a very serious concern. Two people skipped this question. Figure 17a shows a breakdown of all the responses.

*Figure 17a: Have you ever experienced any of the following physical effects due to your lung cancer and its treatment? Please choose an option from 1 – 5, where 1 means this has not affected me and 5 means this has been a very serious concern. Results for 2021*

	1	2	3	4	5	Total	Weighted Average
Answer Choices	Percentage	Percentage	Percentage	Percentage	Percentage	Number	Number
Pain	22%	20%	13%	18%	27%	45	3.07
Breathlessness	22%	20%	22%	18%	18%	45	2.89
Fatigue	7%	11%	24%	30%	28%	46	3.63
Nausea or vomiting	53%	18%	4%	18%	7%	45	2.07
Sleeplessness	22%	17%	28%	17%	15%	46	2.87
Loss of appetite	42%	27%	22%	2%	7%	45	2.04
Weight loss	58%	20%	11%	7%	4%	45	1.8
Weight gain	40%	23%	14%	7%	16%	43	2.37
Fluid retention	59%	20%	7%	7%	9%	46	1.87
Bowel problems	44%	27%	11%	16%	2%	45	2.04
Hair loss	61%	13%	13%	11%	2%	46	1.8
Skin problems	50%	20%	13%	13%	4%	46	2.02
Vision problems	59%	20%	7%	9%	7%	46	1.85

The weighted averages in Figure 17a give an indication of how serious the issues are for patients, compared to each other. A higher number indicates a more serious concern for the respondents. The table shows that, on average, fatigue (3.63) was the most serious issue for respondents, followed by pain (3.07), breathlessness (2.89) and sleeplessness (2.87).

Figure 17b: Have you ever experienced any of the following physical effects due to your lung cancer and its treatment? Please choose an option from 1 – 5, where 1 means this has not affected me and 5 means this has been a very serious concern? Results for 2021



## Where do people turn for support with physical impact of their lung cancer and its treatment?

Respondents were asked whom they go to when they are looking for support with the physical effect of their diagnosis. People could choose from their treatment team, family and friends, patient support group or 'other'. In addition, patients could indicate how often they reached out to those people. Two people skipped this question.

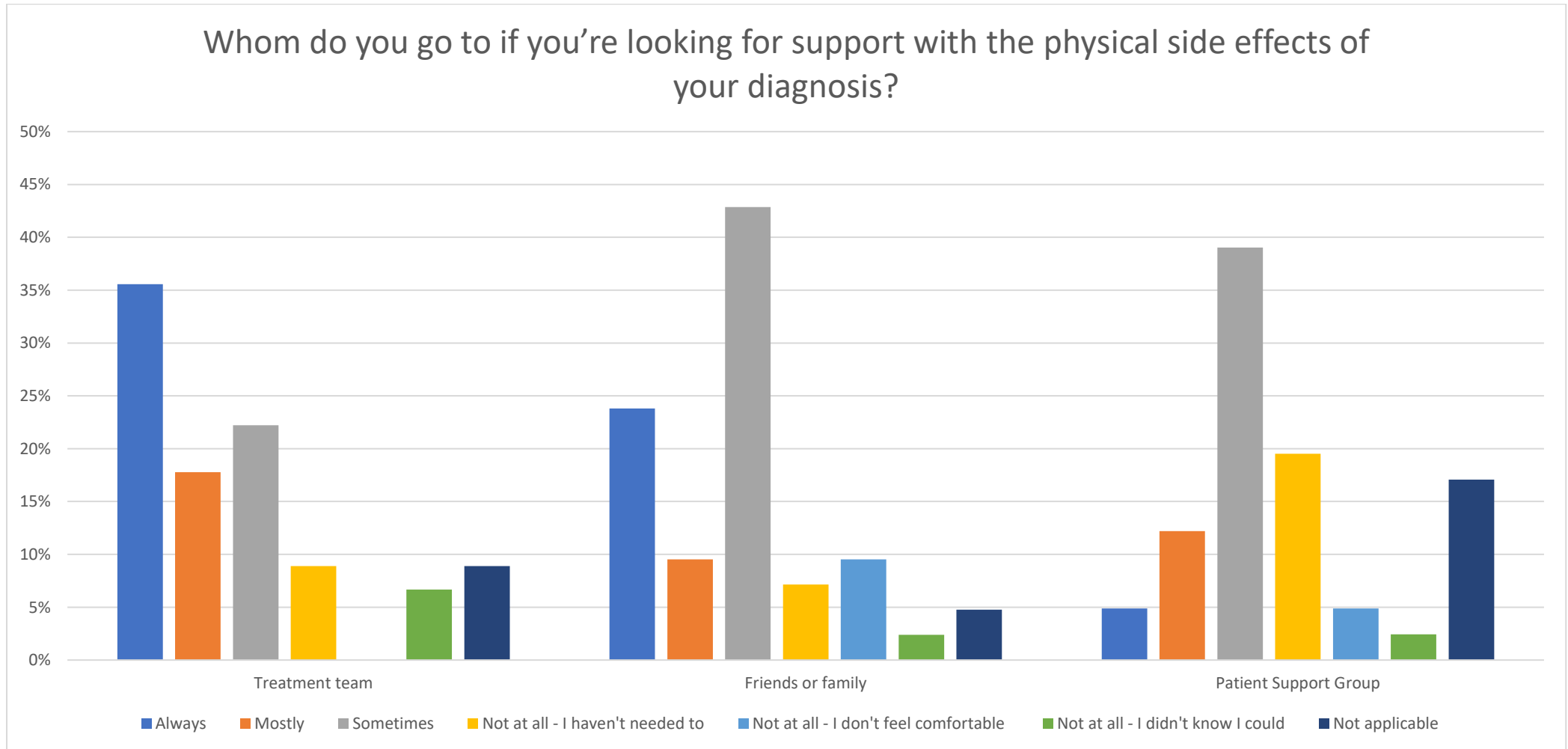
When it came to asking for support with the physical impact of their diagnosis, more respondents said they would go to their treatment team than for emotional support. Around a third of respondents (36%) said they always contacted their treatment team, with 18% mostly turning to their treatment team, and 22% saying they would do so sometimes. While no-one said they would not feel comfortable asking their treatment team for support with the physical impact of lung cancer, a small proportion of respondents (7%) didn't know that they could ask their treatment team for this support.

Friends and family were a common source of support with the physical impact of a lung cancer diagnosis. A quarter (24%) of the respondents said they always reached out to friends and family, with a further 10% mostly doing so and 43% doing so sometimes. 10% of respondents said they wouldn't feel comfortable asking friends and family for this type of support.

A small proportion of respondents (5%) would always ask patient groups for support with physical impacts of lung cancer, but larger proportions would mostly or sometimes turn to a patient group (10% and 40% respectively). Again, a small proportion of respondents (5%) said they don't feel comfortable asking for support from patient support groups, and 2% of respondents said they didn't know they could go to them.

Figure 18a (overleaf) is a breakdown of all the responses.

Figure 18a: Whom do you go to if you're looking for support with the physical effects of your diagnosis? Results for 2021



## The impact of the COVID-19 pandemic on people with lung cancer

The COVID-19 pandemic has had a profound impact on lung cancer patients. In most countries, its impact spans across the entire care pathway. Healthcare systems have struggled to maintain the same level of care throughout the crisis and most had to reduce services and in-person consultations to meet social distancing rules and protect people and staff from the virus. As a result, lung cancer patients have experienced delays to diagnosis and changes in their treatment. These will have consequences for outcomes that will continue to reveal themselves over the months and years ahead.

### Experience of care during the pandemic

Respondents were asked how they would describe their experience during the COVID-19 pandemic. The GLCC was particularly interested in learning how the pandemic had affected people's care, for example by finding out how difficult it was for people to contact their treatment team. People could choose from 13 options, including 'other', where they could describe other forms of services, they had received but that weren't available before the crisis. Two people skipped this question.



Figure 19a: Which of the following describes your experience during COVID-19? (Tick all that apply). Results for 2021

Answer Choices	Percentage	Number
I found it easier to contact my treatment team	6%	3
There has been no difference in how easy it has been to contact my treatment team	30%	14
I found it more difficult to speak to my treatment team	15%	7
I have held back in contacting my treatment team because they are so busy	11%	5
My treatment has continued as normal	36%	17
My treatment has been delayed / cancelled	13%	6
I don't know if my treatment has been affected	11%	5
I have carried on attending appointments during the pandemic	32%	15
I have been reluctant to attend appointments for fear of infection	15%	7
I have missed appointments for fear of infection	4%	2
My face-to-face appointments have been swapped for telephone or video calls	68%	32
I have been offered new services that weren't available to me before the pandemic	13%	6

30% of respondents saying there has been no difference in how easy it was to contact their treatment team, with 15% finding it more difficult. 6% said it had been easier to contact their treatment team during the pandemic.

32% of respondents said they have carried on attending their appointments in person during the pandemic. 68% of respondents said their face-to-face appointments have been swapped for telephone or video calls (a later section looks in more detail at the impact of this). 11% said they held back from contacting their team because they were so busy. 6% had been offered new services, such as home delivery of medicines or online support groups via Zoom.

36% of respondents said their treatment has continued as normal, but 13% had experienced delays to treatment, with 11% unsure about the impact on their treatment.

## Impact of the pandemic on mental and physical wellbeing

Respondents were asked about the impact of the pandemic on their mental and physical wellbeing. People could choose to rank the extent to which they felt affected from 1 – 5, where 1 means this has not affected them and 5 means this has been a very serious concern. Eight people skipped this question.

Figure 20a: To what extent has the COVID-19 pandemic affected your mental or physical wellbeing? Please choose an option from 1 – 5, where 1 means this has not affected me and 5 means this has been a very serious concern. Results for 2021

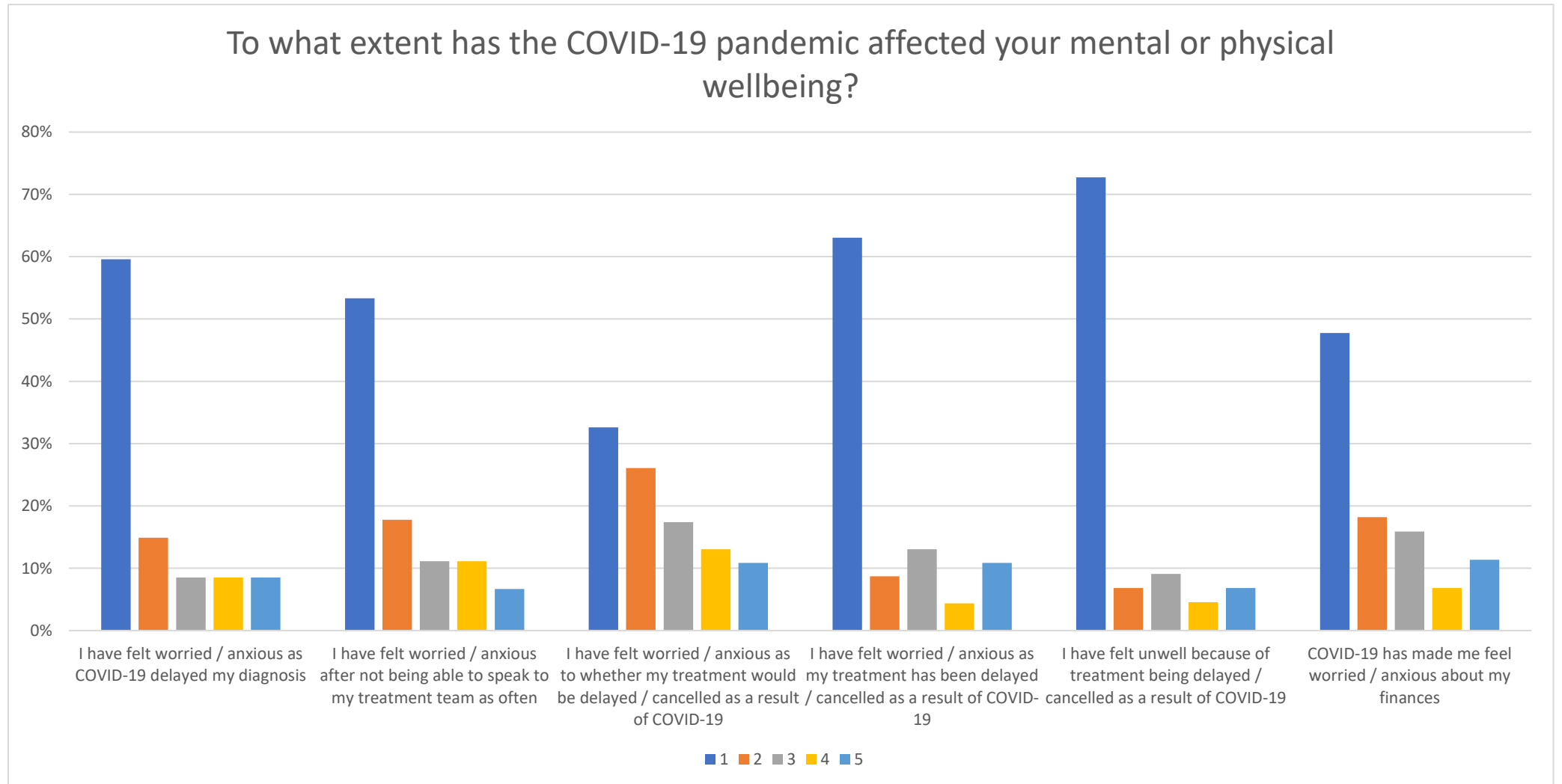


Figure 20b: To what extent has the COVID-19 pandemic affected your mental or physical wellbeing? Please choose an option from 1 – 5, where 1 means this has not affected me and 5 means this has been a very serious concern. Results for 2021

Answer Choices	1	2	3	4	5
I have felt worried / anxious as COVID-19 delayed my diagnosis	60%	15%	9%	9%	9%
I have felt worried / anxious after not being able to speak to my treatment team as often	53%	18%	11%	11%	7%
I have felt worried / anxious as to whether my treatment would be delayed / cancelled as a result of COVID-19	33%	26%	17%	13%	11%
I have felt worried / anxious as my treatment has been delayed / cancelled as a result of COVID-19	63%	9%	13%	4%	11%
I have felt unwell because of treatment being delayed / cancelled as a result of COVID-19	73%	7%	9%	5%	7%
COVID-19 has made me feel worried / anxious about my finances	48%	18%	16%	7%	11%

Most respondents scored a 1 for each of the available options, meaning that they did not feel that the pandemic had considerably affected their mental and physical wellbeing. However, there are groups of respondents who are being affected by the pandemic:

- On feeling anxious about delays to diagnosis as a result of COVID-19, 9% of respondents scored a 5, and another 9% scored a 4
- On worries caused because treatment has being delayed or cancelled as a result of COVID-19, 11% scored it a 5 and 13% scored it a 4
- On worries about finances as a result of the pandemic, 11% and 7% scored it a 5 or 4 respectively

## Communication with treatment team during COVID-19

The COVID-19 pandemic has had a profound impact on lung cancer services. At the early stages of the crisis, new approaches including video and telephone consultations started to be introduced or rolled out more widely in many countries in an effort to maintain support for patients when face-to-face options were not as easily available. New technologies and telehealth are now increasingly used as tool in lung cancer diagnosis, and have enabled healthcare professionals to follow-up with patients during the pandemic when restrictions were in place.<sup>iv</sup> As new measures started to be implemented around the world, we wanted to know how people diagnosed with lung cancer communicated with their treatment team.

Respondents were asked if they had conversations about their lung cancer diagnosis and its treatment with their care team since the start of the COVID-19 and, if so, whether by telephone, video or in person. People could choose more than one option. One person skipped this question.

*Figure 21: Since the start of the COVID-19 pandemic, have you had conversations about your lung cancer and its treatment with the treatment team in the following ways? (Tick all that apply). Results for 2021*

Answer Choices	Percentage	Number
Telephone	81%	39
Video	13%	6
In person	60%	29
No, I have not been in contact with my treatment team at all, but I wanted to	8%	4
No, I have not been in contact with my treatment team at all, but I haven't needed / wanted to	10%	5

60% of respondents have continued to see their treatment team in person. 81% said they have had conversations with their treatment team via telephone, and 13% had done so via video consultation. 8% of respondents said they wanted to be in contact with their treatment team but were not.

## Why were people not able to speak with their treatment team?

For respondents who had said they weren't able to speak to their treatment team, we asked them why this was. Respondents could choose from seven options, including 'other' where they could add the reasons why they couldn't speak to their treatment team.

One person noted that in-person was the only option available and they were worried about infection, while one person noted that a phone call had been offered but they didn't want to speak to their treatment team this way. Another had been offered a phone call but said their hearing made that difficult.

## What do people think of video or telephone consultations?

For respondents who had said they contacted their treatment team by video or telephone, we asked what their opinion was of using these methods. People could choose more than one option. One person skipped this question.

Results show that 59% said they found contacting their treatment team by video or telephone helpful because they didn't have to travel to hospital as much, while 26% found it quicker to have appointments by video or telephone.

However, roughly a half of respondents (49%) still preferred face-to-face appointments. 13% found it harder to understand their team on a phone or video call or to make themselves understood. Two respondents said they don't like it and want to stop as soon as possible.

Figure 22: What is your opinion on contacting you treatment team by video or telephone? Results for 2021

Answer Choices	Percentage	Number
I found it quicker	26%	10
I found it helpful as I don't have to travel to hospital as much	59%	23
I prefer face-to-face appointments	49%	19
I found it more difficult to understand my treatment team / make myself understood	13%	5
I don't like it and I want to stop as soon as possible	5%	2

## When dealing with different situations, what do people think is the best way to speak with their treatment team?

Respondents were asked how they would like to have a conversation with their treatment team when finding out their diagnosis, at the first consultation, regular check-ups, if there was a change to treatment and when they are worried about something. Two people skipped this question.

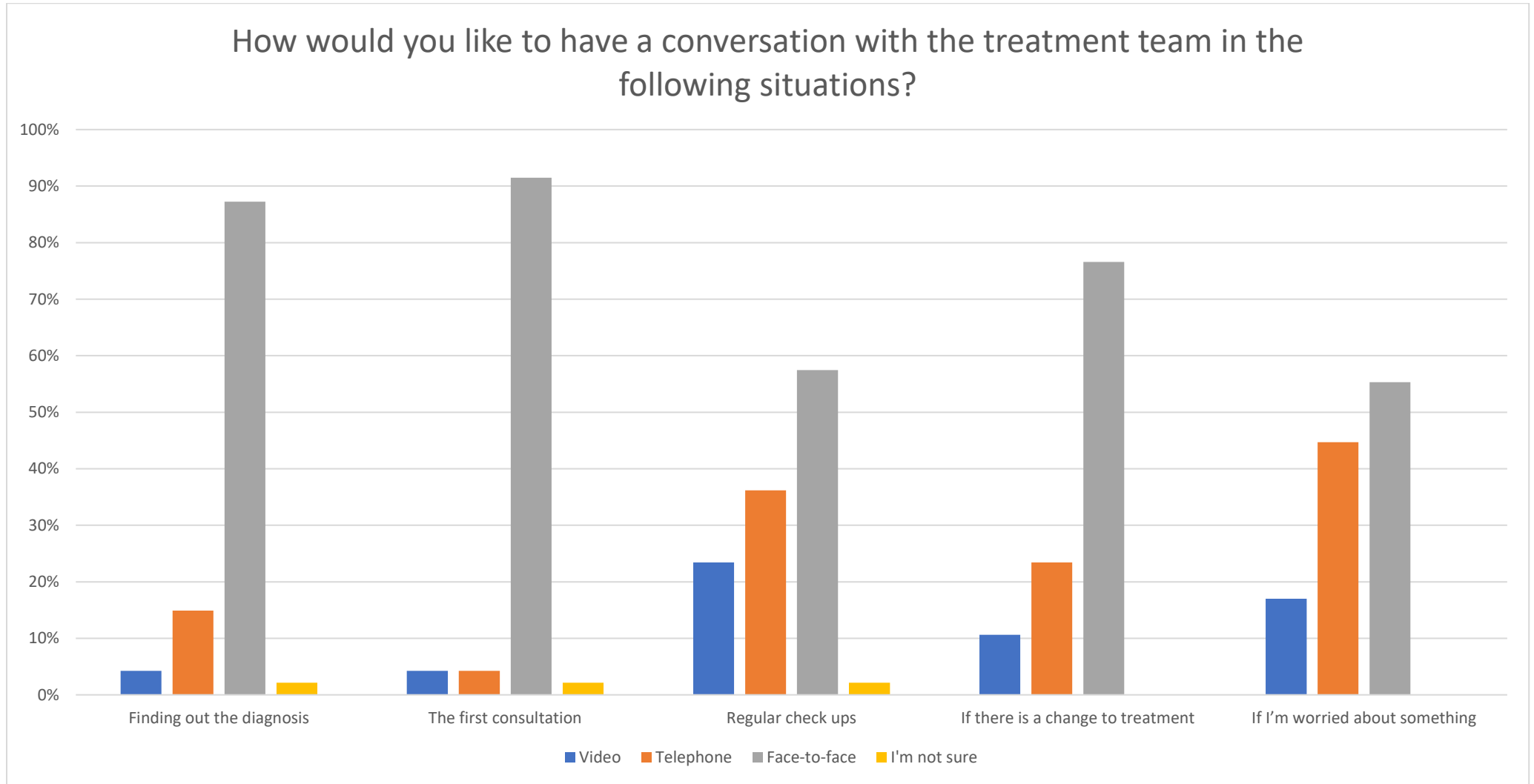
87% of respondents said that the best way to find out by a diagnosis was in person, and 91% said they preferred to have a face-to-face conversation for their first consultation. 77% felt that if there was a change in treatment it was best to have a face-to-face conversation.

For regular check-ups, 57% felt it was best to have a face-to-face conversation, while 36% felt that having a telephone appointment would be appropriate. However nearly a quarter (23%) of respondents would also be open to video consultations for regular check ups.

Respondents said that if they are worried about something, they would prefer to talk in person (55%) or have a telephone (45%) consultation, but 17% were open to a video consultation.

Respondents have a preference for face-to-face appointments in all situations. In future studies, it would be useful to assess whether this is representative of the wider population in Canada. As telehealth is increasingly used, the results suggest that there may be some use in seeking out patients' feedback to determine if and when those approaches work for them, what the biggest difficulties are, and how they can be improved.

Figure 23: How would you like to have a conversation with the treatment team in the following situations? (Tick all that apply). Results for 2021





## Receiving information

During the pandemic, many GLCC member organisations experienced a surge in demand as patients asked for support to understand their risk, how they could protect themselves, and what the impact of COVID-19 might be on their access to treatment. The pandemic has reinforced the need to communicate effectively and efficiently with people to allay fears and avoid misinformation, in the midst of a crisis and at a time of great uncertainty.

The GLCC wanted to find out where people with lung cancer would look for information. Respondents could choose from seven options including ‘treatment team’ and ‘the internet’ plus an ‘other’ option to allow respondents to specify other sources. Five people skipped this question.

Figure 24: If you wanted more information, would you want to get your information from any of the following? (Tick all that apply). Results for 2021

Answer Choices	Yes, I'd like to, and I have done so already		Yes, but I haven't done yet		Yes, and I didn't know I could		No, I don't want to	
	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number
My treatment team	67%	30	20%	9	13%	6	0%	0
Patient support organisations	48%	19	28%	11	10%	4	15%	6
Other people that have been diagnosed with lung cancer	60%	26	21%	9	12%	5	7%	3
Friends or family	65%	28	12%	5	5%	2	19%	8
The internet	76%	32	2%	1	2%	1	19%	8
Social media	52%	22	12%	5	2%	1	33%	14
Pharmaceutical company	38%	15	13%	5	18%	7	33%	13

Among people who had already sought out information the most popular source was the internet, with three quarters (76%) already looking for information online. However, a further 19% said they would not look for information on the internet.

The majority of respondents said they have also sought information from their treatment team (67%), with a further 28% intending to, although 13% of people said they didn't realise they could ask their treatment team for information.

Friends and family were another popular source, with two thirds of respondents (65%) having sought information from friends and family and 12% expecting to. However, 19% of respondents wouldn't turn to friends and family.

Six in ten (60%) of respondents had already sought information from other people with lung cancer, with a further 21% willing to but not having done so yet.

Just under half (48%) of respondents said they had already contacted patient support organisations, with a further 28% not having done so yet.

Around half of the respondents (52%) had sought information on social media, with a further 12% not having done so yet. However, a third (33%) said they would not look for information on social media.

Just over a third of respondents (38%) had received information from a pharmaceutical company, with 13% of respondents not having done so yet and a further 18% not knowing they could. However a third of respondents (33%) wouldn't turn to pharmaceutical companies for information.

Further studies could explore:

- The reasons why people chose certain options
- What kinds of information people want from different sources, and what format should be used to meet patients' needs
- How organisations can signpost patients to the right place to ensure they get accurate and up-to-date information

## How would people diagnosed with lung cancer like to receive information?

We asked respondents how they would like to receive information. Five people skipped this question.

Figure 25: How do you like to receive information? (Tick all that apply). Results for 2021

Answer Choices	Percentage	Number
A conversation in person	74%	35
A conversation over the phone	64%	30
A conversation on video call	38%	18
Something I can read e.g. a leaflet / booklet	55%	26
Something I can view online e.g. a website / social media	62%	29
Something I can listen to e.g. a podcast	32%	15
Something I can watch e.g. a video	49%	23

The findings show that people with lung cancer have different preferences and needs, so information needs to be available in different formats.

For conversations, 74% of respondents said they would like in person conversations, with telephone or video call scoring lower (64% and 38% respectively). This is in line with findings above where respondents expressed preference for face-to-face appointments in most situations.

Written material, which people can keep and refer to when they want, is important too, with 55% of respondents saying they would like a leaflet or booklet. 62% said they would like something to view online. Videos were chosen by around half of the respondents (49%), while podcasts were less popular at 32%.

## More information

The Global Lung Cancer Coalition is an alliance of patient organisations from across the world. Established in 2001, the GLCC comprises 42 non-government patient organisations from 30 nations: Argentina, Australia, Brazil, Bulgaria, Canada, Czech Republic, Denmark, Egypt, France, Germany, Greece, Ireland, Israel, Italy, Japan, Mexico, Netherlands, Norway, Peru, Portugal, Russia, Slovenia, South Africa, Spain, Sweden, Switzerland, Taiwan, Turkey, UK and USA.

The GLCC's members from Canada are:

- [Canadian Lung Association](#)
- [Cancer Advocacy Coalition of Canada](#)
- [Lung Cancer Canada](#)
- [Lung Health Foundation](#)

The GLCC promotes global understanding of lung cancer and the right of patients to effective early detection, better treatment and supportive care. By serving as the international voice of lung cancer patients, the GLCC is committed to improving disease outcomes for all.

For more information about this study and the work of the GLCC please visit our new [site](#) or email our secretariat at: [glcc@roycastle.org](mailto:glcc@roycastle.org)

## References

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<sup>i</sup> American Cancer Society, What is lung cancer? Types of lung cancer, accessed June 2021

<sup>ii</sup> Leong et al., Delayed access to lung cancer screening and treatment during the COVID-19 pandemic: Are we headed for a lung cancer pandemic?, December 2020

<sup>iii</sup> Ohio State News, Depression affects one third of lung cancer patients, December 2019

<sup>iv</sup> IASLC, Bringing Telehealth to the Front Lines of Lung Cancer Care in the COVID-19 Pandemic, August 2020