



GLOBAL LUNG CANCER
COALITION

COVID-19 PANDEMIC: THE IMPACT ON LUNG CANCER PATIENTS

Insights from Mexico

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 Mexico**. Patients from Mexico 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.

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

This year, fewer people from Mexico filled out our survey: six in 2021 compared to 41 in 2020. We appreciate how much pressure people and organisations were under as a result of the pandemic and we are grateful to all of those who were able to respond.

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. This year six people completed the survey, compared with 41 in 2020. Of the six people who answered this question, four people described themselves as a patient and two as a carer. All respondents answered this question.

One respondent said they were not sure if they had filled out the first patient experience survey in 2020. One respondent said they had completed it in 2020 and four respondents said they had not.

Gender

This year, two (40%) of respondents were women and three (60%) were men (Figure 1). In 2020, more women than men filled out the survey (59% of respondents in 2020 were women). One respondent skipped this question.

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
40%	2	60%	3	0%	0	0%	0	0%	0

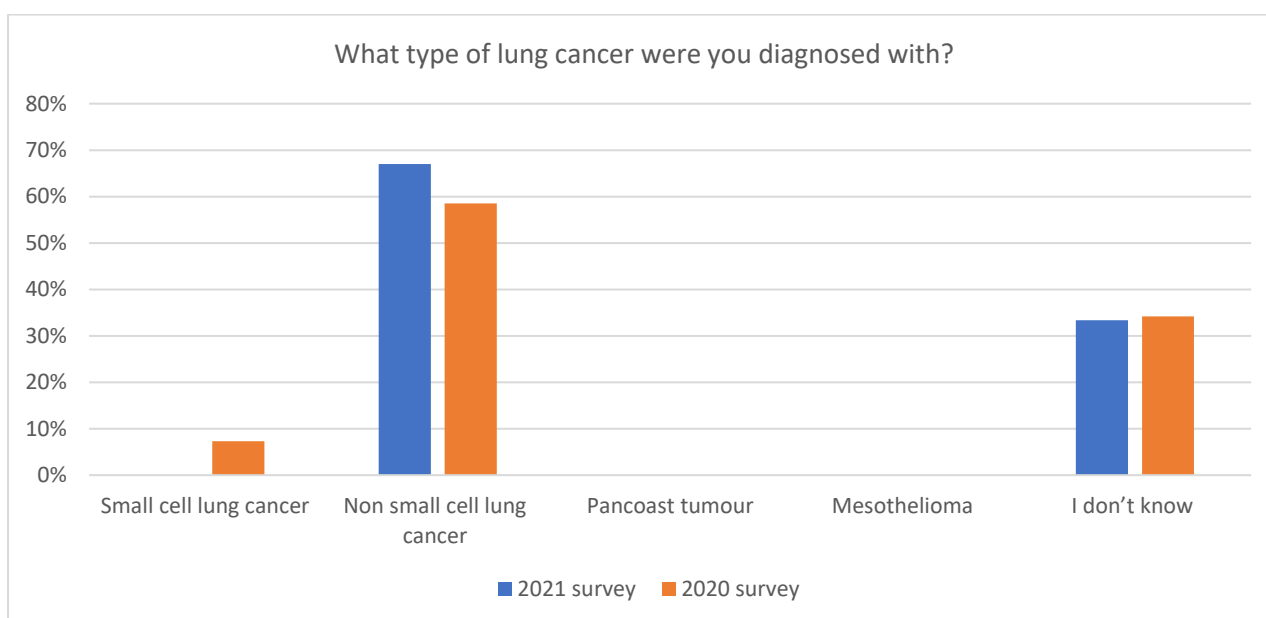
Diagnosis

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.ⁱ As in 2020, the largest proportion of respondents (four people, 67% of respondents in 2021 vs 59% in 2020) stated they had non-small cell lung cancer. No respondents said they had small cell lung cancer or mesothelioma. All respondents answered this question.

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, 34% of respondents from Mexico did not know what type of lung cancer they had. This year two people (33% of the respondents) said they did not know the type of cancer they had or have, and both said they would like to know.

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 concerning that some respondents did not know their type of lung cancer, but would like to know. Therefore health professionals could look at ways of improving communications with patients to ensure they are aware of the type of cancer they have.

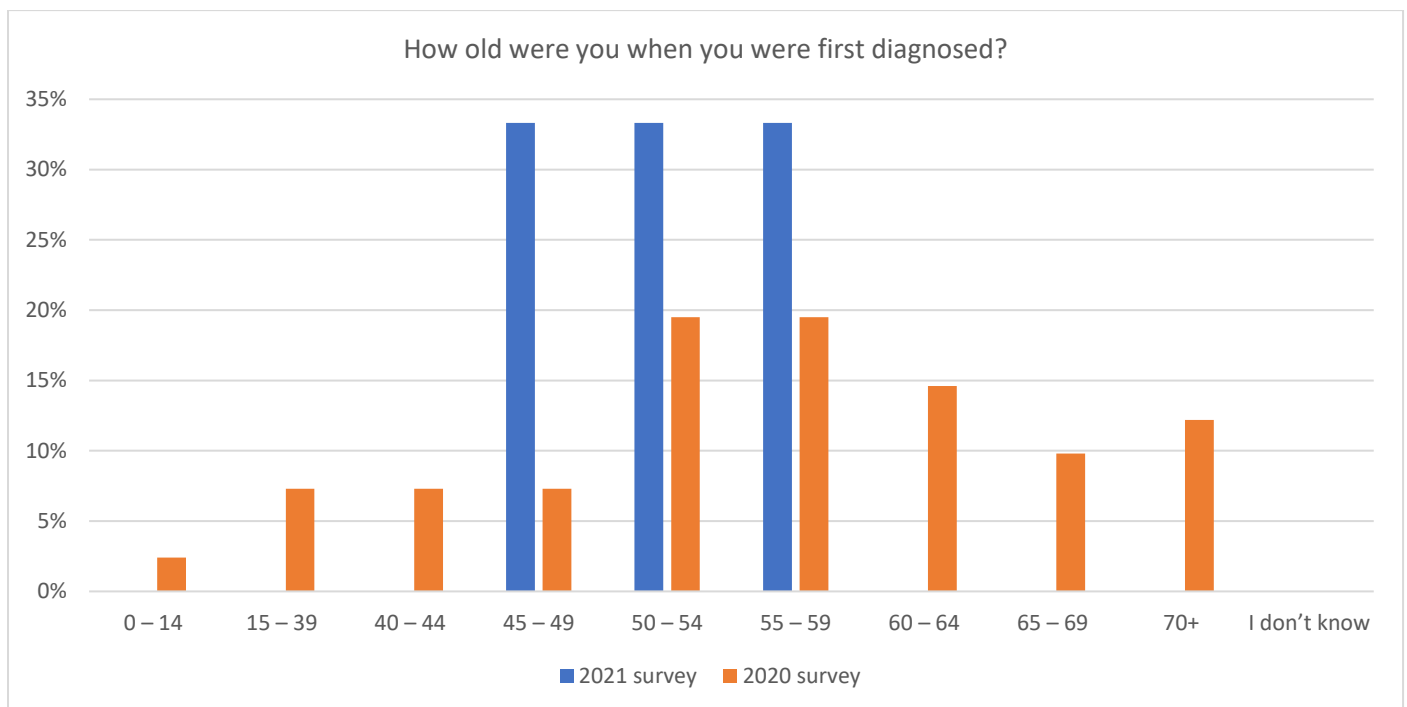
Further survey work could be conducted to determine whether the experience of the respondents reflects that of the wider lung cancer patient population in Mexico (given the relatively small sample size).

Age at diagnosis

Respondents were asked how old they were when they received their diagnosis (Figure 3). All respondents from Mexico answered this question.

A third of the respondents (two people) said they were diagnosed at age 45-49, with the same proportions saying they were diagnosed at age 45-49, and age 50-54.

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

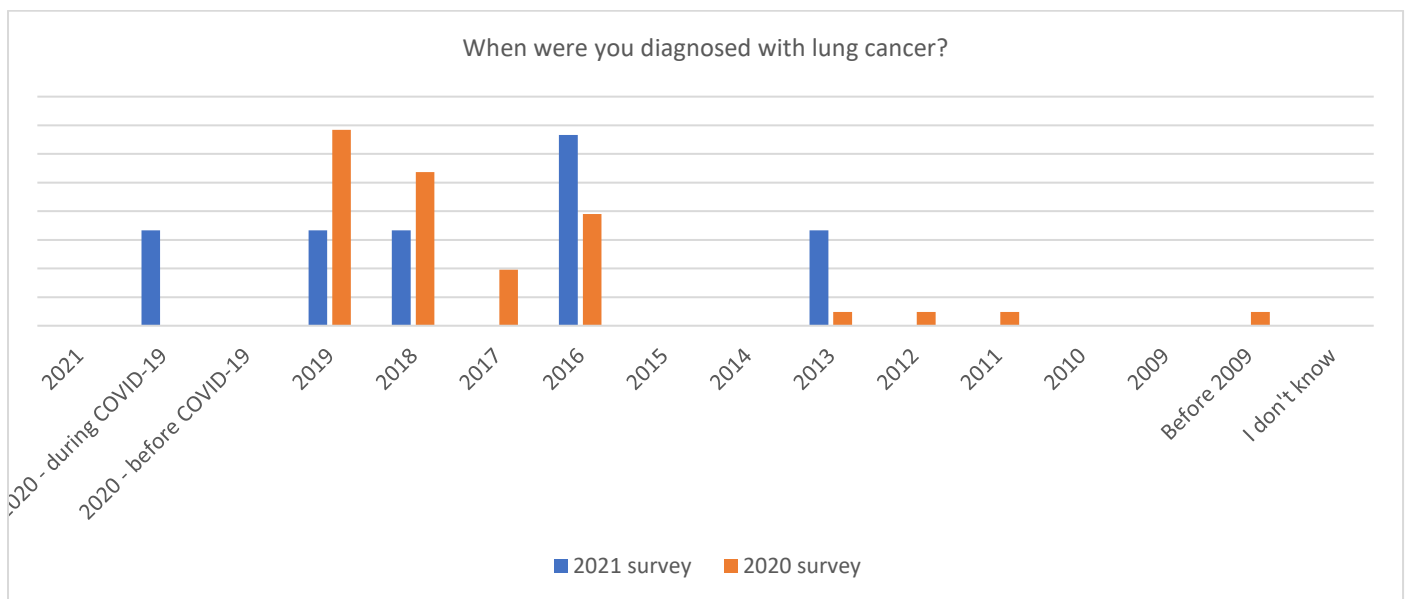


Year of diagnosis

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.ⁱⁱ All respondents answered this question.

Two people said were diagnosed in 2016 (33%). One of the respondents (17%) was diagnosed in 2020 during the pandemic, with one person diagnosed in 2019, another in 2018 and the final person diagnosed in 2013. 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. All respondents from Mexico answered this question.

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	17%	1
Yes, it took too long to see someone to test if I had lung cancer	17%	1
Yes, it took too long to get my test results	17%	1
No, I am satisfied with the time it took to get my diagnosis	50%	3
I'm not sure	0%	0

Three of the respondents from Mexico (50%) said they were satisfied with the time it took to get their diagnosis. One respondent said it took them too long to see someone to get their symptoms checked out. One person felt it took too long to see someone to get tested to see if they had lung cancer and another felt they waited too long for test results.

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 Mexico 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.

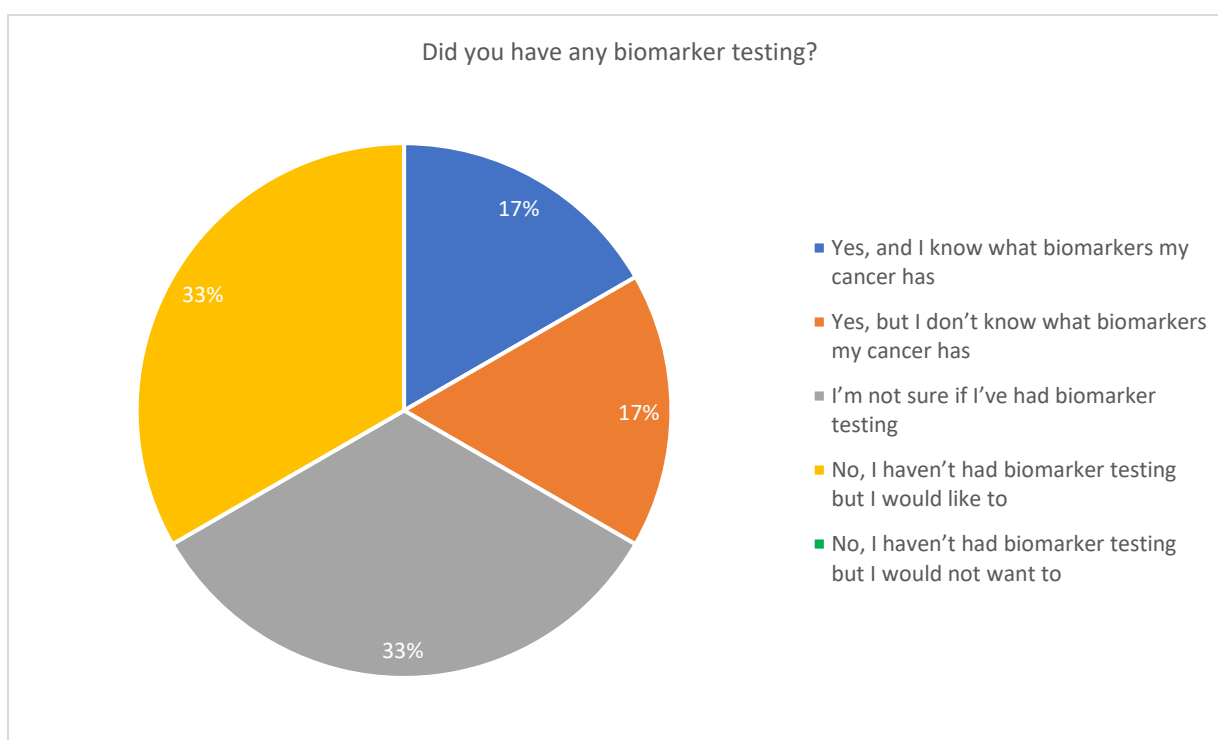
Biomarker testing

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, 39% of respondents from Mexico said they had received a biomarker test, 15% said they hadn't received one, and 46% said they didn't know if they have had one. The results for this year show that, overall, a lower proportion of respondents (34%, two people) knew they had biomarker testing and, of those, one person did not know what biomarkers their cancer has. Two people were not sure if they had biomarker testing. One person said they had not had a biomarker test but would like one.

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. All respondents answered this question.

The majority said they were currently receiving treatment (83%, five people), with one person saying they had finished treatment. No respondents said that treatment was not available to them.

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	0%	0
I am currently having treatment	83%	5
I have finished treatment	17%	1
I chose not to have treatment	0%	0
Treatment wasn't available to me	0%	0

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 and 9b). Respondents were also given the options to select 'other' and specify which other forms of treatment they had received. All respondents answered this question.

All the findings are set out in the Figure 8 below, and some of the results are summarised below:

- **Surgery:** Three people (50% of respondents) had surgery compared to 23% 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:** Three people (50%) said they had received radiotherapy, compared to 23% in 2020
- **Chemotherapy:** all respondents from Mexico had received chemotherapy compared to 63% in 2020
- **Immunotherapy:** no respondents said they had received immunotherapy this year, compared with 13% in 2020 saying they had received immunotherapy
- **Targeted therapies:** One person this year (17%) said they had received targeted therapies, compared to 55% in 2020
- **Symptom management:** Four people (67% of respondent) said they had received treatment to help with symptom management, compared to 35% in 2020
- **No treatment:** no respondents said they have not received any treatment because it was not available to them or because it was delayed by COVID
- **Other treatments:** one respondent picked other, and said their chemotherapy had been delayed due to COVID-19

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	50%	3	50%	3	100%	6	0%	0
2020 survey	23%	9	23%	9	63%	25	13%	5

	Targeted therapies		Symptom management	
	Percentage	Number	Percentage	Number
2021 survey	17%	1	67%	4
2020 survey	55%	22	35%	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	0%	0
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	0%	0
I have not received any treatment because it is not available to me	0%	0
Other (please specify)	17%	1

The respondent who picked 'other' said: "Due to covid my appointments for chemotherapy have been delayed".

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.

All respondents answered this question. The survey results are summarised below and include comparisons with the 2020 patient experience survey:

- **Psychosocial support / counselling:** three people (50% of respondents) to the 2021 survey said they had received psychosocial support and or counselling, compared to 24% in 2020
- **Physical therapy / pulmonary rehabilitation:** four people (67% of respondents) said they had received physical therapy compared with 46% in 2020 (Figure 10a)
- **Occupational therapy:** this year, no respondents said they had received occupational therapy. This was also the case in 2020
- **Dietary advice:** two people (33% of respondents) received dietary advice. The same proportion was observed in 2020
- **Lifestyle advice:** one person (17%) said they had received lifestyle advice, compared with 11% of respondents in 2020
- **Financial advice:** no respondents said they had received financial advice, compared to 5% in 2020
- **Return to work advice:** as in 2020, no respondents said they had received advice on going back to work
- **Smoking cessation:** no respondents said they had received support on how to stop smoking
- **Support group:** one respondent (17%) said they had received support from peer and/or support group
- **No support:** no respondents said they had not received any other support because the pandemic has delayed it. However, one respondent (17%) said that their support was due to start
- **Other type of support:** no respondents said they had received other kinds of support for their condition

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	50%	3	67%	4	0%	0	33%	2
2020 survey	24%	9	46%	17	0%	0	35%	13

	Lifestyle advice		Financial advice		Advice on going back to work	
	Percentage	Number	Percentage	Number	Percentage	Number
2021 survey	17%	1	0%	0	0%	1
2020 survey	11%	4	5%	2	0%	0

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

	Support Group		Smoking cessation		Other	
	Percentage	Number	Percentage	Number	Percentage	Number
2021 survey	17%	1	0%	0	0%	0

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	0%	0
I have not received any other support, but I am due to start	17%	1
I have not received any other support because COVID-19 has delayed it	0%	0
I have not received any other support because I chose not to	0%	0
I have not received any other support because it is not available to me	0%	0

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:

- How useful people found the services they received, and if they would recommend the service to others
- 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 Mexico 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'. 92% felt involved in decision making about their care.

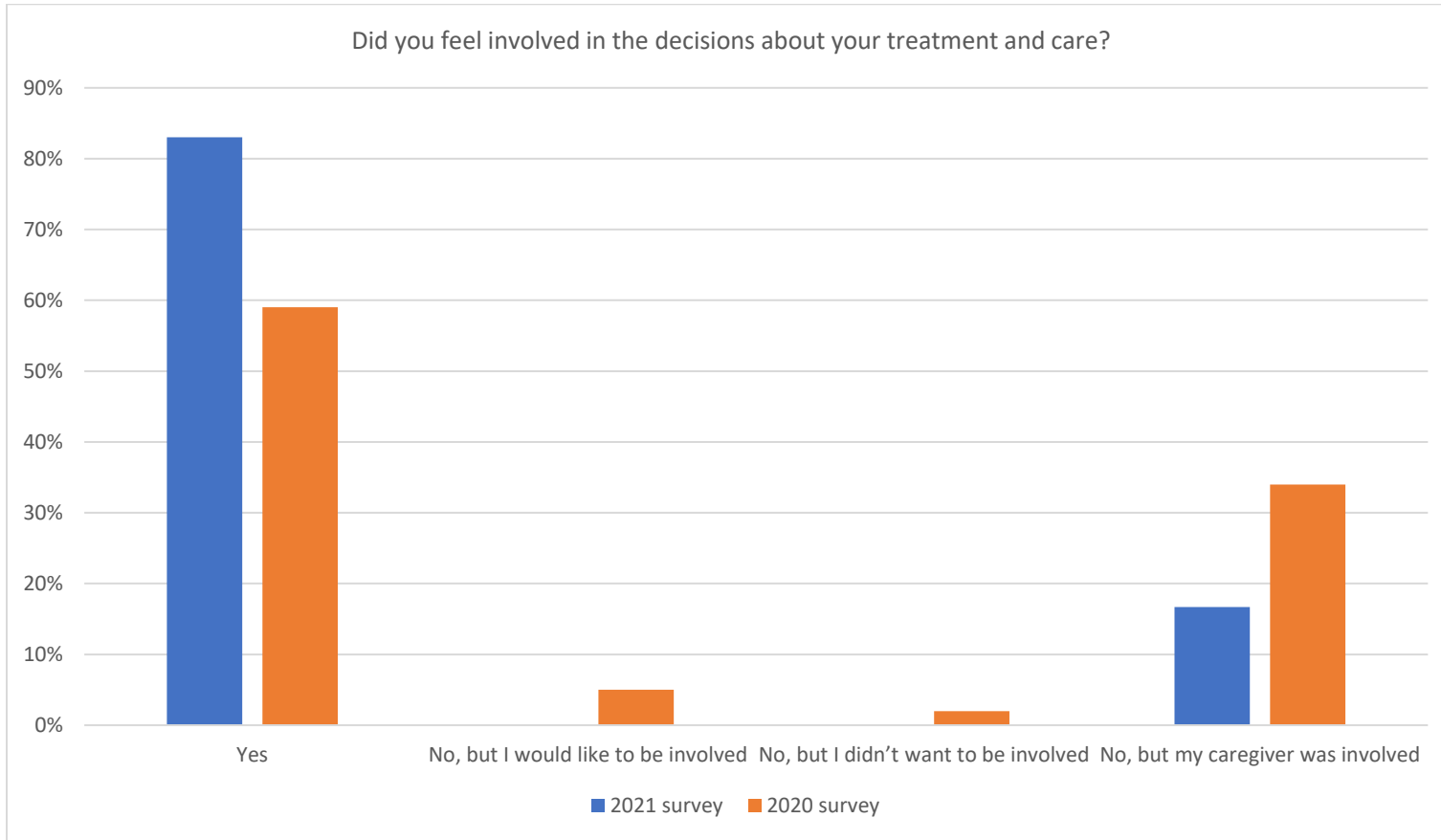
This year, we wanted to examine this further and gave respondents additional options to choose from: 'Yes, I've been fully involved', 'Yes, I've been involved most of the time' and 'Yes, I've been involved sometimes'. All six respondents answered this question.

Two people (33% of respondents) felt they were fully involved in decision-making, one person (17%) felt they were involved most of the time, and two people (33%) felt they were only sometimes involved.

As in 2020, no respondents said they didn't want to be involved in decision-making; however one respondent said their caregiver was involved in decision-making in their place (14 people said this in 2020).

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	33%	2
Yes, I've been involved most of the time	17%	1
Yes, I've been involved sometimes	33%	2
No, but I would like to be involved	0%	0
No, but I didn't want to be involved	0%	0
No, but my caregiver was involved	17%	1

Future studies or surveys could explore:

- Whether this figure reflects the experience of the wider lung cancer patient population in Mexico (given the relatively small sample size)
- Why respondents from Mexico 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 six respondents answered this question. Compared to 2020, we found a slightly lower proportion of respondents said they were always treated with dignity and respect (67% vs 83% in 2020), but this equates to four people. Two people (33%) said they were 'mostly' treated with dignity and respect, and no respondents said they were 'sometimes' treated with dignity and respect, compared with 17% and 0% respectively in 2020 (Figure 12b).

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

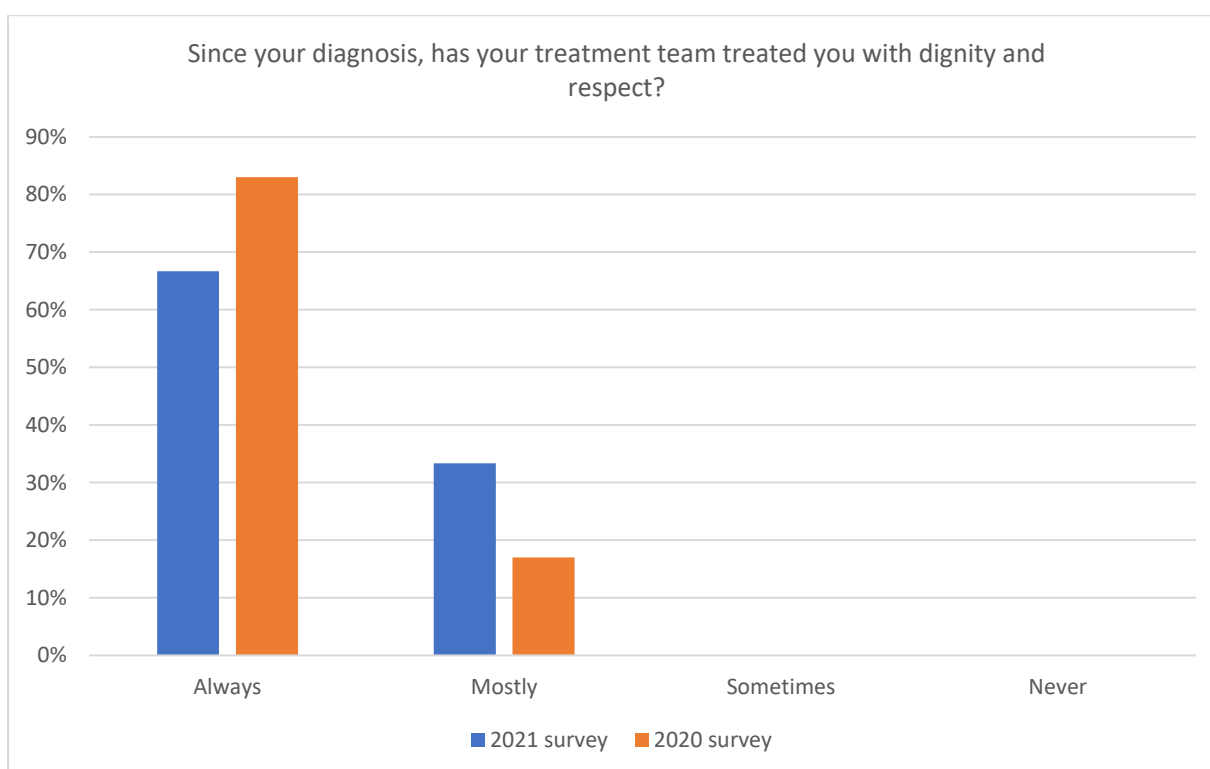


Figure 12b: Data on the number and percentage of respondents feeling treated with dignity and respect by their treatment team, results for 2021 and 2020

	Always		Mostly		Sometimes		Never	
	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number
2021 survey	67%	4	33%	2	0%	0	0%	0
2020 survey	83%	34	17%	7	0%	0	0%	0

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

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.

In the first survey, the GLCC asked people how they describe themselves. Respondents were asked to tick as many of the different descriptions as they felt applied to them. A higher proportion of respondents described themselves as a 'patient' (39%), followed by 'surviving with lung cancer' (24%).

This year, one respondent skipped this question. The most popular choice among respondents was 'warrior' with two people (40% of respondents) describing themselves this way. One person (20% of respondents) described themselves as 'lung cancer survivor', one as a 'thriller', one as 'battling lung cancer' and one chose 'surviving with lung cancer'.

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 'warrior'. There was also the option to pick 'other' for people to include their own description.

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

	Living with lung cancer		Patient		Surviving with lung cancer		Lung cancer survivor		Overcomer		Other	
	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number
2021 survey	0%	0	20%	1	20%	1	20%	1	0%	0	0%	0
2020 survey	20%	8	29%	12	24%	10	12%	5	2%	1	17%	7

	Survivor		Advocate		Thrifer	
	Percentage	Number	Percentage	Number	Percentage	Number
2021 survey	0%	0	0%	0	20%	1
2020 survey	7%	3	12%	5	7%	3

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	20%	1	0%	0	0%	0	40%	2	0%	0

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.ⁱⁱⁱ It is important to recognise these changes to ensure the right emotional support is offered to people diagnosed with lung cancer.

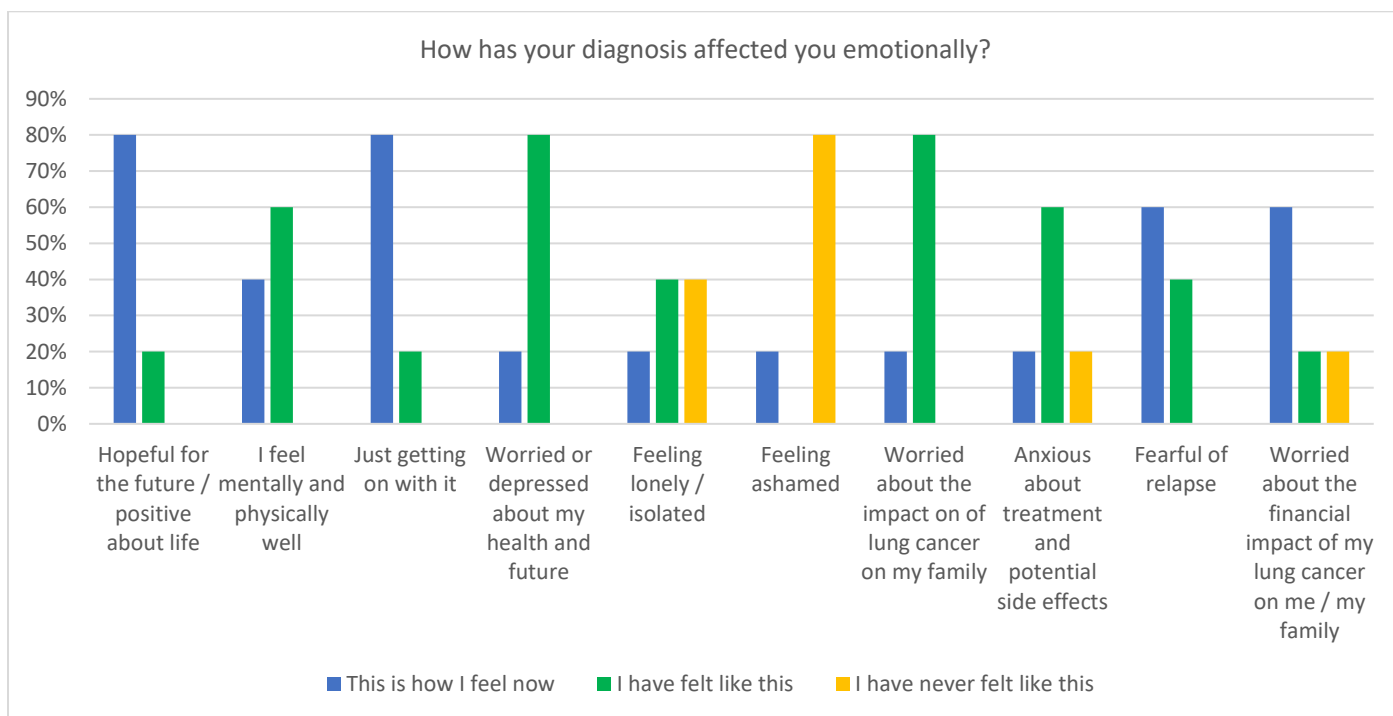
This year, the GLCC decided to ask people questions to understand how their diagnosis has affected them both emotionally and physically, and what type of support they sought.

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. 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.

Four people (80% of respondents) said they were just getting on with their cancer. Four people (80%) said they feel hopeful or positive about life, and one person (20%) used to feel this way.

One person (20%) said they currently feel worried or depressed about their health and future, and the other four respondents said they (80% have felt this way). Three of the five respondents to this question (60%) are fearful of relapse. One person (20%) said they are feeling lonely or isolated, and another two (40%) said they have felt this way at some point.

There is a stigma associated with lung cancer, and one person (20% of respondents) said they feel this way now, although the other four people (80%) said they never felt ashamed.

When it came to their mental and physical wellbeing, two people (40% of respondents) feel well at the moment, while the other three people (60%) said they have felt well previously. One person (20%) said they are currently anxious about treatment while three others (60%) have felt this way.

One person (20%) said they are currently worried about the impact of their condition on their family, while the other four who answered the question (80%) have felt this way.

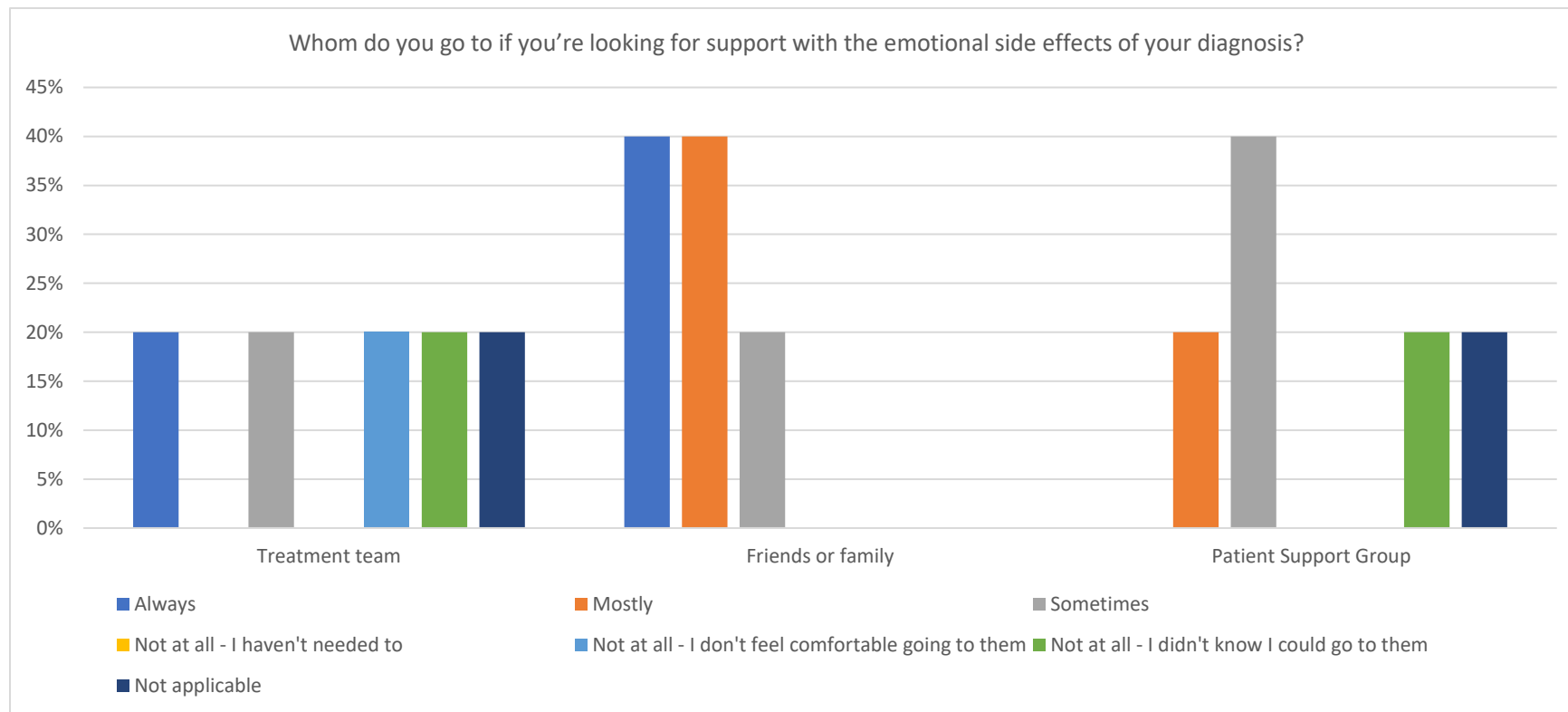
Further studies could explore:

- 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
- Why some people felt lonely, anxious or stigmatised, and what can be done to support them

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 four options. One respondent 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. Two of the five people (40%) said they always reached out to friends and family for support, while two more said they would mostly speak to friends and family and the other person saying they would do this sometimes.

One person (20%) said they always reached out to their treatment team for help, with another doing so sometimes.. However, one of the respondents said they didn't know they could ask their treatment team for this kind of support, and one said they don't feel comfortable doing so.

One person (20%) said they would mostly ask patient groups for emotional support, with two more (40%) saying they would do so sometimes. One person said they did not know they could turn to patient groups 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 people might 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?

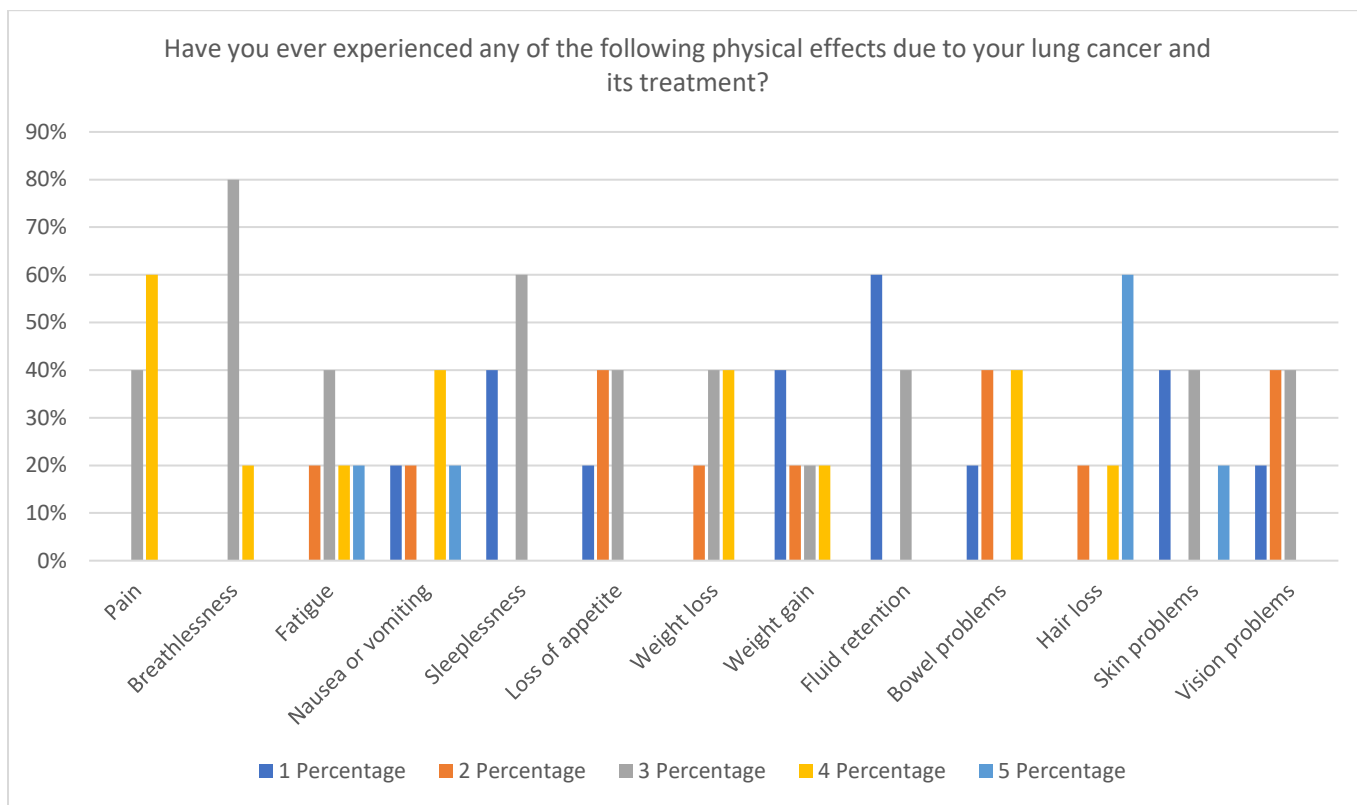
Respondents were asked about the physical effects they experienced because of their cancer and its treatment. We gave respondents 13 options and, for each option, people could select a number from 1 to 5, where 1 means this has not affected them and 5 means this has been a very serious concern. One person 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	0%	0%	40%	60%	0%	5	3.6
Breathlessness	0%	0%	80%	20%	0%	5	3.2
Fatigue	0%	20%	40%	20%	20%	5	3.4
Nausea or vomiting	20%	20%	0%	40%	20%	5	3.2
Sleeplessness	40%	0%	60%	0%	0%	5	2.2
Loss of appetite	20%	40%	40%	0%	0%	5	2.2
Weight loss	0%	20%	40%	40%	0%	5	3.2
Weight gain	40%	20%	20%	20%	0%	5	2.2
Fluid retention	60%	0%	40%	0%	0%	5	1.8
Bowel problems	20%	40%	0%	40%	0%	5	2.6
Hair loss	0%	20%	0%	20%	60%	5	4.2
Skin problems	40%	0%	40%	0%	20%	5	2.6
Vision problems	20%	40%	40%	0%	0%	5	2.2

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, hair loss (4.2) was the most serious issue for respondents, followed by pain (3.6), and fatigue (3.4).

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

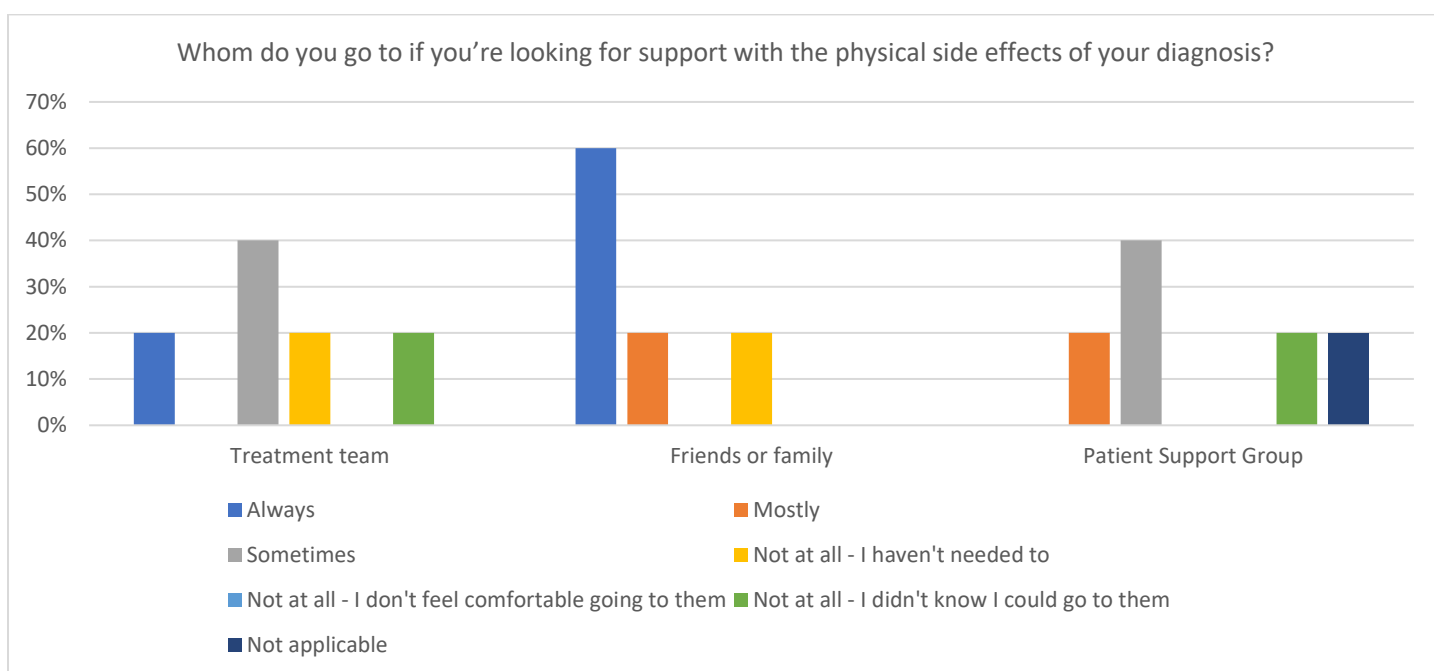


Three respondents (60%) gave a 5 when describing the impact of hair loss, and three out of five (60%) scored a 4 for pain, meaning that it has been a very serious concern for respondents. For fatigue, one respondent scored a 5, one scored a 4, and two scored a 3.

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. One person skipped this question. 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



When it came to asking for support with the physical impact of their diagnosis, the highest proportion of respondents (three out of five, 60%) said they would go to friends and family. One person said they would mostly turn to friends and family.

One person said they would always go to their treatment team for support with physical impact of lung cancer, with two people (40%) saying they would do so sometimes. One person (20%) said they didn't know they could go to their treatment team.

On patient support groups, one person said they would mostly go to a patient support group, with two people saying they would turn to them sometimes. Again, one person said they did not know that they could ask a patient support group for help.

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. One person 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	20%	1
There has been no difference in how easy it has been to contact my treatment team	20%	1
I found it more difficult to speak to my treatment team	40%	2
I have held back in contacting my treatment team because they are so busy	0%	0
My treatment has continued as normal	60%	3
My treatment has been delayed / cancelled	40%	2
I don't know if my treatment has been affected	0%	0
I have carried on attending appointments during the pandemic	60%	3
I have been reluctant to attend appointments for fear of infection	20%	1
I have missed appointments for fear of infection	20%	1
My face-to-face appointments have been swapped for telephone or video calls	0%	0
I have been offered new services that weren't available to me before the pandemic	0%	0
Other	0%	0

One person (20% of respondents) said there has been no difference in how easy it was to contact their treatment team, but two people (40%) said they found it more difficult. One person said it had been easier to contact their treatment team during the pandemic.

Three of the five respondents to this question said they have carried on attending their appointments in person during the pandemic. No 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). Three of the five respondents said their treatment has continued as normal, but two people had experienced delays to treatment.

One person had been reluctant to attend appointments for fear of infection, while one person said they had missed appointments because they were worried about infection.

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. One person 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

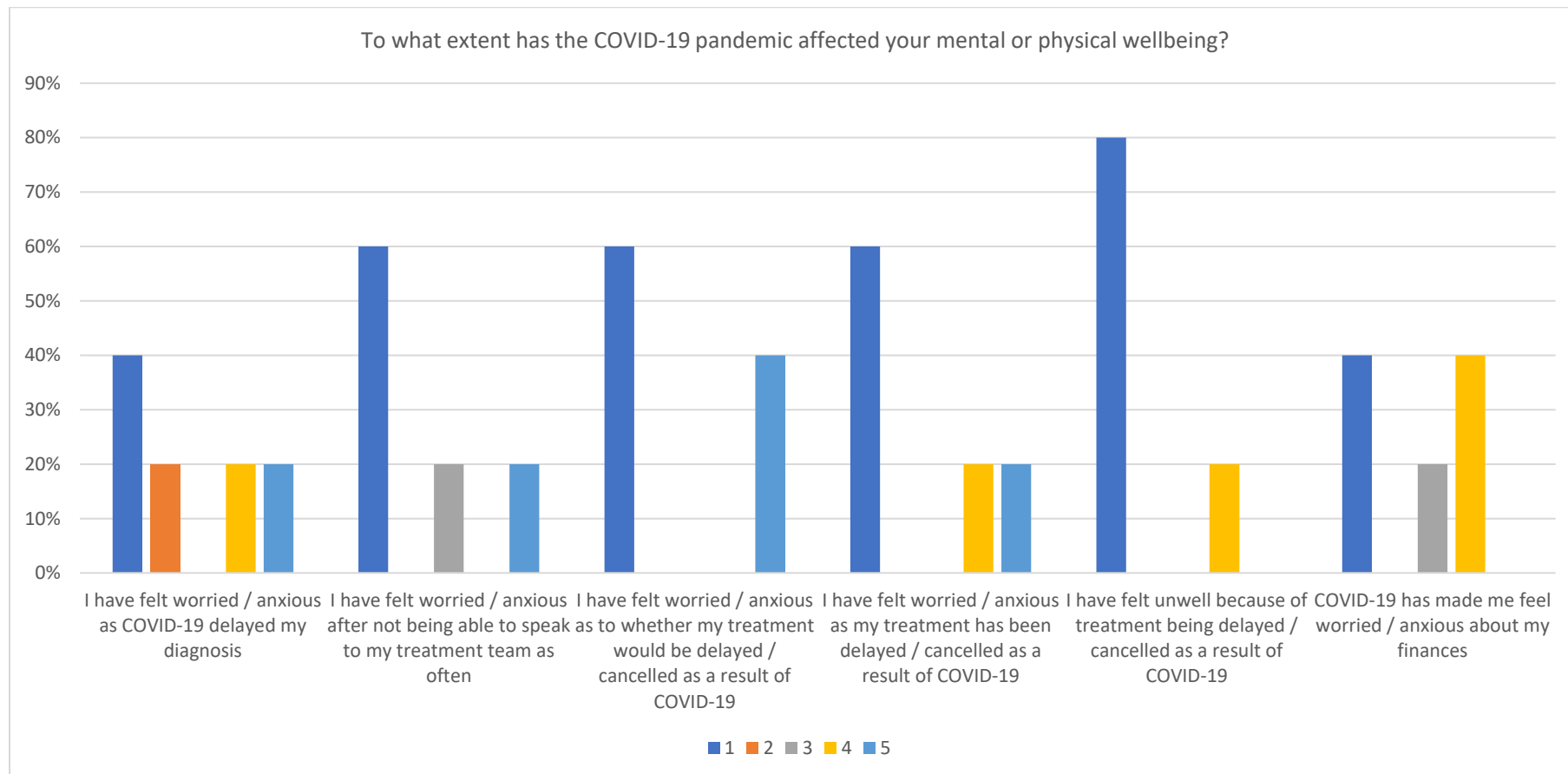


Figure 20b: To what extent has the COVID-19 pandemic affected your mental or physical wellbeing? Please choose an option from 1 – 5, where 1 means this has not affected me and 5 means this has been a very serious concern. Results for 2021

Answer Choices	1	2	3	4	5
I have felt worried / anxious as COVID-19 delayed my diagnosis	40%	20%	0%	20%	20%
I have felt worried / anxious after not being able to speak to my treatment team as often	60%	0%	20%	0%	20%
I have felt worried / anxious as to whether my treatment would be delayed / cancelled as a result of COVID-19	60%	0%	0%	0%	40%
I have felt worried / anxious as my treatment has been delayed / cancelled as a result of COVID-19	60%	0%	0%	20%	20%
I have felt unwell because of treatment being delayed / cancelled as a result of COVID-19	80%	0%	0%	20%	0%
COVID-19 has made me feel worried / anxious about my finances	40%	0%	20%	40%	0%

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, one person (20% of respondents) scored a 5, and another person scored a 4
- On worries caused because treatment has being delayed or cancelled as a result of COVID-19, two people scored it a 5
- On feeling unwell because of treatment being delayed or cancelled as a result of the pandemic, one person scored a 4
- Two people said they felt anxious after not being able to speak with their treatment team as often (one scored a 4, and one scored a 5)

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 in many countries as tool in lung cancer diagnosis, and have enabled healthcare professionals to follow-up with patients during the pandemic when restrictions were in place.^{iv} 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	20%	1
Video	0%	0
In person	80%	4
No, I have not been in contact with my treatment team at all, but I wanted to	20%	1
No, I have not been in contact with my treatment team at all, but I haven't needed / wanted to	0%	0

Four of the five respondents said they have continued to see their treatment team in person. One person said they have had conversations with their treatment team via telephone, but no respondents said they had video consultation. One respondent said they have not been in contact with their treatment team at all but wanted to.

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 respondent from Mexico noted that they weren't able to speak to their treatment team but wanted to, and so was eligible to answer this question. They said in person was the only option available and they were worried about infection.

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 answered this question.

Results show that the respondent found it quicker to have appointments by video or telephone, but still preferred face-to-face appointments.

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	100%	1
I found it helpful as I don't have to travel to hospital as much	0%	0
I prefer face-to-face appointments	100%	1
I found it more difficult to understand my treatment team / make myself understood	0%	0
I don't like it and I want to stop as soon as possible	0%	0

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. One person skipped this question.

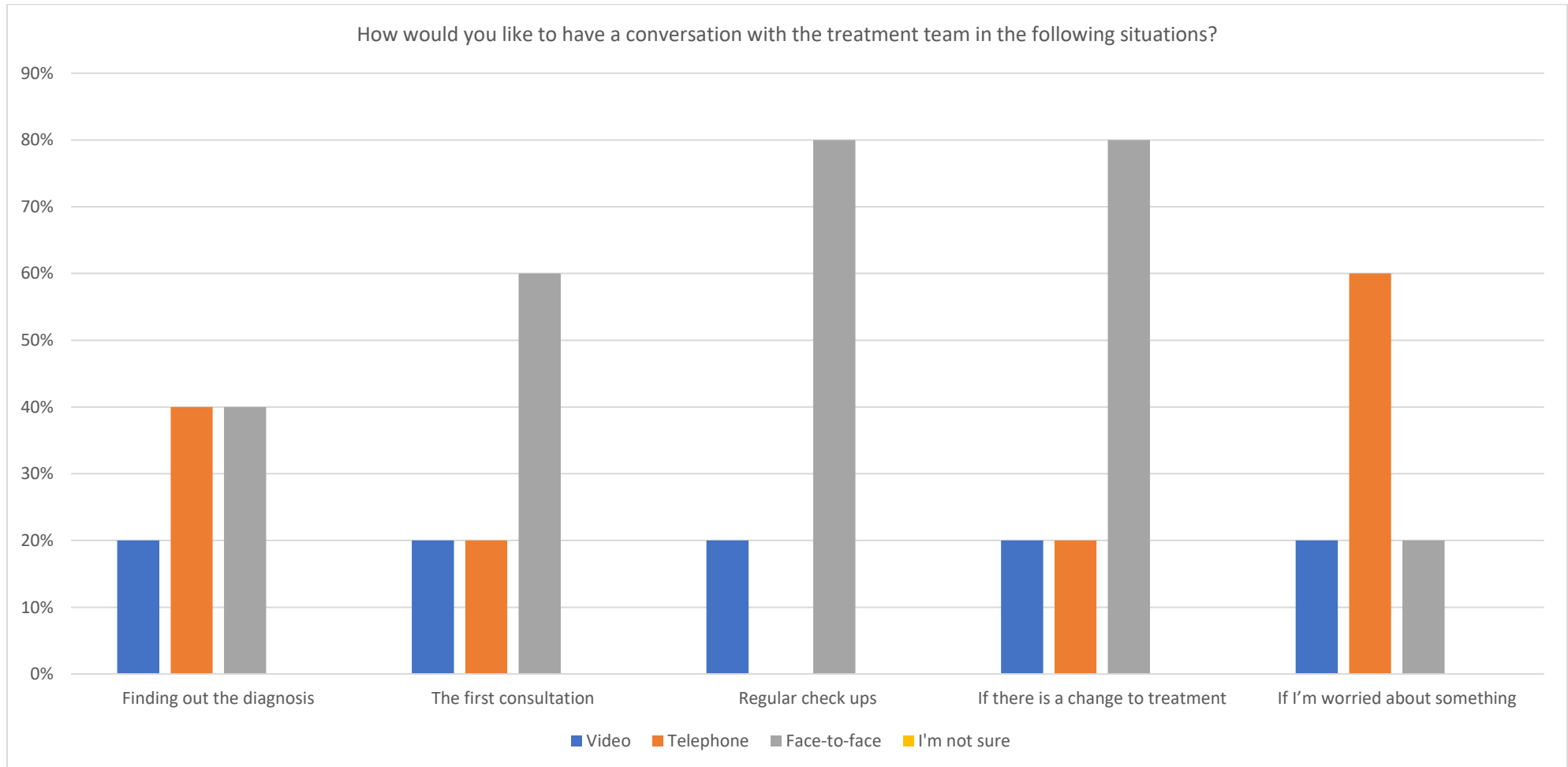
Two of the five respondents (40%) said that the best way to find out by a diagnosis was in person, and three of the five (60%) said they preferred to have a face-to-face conversation for their first consultation.

Four of the five (80%) felt that if there was a change in treatment it was best to have a face-to-face conversation, while one person (20%) felt that having a telephone appointment would be appropriate.

For regular check-ups, four of the five respondents (80%) felt it was best to have a face-to-face conversation. Respondents said that if they are worried about something, they would prefer to have a telephone (three people, 60%) or video consultation (one person, 20%).

Respondents have a preference for face-to-face appointments in most situations. In future studies, it would be useful to assess whether this is representative of the wider population in Mexico. 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. One person skipped this question, and no respondents picked ‘other’.

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
My treatment team	60%	20%	20%	0%
Patient support organisations	60%	20%	20%	0%
Other people that have been diagnosed with lung cancer	40%	40%	0%	20%
Friends or family	40%	40%	0%	20%
The internet	20%	60%	0%	20%
Social media	0%	20%	40%	40%
Pharmaceutical company	20%	0%	60%	20%

The results show that three of the five respondents have sought information from their treatment team (60%) with one person saying they hadn't done so yet, but one person not knowing they could ask their treatment team for information.

Patient support organisations were another popular source of support with three people (60%) having already sought information from a patient group, one open to doing so but not having done so yet, and one not knowing they could.

Two people had sought information from other people who have been diagnosed with lung cancer (40%) and two people would be willing to talk to another person (although one person said they wouldn't want to).

The same applied to friends and family: two people had sought information from friends and family, two would be open to doing so and one person wouldn't want to.

A mixed picture was seen on the internet and social media. One respondent had sought out information on the internet, but no-one had looked for information on social media. Three of the five people said they would be open to finding information on the internet but hadn't yet; one person said they wouldn't want to. One person said they knew they could find information on social media but hadn't looked for it yet, while two hadn't realized they could look at social media. Two people didn't want to use social media for information.

One person had sought information from a pharmaceutical company, three people said they didn't know they could, and one person said they wouldn't want to.

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. One person 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	60%	3
A conversation over the phone	40%	2
A conversation on video call	20%	1
Something I can read e.g. a leaflet / booklet	20%	1
Something I can view online e.g. a website / social media	20%	1
Something I can listen to e.g. a podcast	0%	0
Something I can watch e.g. a video	20%	1

The findings show that people with lung cancer have different preferences and needs, so information needs to be available in different formats. For conversations, three of the five people (60%) said they would like in person conversations, with telephone or video call scoring lower (two people, 40% and one person, 20% respectively). This is in line with findings above where respondents expressed preference for face-to-face appointments in most situations.

Written material, to which people can keep and refer when they want, is important too. One person (20%) said they would like something to view online or to have something to read. One person said they would like a video but no-one chose a podcast.

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 member from Mexico is: [Respirando Con Valor](#)

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

References

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