



GLOBAL LUNG CANCER
COALITION

COVID-19 PANDEMIC: THE IMPACT ON LUNG CANCER PATIENTS

Insights from South Africa

2021 Patient Experience Survey

Table of contents

Introduction	2
Methodology	3
Insights from the 2021 patient experience survey	4
Demographics of respondents	4
Background information on respondents	4
Gender	4
Diagnosis	5
Type of lung cancer	5
Age at diagnosis.....	6
Year of diagnosis	7
Delay in diagnosis.....	8
Biomarker testing.....	9
Interventions	10
Respondent profile	10
Treatment.....	11
What support did people receive?	13
Respondent experiences	16
Feeling involved in decisions about their treatment and care	16
Being treated with dignity and respect	18
How do people diagnosed with lung cancer describe themselves?.....	20
Emotional and physical wellbeing	22
How were people affected emotionally after a lung cancer diagnosis?	22
Where do people turn for emotional support?.....	24
What are the physical effects people have experienced due to their lung cancer and its treatment?	26
Where do people turn for support with physical impact of their lung cancer and its treatment?	28
The impact of the COVID-19 pandemic on people with lung cancer	30
Experience of care during the pandemic	30
Impact of the pandemic on mental and physical wellbeing.....	32
Communication with treatment team during COVID-19	35
Why were people not able to speak with their treatment team?	35
What do people think of video or telephone consultations?.....	36
When dealing with different situations, what do people think is the best way to speak with their treatment team?	36
Receiving information	38
How would people diagnosed with lung cancer like to receive information?	40
More information	41
References	41

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/>.

In early 2020, 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. South Africa did not take part in the first survey but, as we repeated questions that we asked in 2020 we can draw on respondents' responses to understand the impact of the pandemic. We also asked 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 South Africa**. 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

Five people from South Africa filled out our survey.

Insights from the 2021 patient experience survey

Demographics of respondents

Background information on respondents

The survey was open to people from any country in Africa. To develop a better understanding of the respondents, we asked people to state the country they were responding from and the treatment facility at which they were receiving care. All five respondents said they were from South Africa. Respondents said they were receiving treatment at: Westrand Oncology Centre; Sandton Oncology Centre; Parklands Hospital, Durban; and Cancer Association of South Africa.

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. Five people filled out the survey. All respondents answered this question, with two people describing themselves as a patient and three as a carer.

Gender

Of the five respondents, four respondents were women, and one was a man (Figure 1).

Figure 1: Number and percentage of respondents

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
80%	4	20%	1	0%	0	0%	0	0	0%

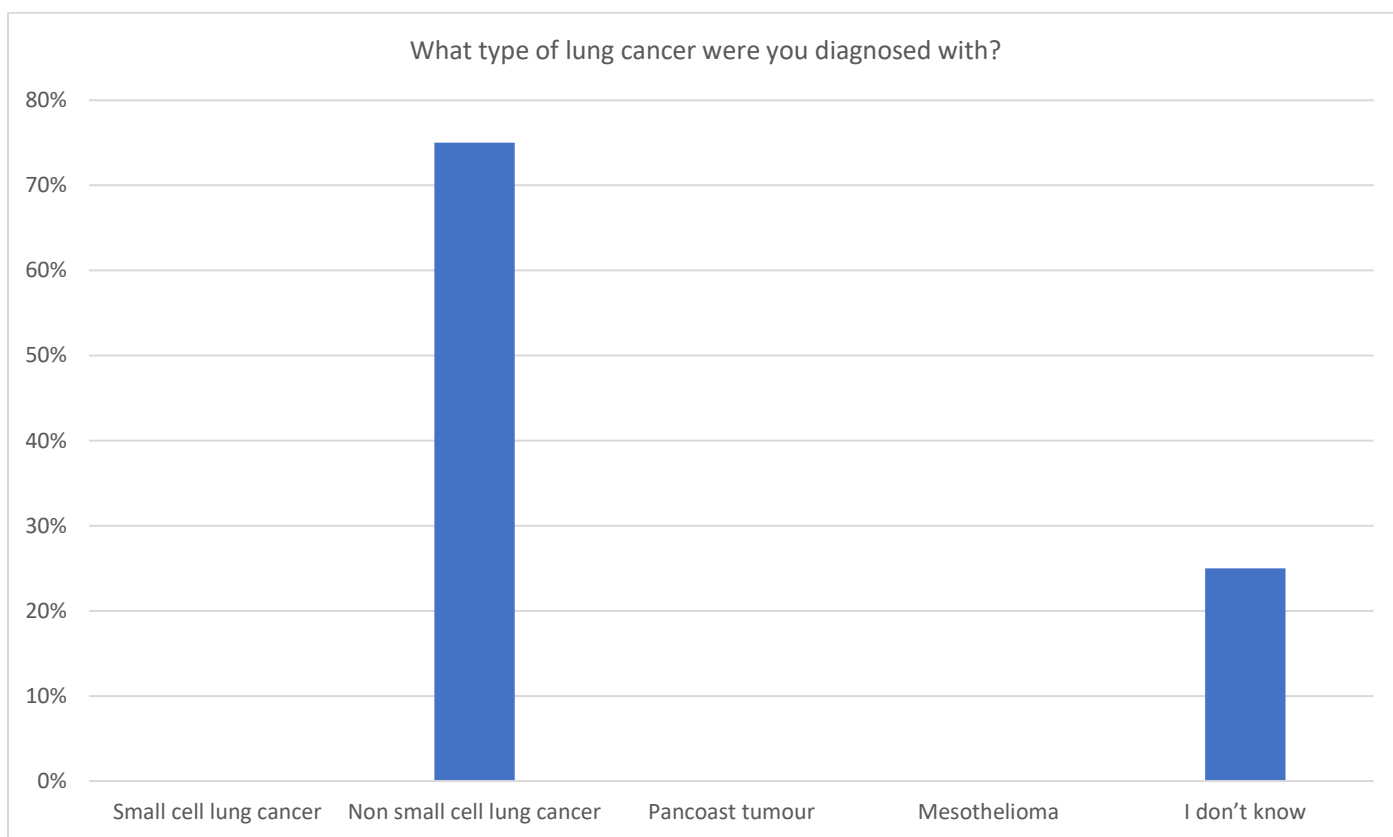
Diagnosis

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, 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 The largest proportion of respondents (three in four, 75%) stated they had non-small cell lung cancer. No respondents said they had small cell lung cancer, a pancoast tumour or mesothelioma. One respondent skipped this question.

Figure 2: Type of lung cancer among respondents



One respondent said they do not know which type of lung cancer they had or have; when asked if they would want to know, they said they did not.

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 to see that most respondents know their type of lung cancer, but the survey indicates that there are some who do not know their tumour type.

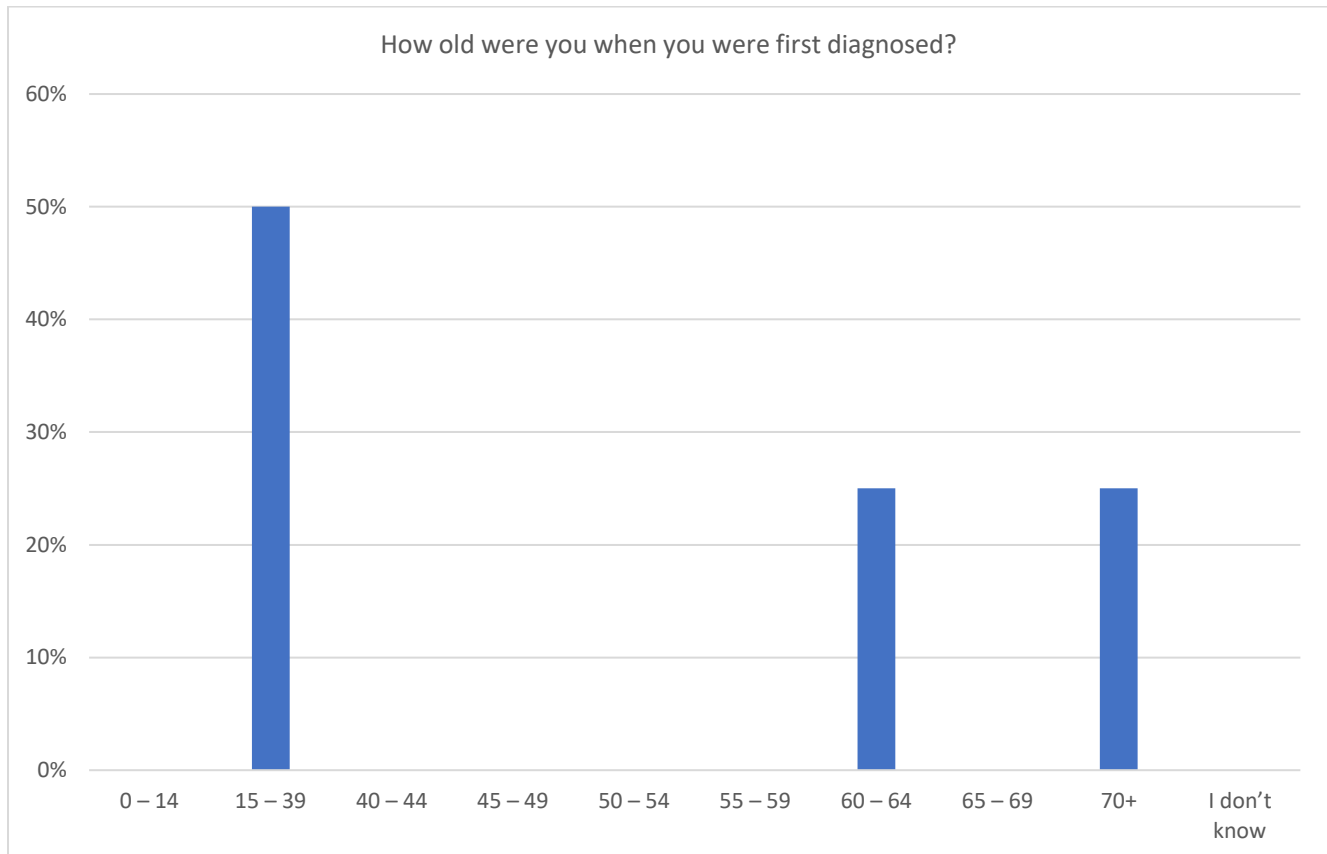
Further survey work could be conducted to determine whether the experience of the respondents reflects that of the wider lung cancer patient population in Africa.

Age at diagnosis

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

In Africa, two respondents said they were diagnosed at age 15-39 (50%). One patient was diagnosed at age 60-64 (25%) and another at age 70 or over (25%). One respondent skipped this question.

Figure 3: Age profile of respondents

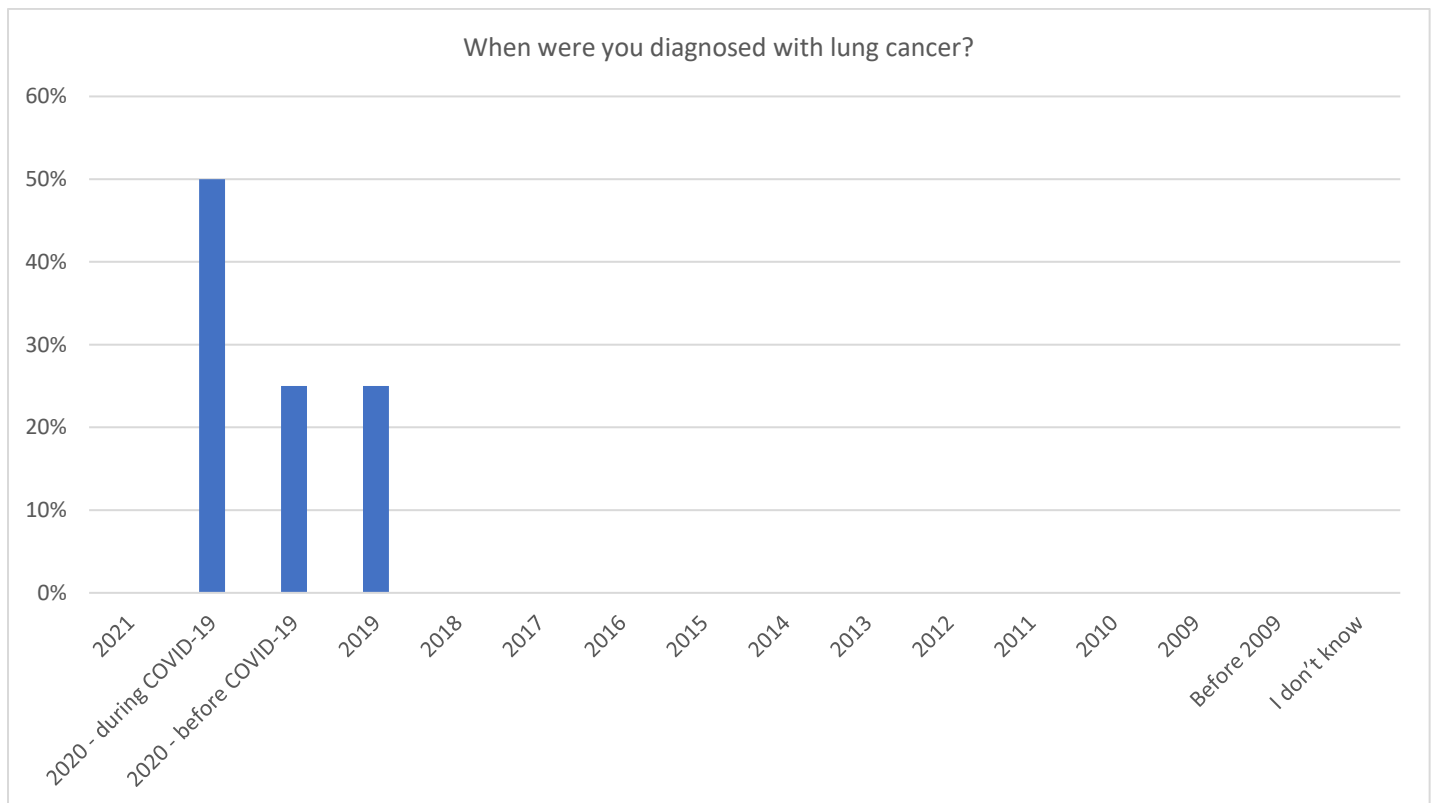


Year of diagnosis

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 One respondent skipped this question.

Three respondents (75%) were diagnosed in 2020; one respondent was diagnosed before the COVID-19 pandemic and two during the pandemic. One respondent was diagnosed in 2019. Figure 4 shows the survey responses.

Figure 4: Year of diagnosis amongst respondents



Delay in diagnosis

Earlier diagnosis is a key part of improving survival rates for people diagnosed with lung cancer. We asked people if they felt that there was an unnecessary delay in getting their diagnosis. We asked this question because we wanted 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. One respondent skipped this question.

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

Answer Choices	Percentage	Number
Yes, it took me too long to see someone to get my symptoms checked out	25%	1
Yes, it took too long to see someone to test if I had lung cancer	25%	1
Yes, it took too long to get my test results	25%	1
No, I am satisfied with the time it took to get my diagnosis	50%	2
I'm not sure	0%	0

Two of the respondents (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 respondent 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.

Nevertheless, these results show a level of concern among some respondents as to how long it took to get their diagnosis. Given the small sample size, future analysis should be undertaken to understand if these statistics are representative of the wider population and to what extent they may change as services recover from COVID-19.

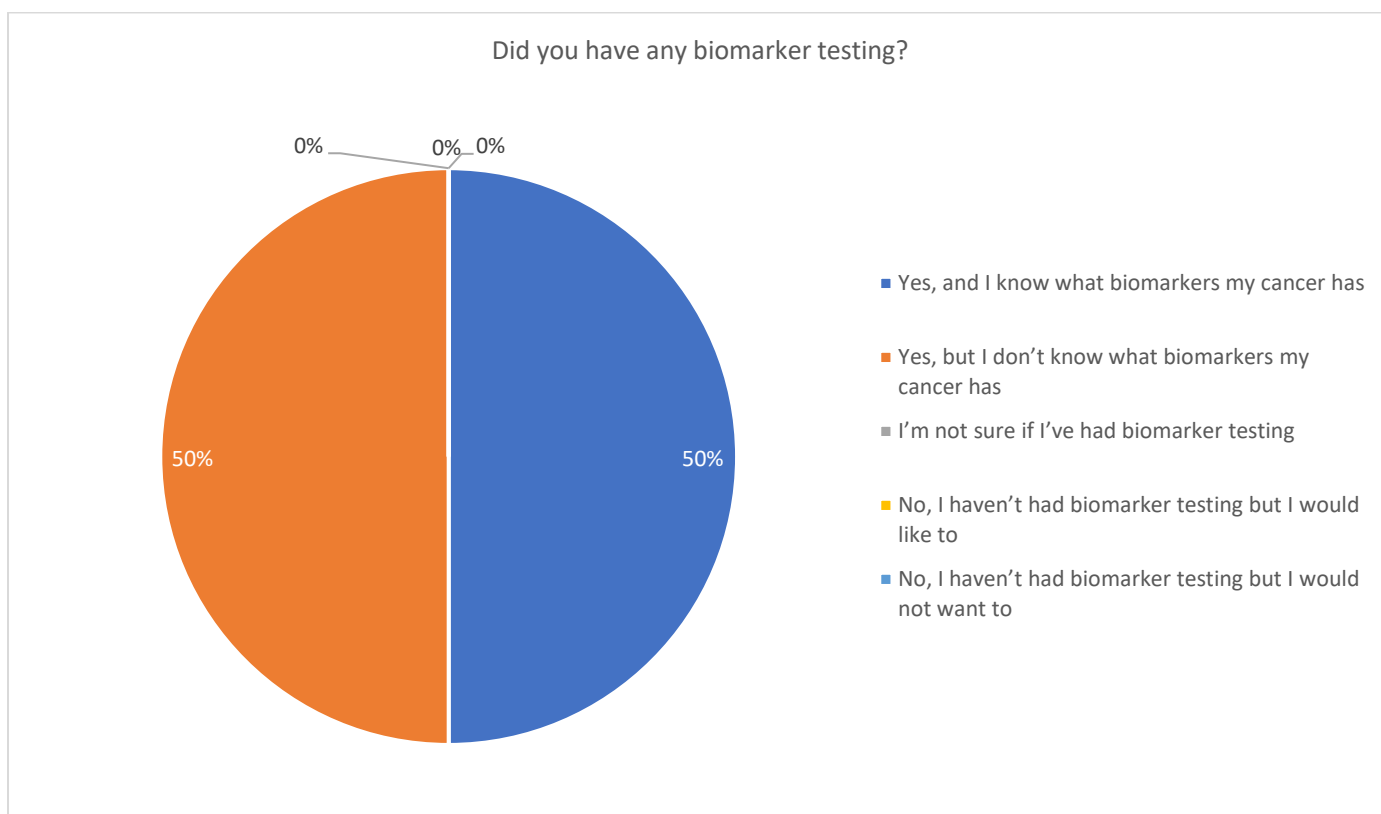
Biomarker testing

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.

The results show that the four respondents (100%) knew they had biomarker testing but, amongst those, two did not know what biomarkers their cancer has.

Figure 6: Did you have any biomarker testing?



Interventions

Respondent profile

Respondents were asked where they were in their cancer journey and could choose from five options. Three respondents said they were currently receiving treatment (75%), with one respondent saying they had finished treatment. One respondent skipped this question.

Figure 7: Which of the following best describes you?

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	75%	3
I have finished treatment	25%	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 9). Respondents were also given the options to select 'other' and specify which other forms of treatment they had received. One respondent skipped this question.

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

- **Surgery:** no respondents had surgery. 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:** all four respondents said they had received radiotherapy
- **Chemotherapy:** two of the respondents had received chemotherapy
- **Immunotherapy:** only one respondent said they had received immunotherapy
- **Targeted therapies:** two of the respondents said they had received targeted therapies
- **Symptom management:** three of the respondents said they had received treatment to help with symptom management
- **No treatment:** no respondents said they had not received any treatment because it was not available to them
- **Other treatments:** no respondents said they had received additional forms of treatment

Figure 8: Types of treatment received

	Surgery		Radiotherapy		Chemotherapy		Immunotherapy	
	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number
2021 survey	0%	0	100%	4	50%	2	25%	1

	Targeted therapies		Symptom management	
	Percentage	Number	Percentage	Number
2021 survey	50%	2	75%	3

Figure 9: Respondents who did not receive any treatment

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)	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. We also had 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.

Out of five respondents, one person skipped this question. The results are summarised below:

- **Psychosocial support / counselling:** two of the respondents said they had received psychosocial support and or counselling
- **Physical therapy / pulmonary rehabilitation:** no respondents said they had received physical therapy
- **Occupational therapy:** no respondents said they had received occupational therapy
- **Dietary advice:** no respondents said they received dietary advice
- **Lifestyle advice:** one respondent said they had received lifestyle advice
- **Financial advice:** no respondents said they had received financial advice
- **Return to work advice:** no respondents said they had received advice on going back to work
- **Smoking cessation:** two of the respondents said they had received support on how to stop smoking
- **Support group:** two respondents said they had received support from peer and/or support group
- **No support:** only one respondent had not received any other support as COVID-19 had delayed it (figure 10b)
- **Other type of support:** no participants shared with us other forms of support they received

Figure 10a: Types of support respondents received

	Psychosocial support / counselling		Physical therapy / pulmonary rehabilitation		Occupational therapy		Dietary advice	
	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number
2021 survey	50%	2	0%	0	0%	0	0%	0

	Lifestyle advice		Financial advice		Advice on going back to work		Other	
	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number
2021 survey	25%	1	0%	0	0%	0	0%	0

	Support Group		Smoking cessation	
	Percentage	Number	Percentage	Number
2021 survey	50%	2	50%	2

Figure 10b: Responses from respondents who did not receive other forms of support

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	0%	0
I have not received any other support because COVID-19 has delayed it	25%	1
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:

- Which services were offered and if some people chose not to take them up
- How useful people found the services they received, and if they would recommend the service to others
- If people who did not received 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 South Africa feel involved in making decisions about their treatment and care.

Respondents could choose from 'Yes, I've been fully involved', 'Yes, I've been involved most of the time', 'Yes, I've been involved sometimes', 'No', 'No, but I didn't want to be involved' and 'No, but my caregiver was involved'.

Four of five respondents answered this question. Three respondents (75%) felt they were fully involved in decision-making, and one (25%) felt they were involved most of the time.

Figure 11a: Proportion of patients feeling involved in decisions on their treatment and care

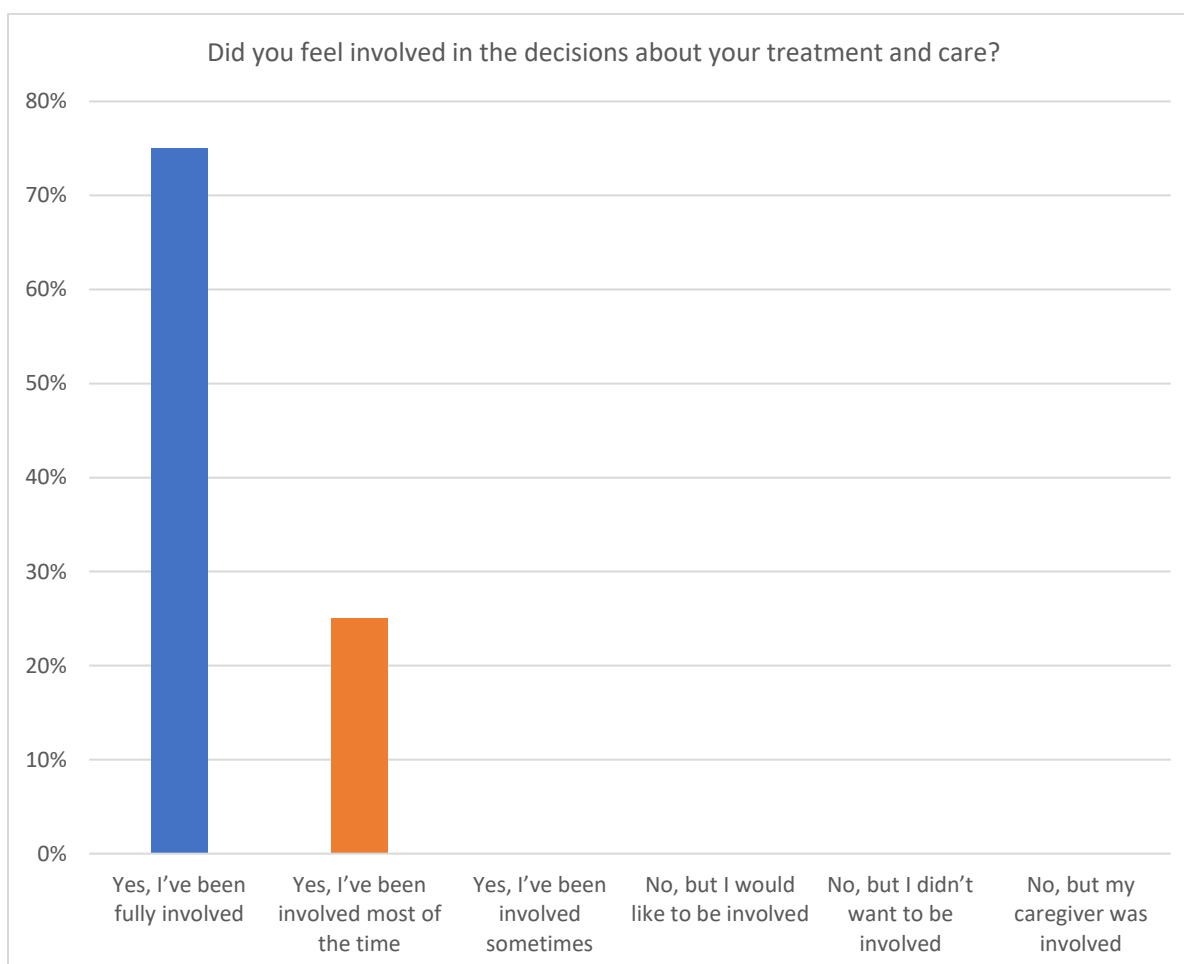


Figure 11b: Number and proportion of respondents feeling involved in decisions on their treatment and care

Answer Choices	Percentage	Number
Yes, I've been fully involved	75%	3
Yes, I've been involved most of the time	25%	1
Yes, I've been involved sometimes	0%	0
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	0%	0

Future studies or surveys could explore:

- Whether this figure reflects the experience of the wider lung cancer patient population in South Africa
- What healthcare professionals can do to ensure people feel more involved 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.

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.

Out of five respondents, one respondent skipped this question. Three respondents said they were always treated with dignity and respect (75%). One respondent said they were 'mostly' treated with dignity and respect.

Figure 12a: Proportion of patients feeling treated with dignity and respect by their treatment team

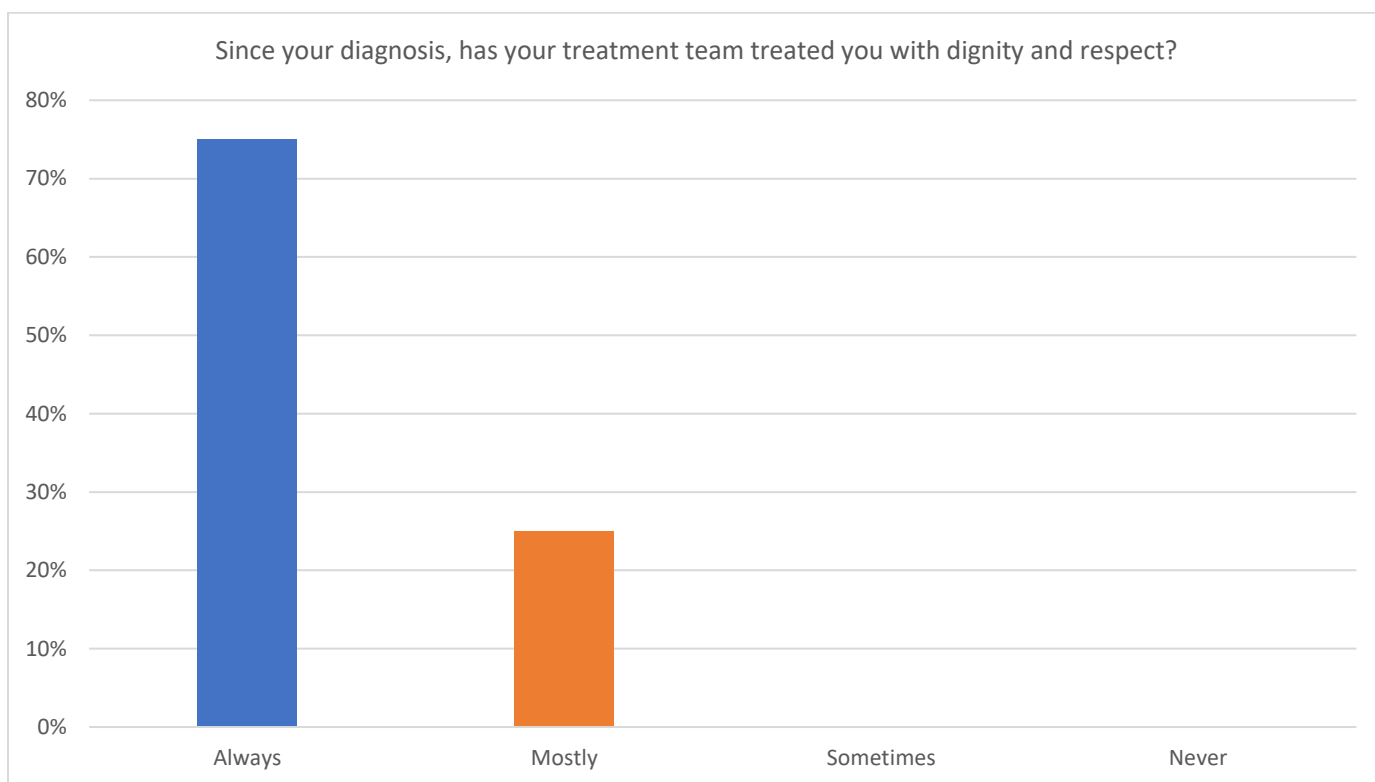


Figure 12b: Data on the number and percentage of respondents feeling treated with dignity and respect by their treatment team

	Always		Mostly		Sometimes		Never	
	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number
2021 survey	75%	3	25%	1	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
- If some people who did not respond to the survey 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 example.

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.

All five respondents answered this question. Three of the respondents described themselves as 'surviving with lung cancer' with only one respondent thinking of themselves as a 'patient'.

Two of the respondents described themselves as 'living with lung cancer', and two as 'battling lung cancer'. Two respondents described themselves as 'fighter' and one as a 'warrior'.

Figure 13 (overleaf) shows all the responses. There was also the option to pick 'other' for people to include their own description, however, no respondents responded to this.

Figure 13: How respondents described themselves

	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	40%	2	20%	1	60%	3	20%	1	20%	1

	Survivor		Advocate		Thrifer		Other	
	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number
2021 survey	20%	1	20%	1	0%	0	0%	0

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

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 ‘fighter’

Emotional and physical wellbeing

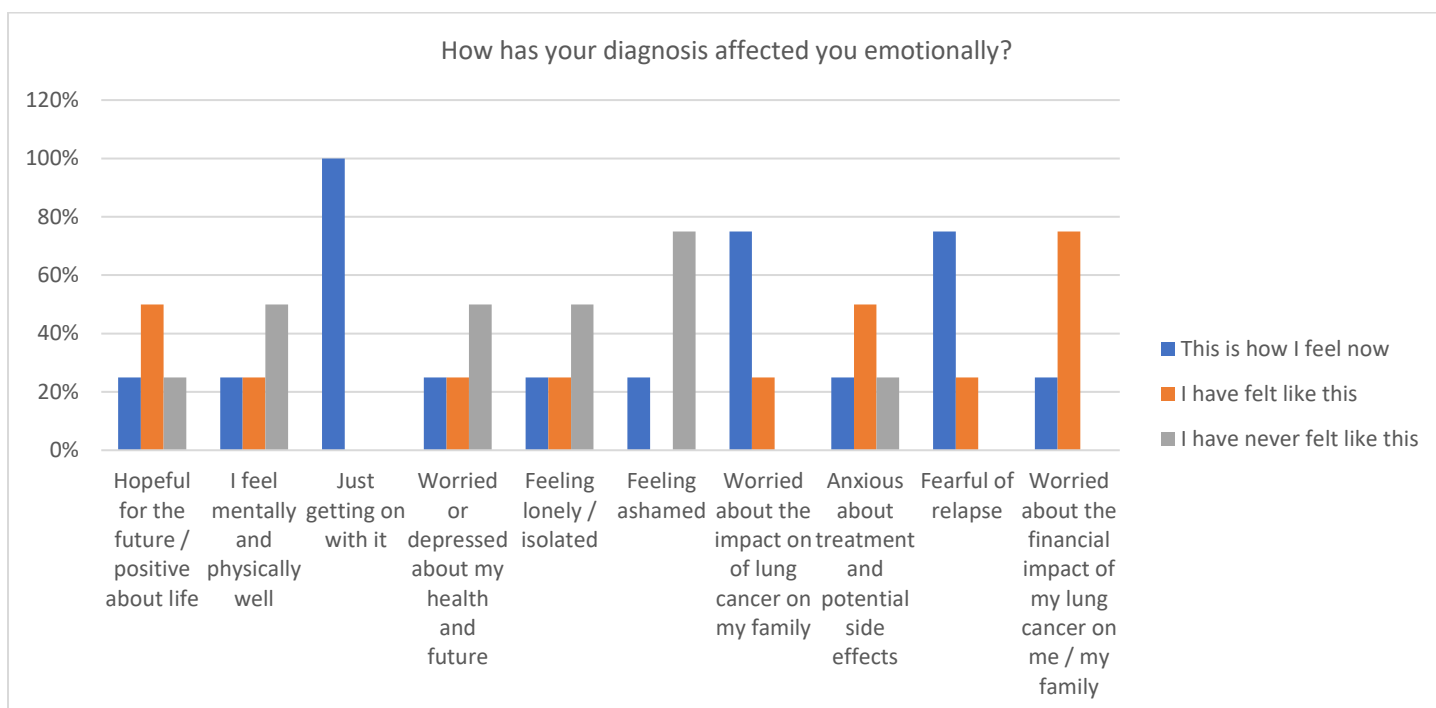
A cancer diagnosis can considerably affect the emotional health of a patient and that of their families and caregivers. Common feelings include distress, depression, anxiety and may involve loss of self-esteem and feelings of isolation. A 2019 study found that about one third of patients newly diagnosed 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.

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.

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. One person skipped this question. Respondents could also choose the 'other' option and indicate other forms of support they have received, however, no respondents left further comments. Figure 14 summarises key findings.

Figure 14: How diagnosis affected respondents emotionally



The results show that respondents experience a wide range of emotions. Despite some of the stigma associated with lung cancer, three of the respondents said they never felt ashamed, but one respondent feels this way now.

Two respondents said they are feeling or have felt lonely or isolated, but one respondent was feeling lonely or isolated and one had previously felt this way.

All four respondents said they were just getting on with their cancer. One respondent said they feel hopeful or positive about life, but another respondent had never felt hopeful and two used to feel this way. One respondent was currently feeling worried or depressed about their health and future, and three respondents are fearful of relapse.

When it came to their mental and physical wellbeing, one respondent said they feel well at the moment, while two said they have felt well, and one never felt well.

One respondent was anxious about treatment while two have felt this way. One respondent was worried about the impact of their condition on their family, while the other three respondents have felt this way.

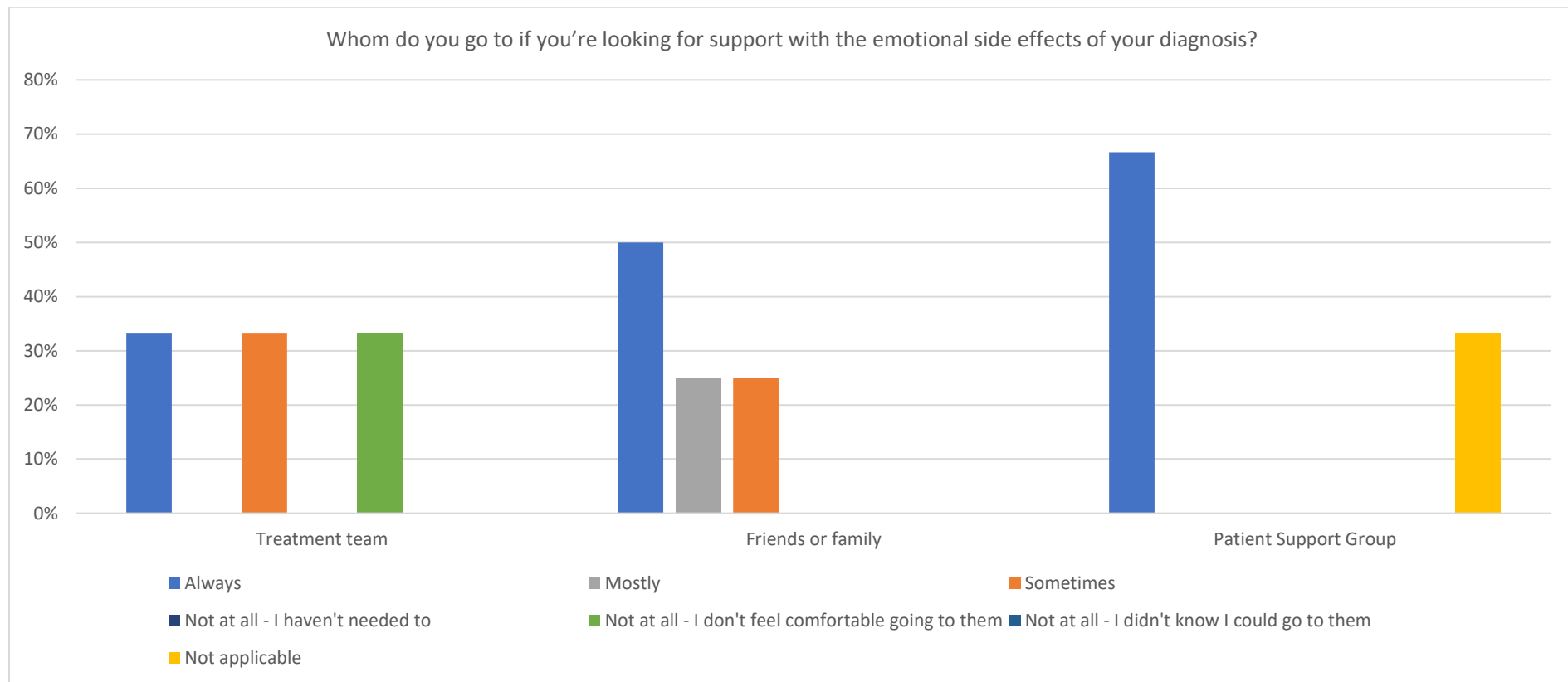
Further studies could explore:

- 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

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, including 'other' to which they could add information about where they would turn for help. Out of the five respondents, one person skipped this question. No respondents selected the 'other' option.

Figure 15: Where do people turn for support with the emotional impact of their diagnosis?



One respondent said they would always ask their treatment team for emotional support, with another saying they would sometimes ask their treatment team. One respondent said they wouldn't feel comfortable going to their treatment team for emotional support.

All four respondents said they would turn to family or friends for support; two would always turn to family and friends, one said 'mostly', and one said 'sometimes'.

Three of the four respondents said they would always feel comfortable with asking patient groups for support, while one said this was not applicable for them.

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 someone might not feel comfortable to do so
- Should more support be offered to family members given the fact that they are often an 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?

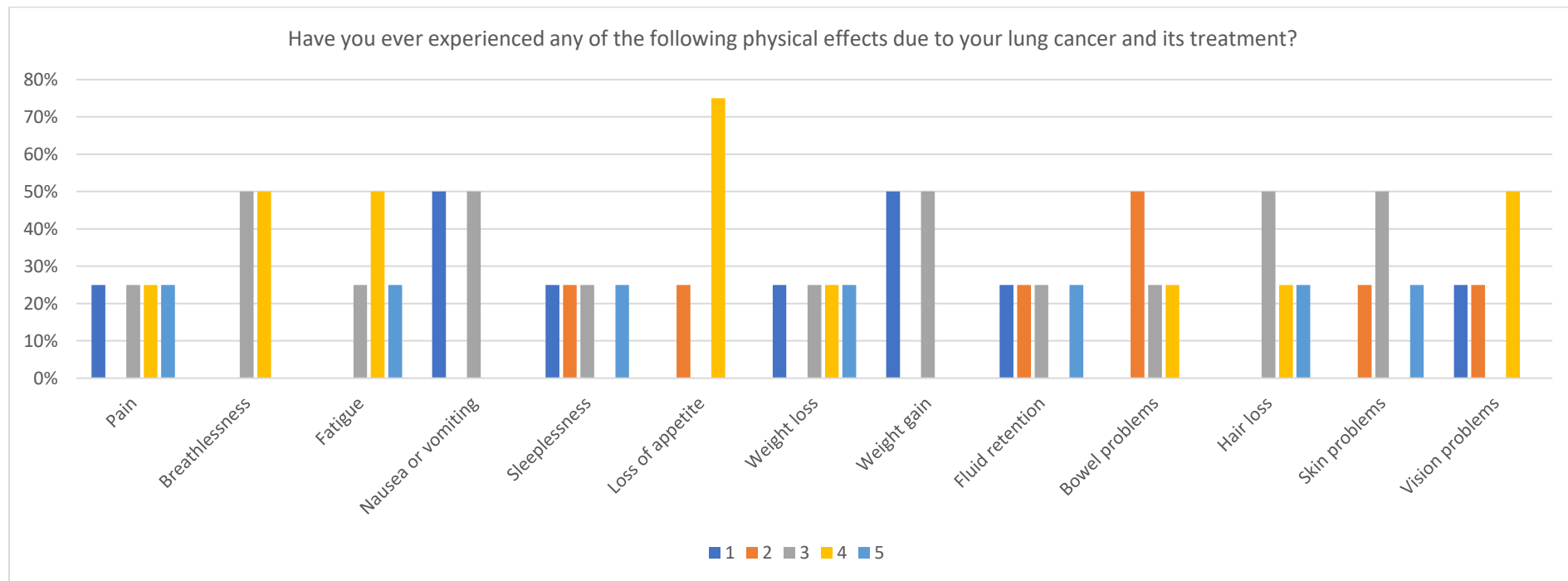
Respondents were asked about the physical effects they experienced because of their cancer and its treatment. We gave respondents 13 options and, for each option, people could select a number from 1 to 5, where 1 means this has not affected them and 5 means this has been a very serious concern. One person skipped this question. No respondents picked 'other' to describe other forms of physical effects they experienced. Figures 16a and 16b shows a breakdown of all the responses.

Figure 16a: 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

	1	2	3	4	5	Total	Weighted Average
Answer Choices	Percentage	Percentage	Percentage	Percentage	Percentage	Number	Number
Pain	25%	0%	25%	25%	25%	4	3.25
Breathlessness	0%	0%	50%	50%	0%	4	3.5
Fatigue	0%	0%	25%	50%	25%	4	4
Nausea or vomiting	50%	0%	50%	0%	0%	4	2
Sleeplessness	25%	25%	25%	0%	25%	4	2.75
Loss of appetite	0%	25%	0%	75%	0%	4	3.5
Weight loss	25%	0%	25%	25%	25%	4	3.25
Weight gain	50%	0%	50%	0%	0%	4	2
Fluid retention	25%	25%	25%	0%	25%	4	2.75
Bowel problems	0%	50%	25%	25%	0%	4	2.75
Hair loss	0%	0%	50%	25%	25%	4	3.75
Skin problems	0%	25%	50%	0%	25%	4	3.25
Vision problems	25%	25%	0%	50%	0%	4	2.75

The weighted averages in Figure 16a 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 (4) was the most serious issue for respondents, followed by hair loss (3.75), loss of appetite (3.5), and breathlessness (3.5).

Figure 16b: 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?



One respondent gave a 5 when describing the impact of fatigue, and two scored a 4 meaning that fatigue has been a very serious concern for them. One gave a 5 to describe the impact of hair loss. In terms of loss of appetite, three scored a 4. Two scored breathlessness at a 4.

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

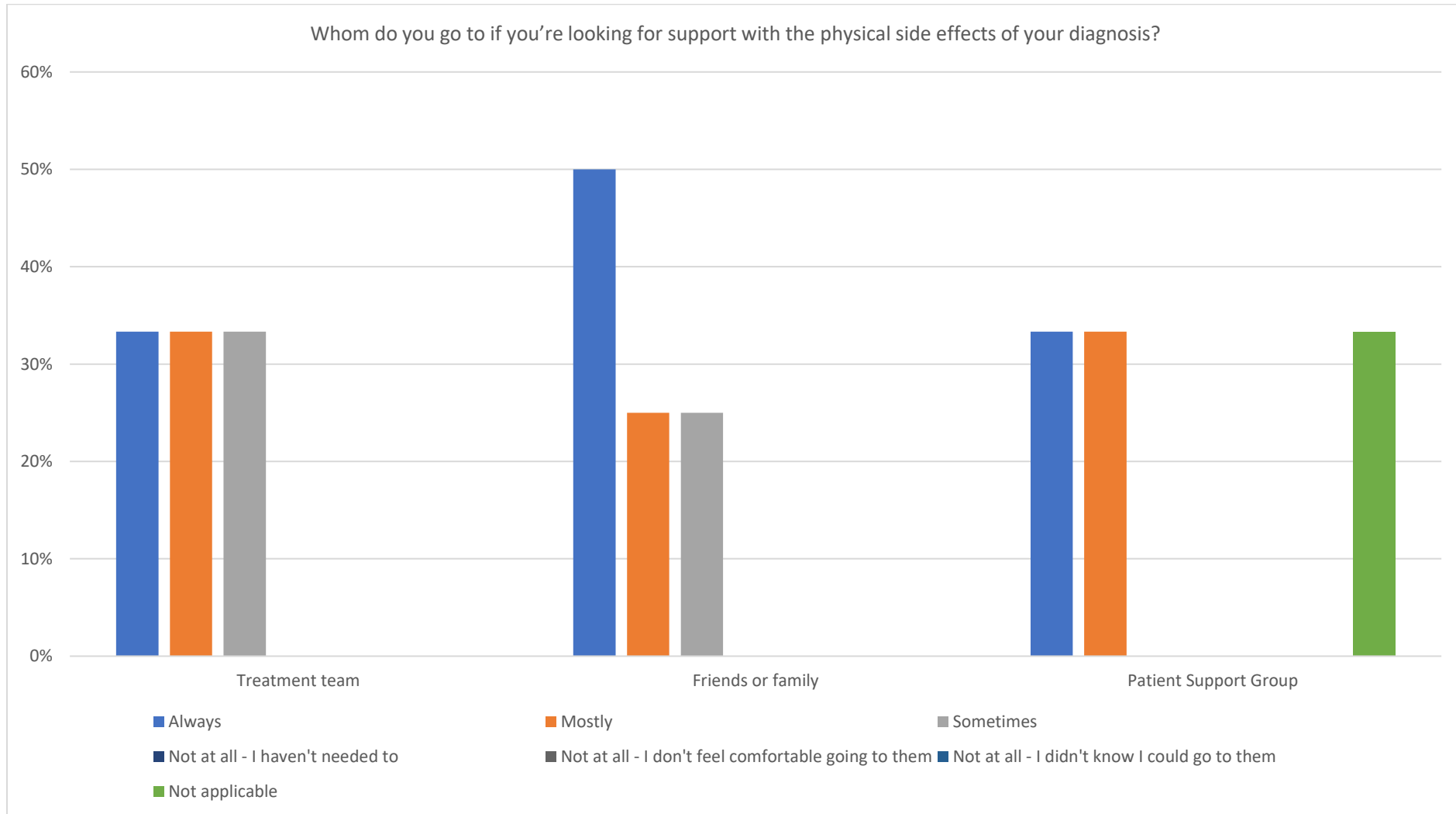
Respondents were asked whom they go to when they are looking for support with the physical effects of their diagnosis. People could choose from their treatment team, family and friends, patient support group or 'other'. In addition, patients could indicate how often they reached out to those people. One person skipped this question. Figure 17 (overleaf) is a breakdown of all the responses.

When it came to asking for support with the physical impact of their diagnosis, the highest proportion of respondents said they would go to their family and friends. Two respondents said they always contacted their family or friends, one said 'mostly' and one said 'sometimes'.

One respondent said they always contacted their treatment team with the physical impact of their diagnosis, one said 'mostly' and one said 'sometimes'.

One respondent said they always contacted patient support groups, and one said they 'mostly' contacted support groups, with another respondent saying this was not applicable for them.

Figure 17: Whom do you go to if you're looking for support with the physical effects of your diagnosis?



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 18: Which of the following describes your experience during COVID-19? (Tick all that apply)

Answer Choices	Percentage	Number
I found it easier to contact my treatment team	0%	0
There has been no difference in how easy it has been to contact my treatment team	75%	3
I found it more difficult to speak to my treatment team	25%	1
I have held back in contacting my treatment team because they are so busy	0%	0
My treatment has continued as normal	50%	2
My treatment has been delayed / cancelled	0%	0
I don't know if my treatment has been affected	0%	0
I have carried on attending appointments during the pandemic	75%	3
I have been reluctant to attend appointments for fear of infection	25%	1
I have missed appointments for fear of infection	0%	0
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

No respondents said it had been easier to contact their treatment team during the pandemic, but three of the four respondents to the question said there had been no difference. One person found it more difficult.

Three respondents said they have carried on attending their appointments in person during the pandemic. One respondent said they were reluctant to attend appointments because they feared being infected. None of the respondents said their face-to-face appointments have been swapped for telephone or video calls (a later section of this report looks in more detail at the impact of this).

Two respondents said their treatment has carried out as normal, with no respondents saying they experienced delays to 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. One person skipped this question.

Figure 19a: 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

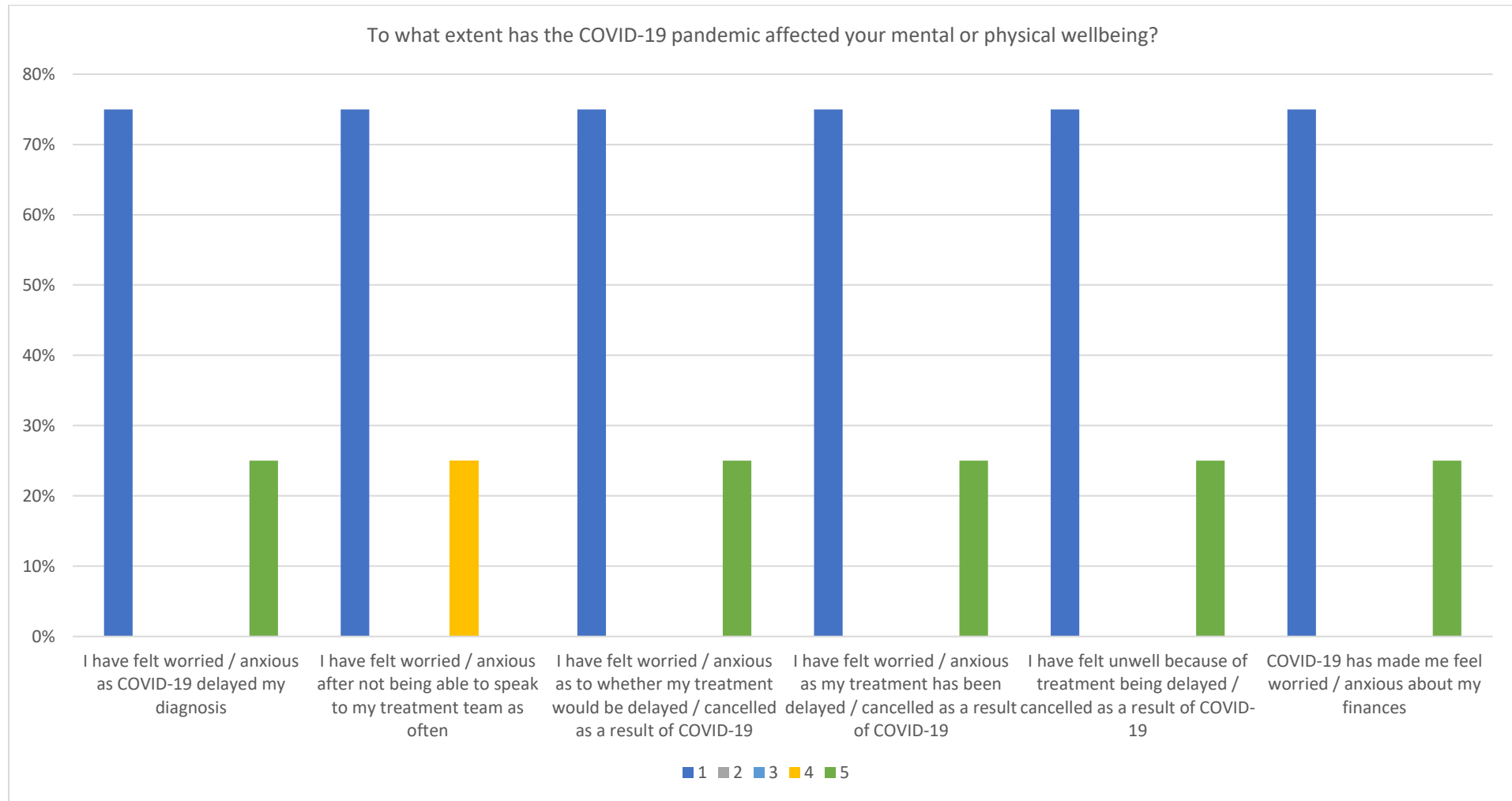


Figure 19b: To what extent has the COVID-19 pandemic affected your mental or physical wellbeing? Please choose an option from 1 – 5, where 1 means this has not affected me and 5 means this has been a very serious concern

Answer Choices	1	2	3	4	5
I have felt worried / anxious as COVID-19 delayed my diagnosis	75%	0%	0%	0%	25%
I have felt worried / anxious after not being able to speak to my treatment team as often	75%	0%	0%	25%	0%
I have felt worried / anxious as to whether my treatment would be delayed / cancelled as a result of COVID-19	75%	0%	0%	0%	25%
I have felt worried / anxious as my treatment has been delayed / cancelled as a result of COVID-19	75%	0%	0%	0%	25%
I have felt unwell because of treatment being delayed / cancelled as a result of COVID-19	75%	0%	0%	0%	25%
COVID-19 has made me feel worried / anxious about my finances	75%	0%	0%	0%	25%

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 were respondents who are being affected by the pandemic:

- On feeling anxious about delays to diagnosis as a result of COVID-19, one respondent scored a 5
- On worries caused because treatment has been delayed or cancelled as a result of COVID-19, one respondent scored a 5
- On worries about finances as a result of the pandemic, one respondent scored a 5
- On whether their treatment would be delayed or cancelled because of COVID-19, one respondent scored a 5

One respondent said they felt anxious after not being able to speak with their treatment team as often (scored a 4).

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, in some countries, new approaches including video and telephone consultations started to be introduced or rolled out more widely in an effort to maintain support for patients when face-to-face options were not as easily available. New technologies and telehealth are now being used as tool in lung cancer diagnosis in some places 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 20: 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)

Answer Choices	Percentage	Number
Telephone	0%	0
Video	0%	0
In person	75%	3
No, I have not been in contact with my treatment team at all, but I wanted to	0%	0
No, I have not been in contact with my treatment team at all, but I haven't needed / wanted to	25%	1

Three of the four respondents to this question continued to see their treatment team in person. No respondents have had conversations with their treatment team via telephone or by video consultation.

One respondent said they have not been in contact with their treatment team at all but haven't needed 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. No respondents from South Africa noted that they weren't able to speak to their treatment team but wanted to, and so were not eligible to answer this question.

Figure 21: Why were you not able to speak to your treatment team?

Answer Choices	Percentage	Number
In person is the only option and I am worried about infection	0%	0
In person is the only option and I can't travel	0%	0
A video call has been offered but I don't have a computer / smartphone	0%	0
A video call has been offered but I don't know how	0%	0
A phone call has been offered but I can't hear well on a phone call	0%	0
A phone call has been offered but I don't want to do a phone call	0%	0

Other (please specify)

0%

0

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. No respondents from South Africa answered this question since no one had used these methods.

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

Answer Choices	Percentage	Number
I found it quicker	0%	0
I found it helpful as I don't have to travel to hospital as much	0%	0
I prefer face-to-face appointments	0%	0
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

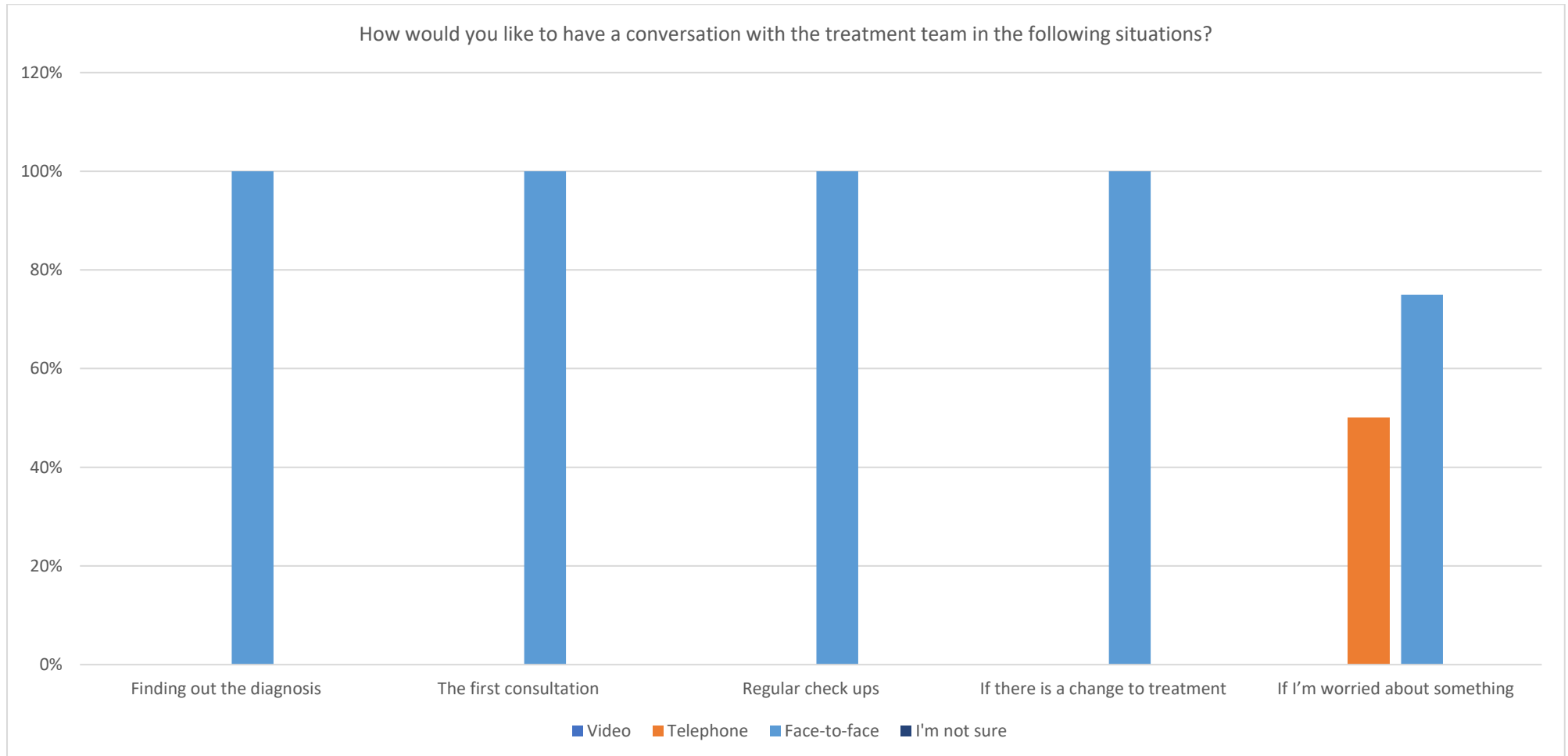
When dealing with different situations, what do people think is the best way to speak with their treatment team?

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.

Respondents prefer face-to-face appointments in all situations. All respondents said that the best way to find out by a diagnosis was in person. In addition, all respondents preferred to have the first consultation, regular checks, and conversations about changes to treatment face-to-face. Whilst most respondents (three of the four who answered the question) preferred to talk in person if they are worried about something, two said they would also be happy to have a telephone consultation.

In future studies, it would be useful to assess whether this is representative of the wider population in South Africa. As telehealth is increasingly used, the results suggest that there may be some use in seeking out patients' feedback to determine whether these approaches are being used and, if so, whether they work well 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)



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 one 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)

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	50%	0%	50%	0%
Patient support organisations	50%	25%	25%	0%
Other people that have been diagnosed with lung cancer	50%	25%	25%	0%
Friends or family	75%	0%	25%	0%
The internet	50%	25%	25%	0%
Social media	75%	0%	25%	0%
Pharmaceutical company	0%	25%	75%	0%

The results show that three of the respondents have already sought information from family and friends or social media, with the other not knowing that they could.

Two respondents said they have already reached out to their treatment team, but two didn't know that they could. Two respondents said they had already contacted patient support groups and other people diagnosed with lung cancer for information; one knew these sources were there but hadn't done this yet, while one didn't know these were an option.

Three of the respondents said they didn't know they could ask pharmaceutical companies for information but would be happy to have information from this source.

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)

Answer Choices	Percentage	Number
A conversation in person	75%	3
A conversation over the phone	50%	2
A conversation on video call	50%	2
Something I can read e.g. a leaflet / booklet	50%	2
Something I can view online e.g. a website / social media	75%	3
Something I can listen to e.g. a podcast	50%	2
Something I can watch e.g. a video	75%	3

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 respondents said they would like in person conversations, with telephone or video scoring lower (two respondents). 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. Three respondents said they would like something to view online and two said they would like to have something to read. Videos are popular with three of the respondents selecting that option. Two respondents would like podcasts.

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 member from South Africa is [Campaign for Cancer](#).

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

ⁱ American Cancer Society, What is lung cancer? Types of lung cancer, accessed June 2021

ⁱⁱ 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

ⁱⁱⁱ Ohio State News, Depression affects one third of lung cancer patients, December 2019

^{iv} IASLC, Bringing Telehealth to the Front Lines of Lung Cancer Care in the COVID-19 Pandemic, August 2020