



GLOBAL LUNG CANCER
COALITION

COVID-19 PANDEMIC: THE IMPACT ON LUNG CANCER PATIENTS

Insights from Italy

2021 Patient Experience Survey

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Introduction

In 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. Italy 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 Italy**. 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 survey 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

105 people from Italy filled out our survey (fourth highest out of all countries).

Insights from the 2021 patient experience survey

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. 105 people from Italy filled out the survey. All respondents answered this question, with 71 people describing themselves as a patient and 34 as a carer.

Gender

Of the 105 respondents, 87 (84%) were women and 16 (15%) were men (Figure 1). One person identified as gender neutral.

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
84%	87	15%	16	1%	1	0%	0	0	0%

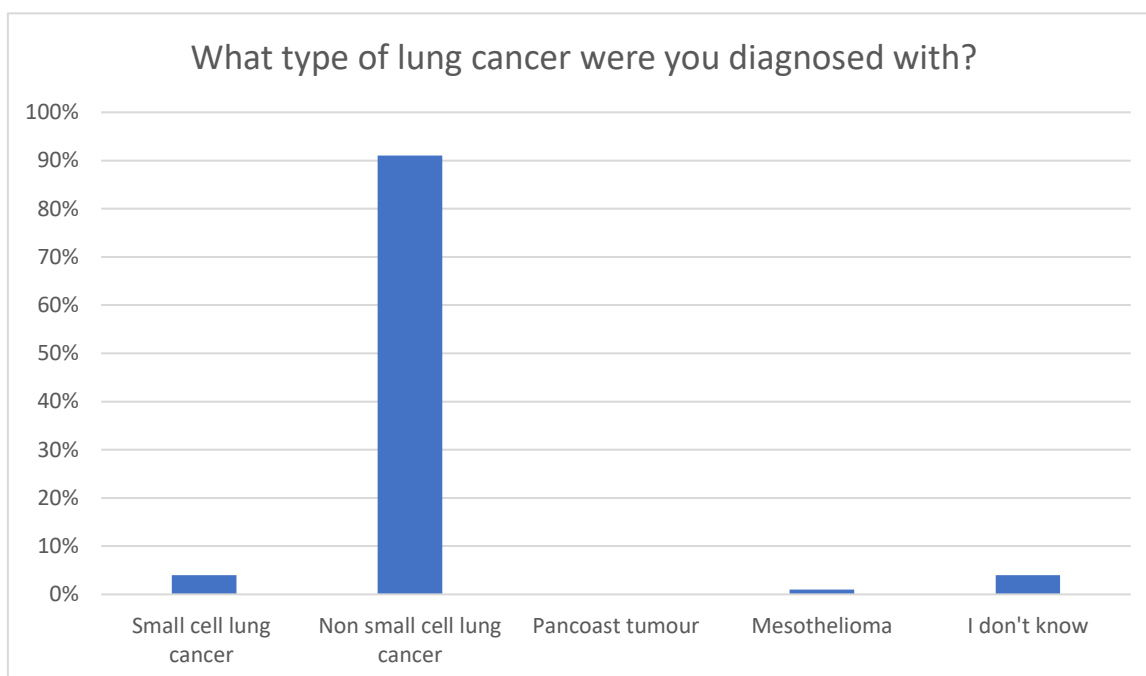
Diagnosis

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 (91%, 96 people) stated they had non-small cell lung cancer. Four respondents (4%) said they had small cell lung cancer, and one patient said they had mesothelioma.

Figure 2: Type of lung cancer among respondents



4% of respondents said they do not know which type of lung cancer they had or have. Of these, all 4 respondents said they did not know the type of cancer they had or have but 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, 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 but want to know their tumour type.

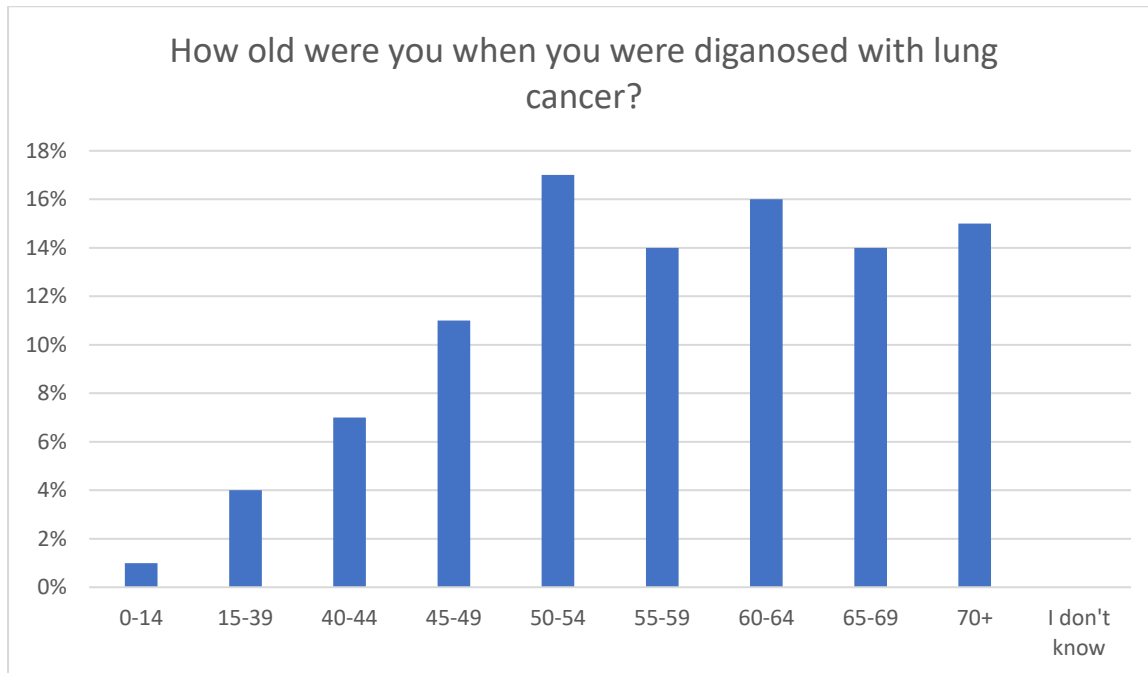
Further survey work could be conducted to determine whether the experience of the respondents reflects that of the wider lung cancer patient population in Italy.

Age at diagnosis

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

In Italy, the largest proportions of respondents said they were diagnosed at age 50-54 (17%) and 60-64 (16%) followed by 15% at age 70+.

Figure 3: Age profile of respondents

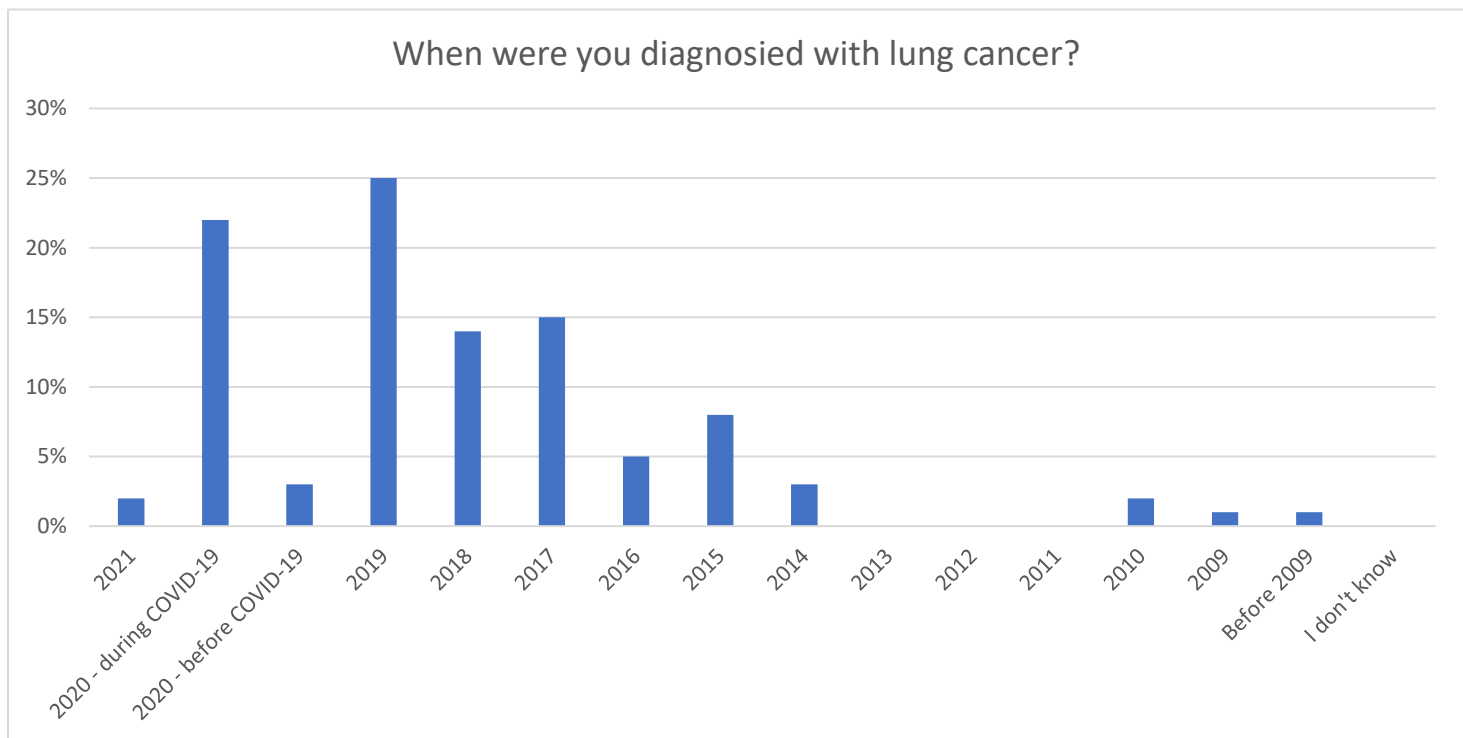


Year of diagnosis

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

Nearly a third of respondents (24%) were diagnosed since the start of the pandemic. 22% of respondents were diagnosed in 2020, after the pandemic had hit Italy, and a further 2% were diagnosed in 2021. The largest proportion of respondents were diagnosed in 2019 (25%). 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.

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	6%	6
Yes, it took too long to see someone to test if I had lung cancer	14%	15
Yes, it took too long to get my test results	16%	17
No, I am satisfied with the time it took to get my diagnosis	59%	62
I'm not sure	7%	7

Six in ten respondents from Italy (59%) said they were satisfied with the time it took to get their diagnosis.

However 6% of respondents said it took them too long to see someone to get their symptoms checked out. 14% felt it took too long to see someone to get tested to see if they had lung cancer and 16% felt they waited too long for test results.

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. Future analysis should help determine if these statistics are representative of the wider population and to what extent they may change as services recover from COVID-19.

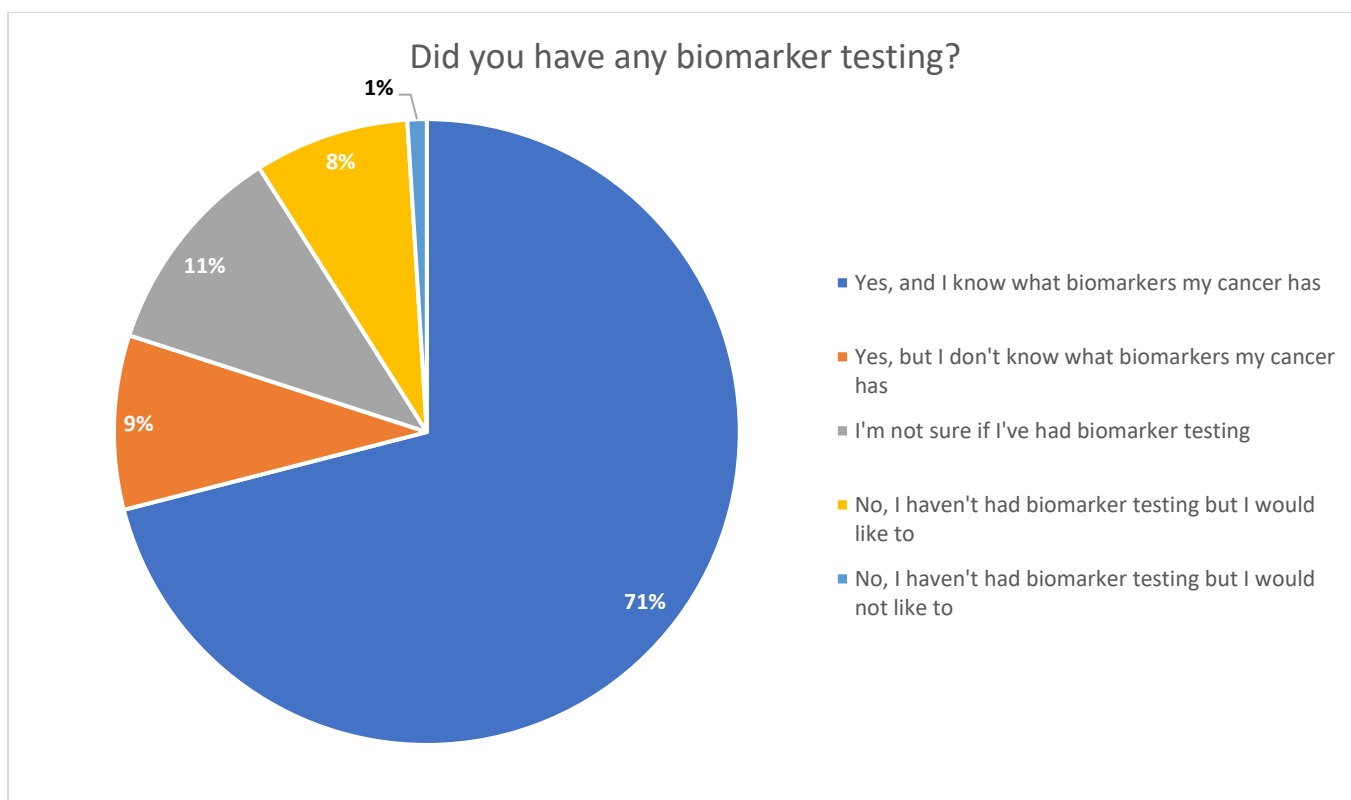
Biomarker testing

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. All 105 respondents answered this question.

The results show that around eight in ten respondents (80%) knew they had biomarker testing but, amongst those, 9% did not know what biomarkers their cancer has. 8% of respondents said they did not get a test but would like one. 11% of respondents were not sure if they'd had a biomarker test. Only one person said they would not want to have biomarker testing.

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. The majority said they were currently receiving treatment (75%), followed by 21% saying they had finished treatment. Four people had not yet started treatment. Encouragingly, no one said that treatment was not available to them. Four respondents 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	4%	4
I am currently having treatment	75%	76
I have finished treatment	21%	21
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. 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:** 30% of 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:** 36% of respondents said they had received radiotherapy
- **Chemotherapy:** 44% of respondents had received chemotherapy
- **Immunotherapy:** 32% said they had received immunotherapy
- **Targeted therapies:** 41% of respondents said they had received targeted therapies
- **Symptom management:** 22% of 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, but two respondents had just been diagnosed and were waiting for treatment to start
- **Other treatments:** five respondents told us they had received additional forms of treatment. Figure 9b includes some of their responses

Figure 8: Types of treatment received

	Surgery		Radiotherapy		Chemotherapy		Immunotherapy	
	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number
2021 survey	30%	31	36%	37	44%	46	32%	33

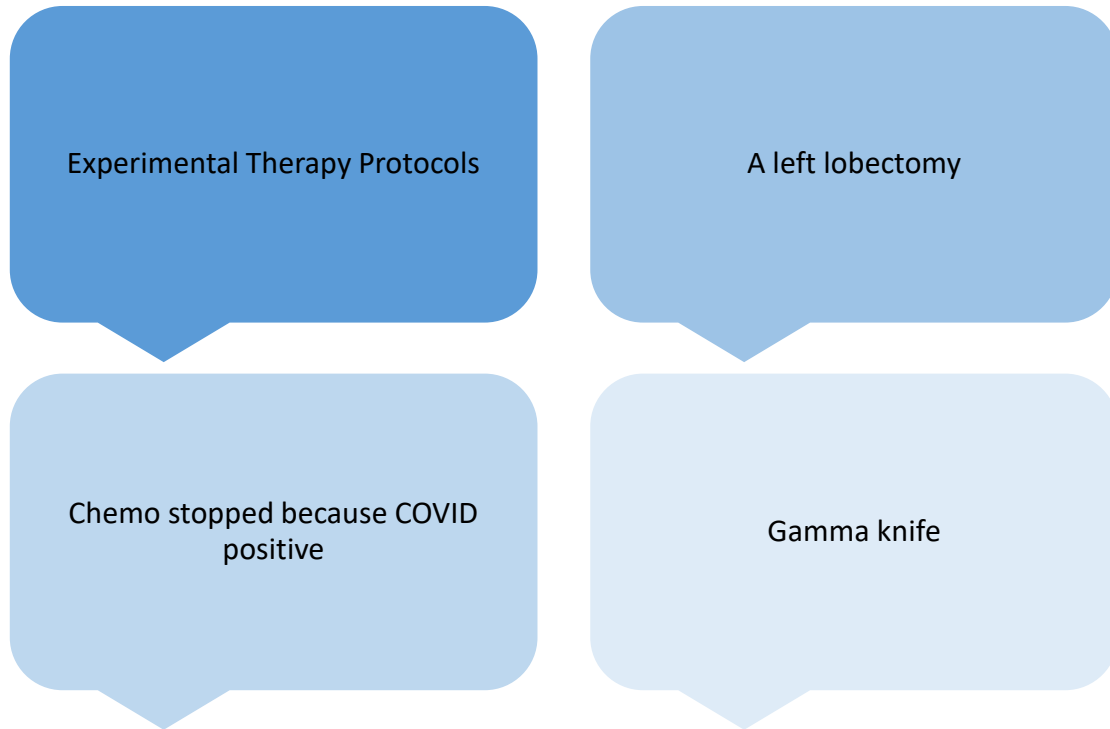
	Targeted therapies		Symptom management	
	Percentage	Number	Percentage	Number
2021 survey	41%	43	22%	23

Figure 9a: 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	2%	2
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)	5%	5

Figure 9b: Which types of treatment have you received?

The figure below shows some of the responses from participants (five respondents) who selected the 'other' option.



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 the 105 respondents, six people skipped this question. The results are summarised below:

- **Psychosocial support / counselling:** 19% of respondents said they had received psychosocial support and or counselling
- **Physical therapy / pulmonary rehabilitation:** 9% of respondents said they had received physical therapy
- **Occupational therapy:** no respondents said they had received occupational therapy
- **Dietary advice:** 20% of respondents received dietary advice
- **Lifestyle advice:** 18% said they had received lifestyle advice
- **Financial advice:** one respondent said they had received financial advice
- **Return to work advice:** one respondent said they had received advice on going back to work
- **Smoking cessation:** 4% of respondents said they had received support on how to stop smoking
- **Support group:** 4% said they had received support from peer and/or support group
- **No support:** 37 respondents said they had not had other support. Three were newly diagnosed, while a further three were waiting for other type of support to start. Four said other support had been delayed because of COVID-19. 13 respondents said they chose not to receive any other support, 14 said it was not available to them. Figure 10b contains further information on respondents' responses
- **Other type of support:** participants also shared with us other forms of support they received. 17 respondents said they had received other kinds of support for their condition (17%). In Figure 10c, we outline some of the responses

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	19%	19	9%	9	0%	0	20%	20

	Lifestyle advice		Financial advice		Advice on going back to work		Other	
	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number
2021 survey	18%	18	1%	1	1%	1	17%	17

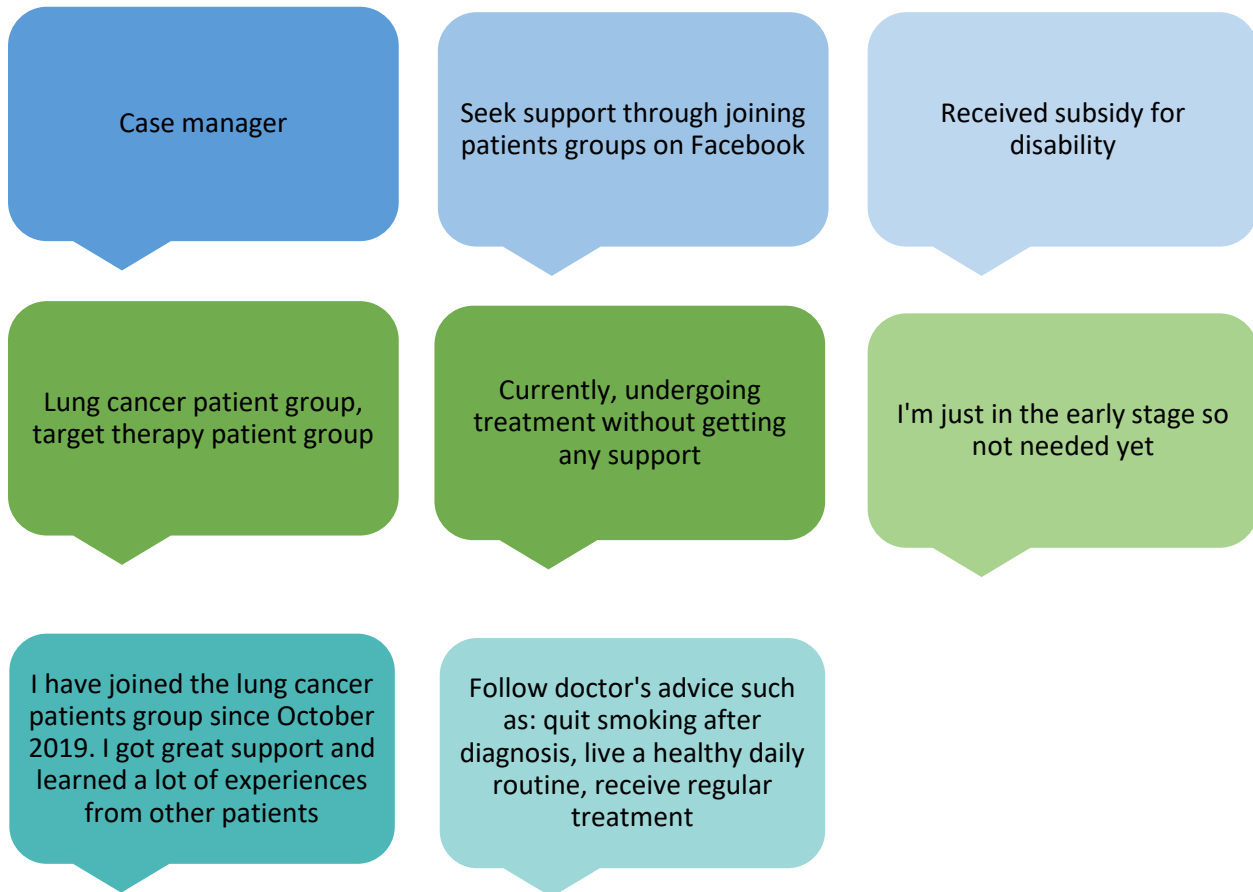
	Support Group		Smoking cessation	
	Percentage	Number	Percentage	Number
2021 survey	4%	4	4%	4

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	3%	3
I have not received any other support, but I am due to start	3%	3
I have not received any other support because COVID-19 has delayed it	4%	4
I have not received any other support because I chose not to	13%	13
I have not received any other support because it is not available to me	14%	14

Figure 10c: Have you had any other types of care and support?

The figure below shows some of the responses from participants (17 respondents) who selected the 'other' option.



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

- Which services were offered and why some people (13%) 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 receive additional support because of COVID-19 were offered it at a later point
- What other types of support people would have liked to have been offered

Respondent experiences

Feeling involved in decisions about their treatment and care

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

All respondents answered this question. 34% of respondents felt they were fully involved in decision-making, 26% felt they were involved most of the time, and a tenth of respondents (15%) felt they were only sometimes involved.

18 people (17%) felt they were not involved in decision-making but would have wanted to be. Four people (4%) said they didn't want to be involved in decision-making, and four respondents (4%) said their caregiver was involved in decision-making in their place. Figure 11b shows the breakdown of the data.

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

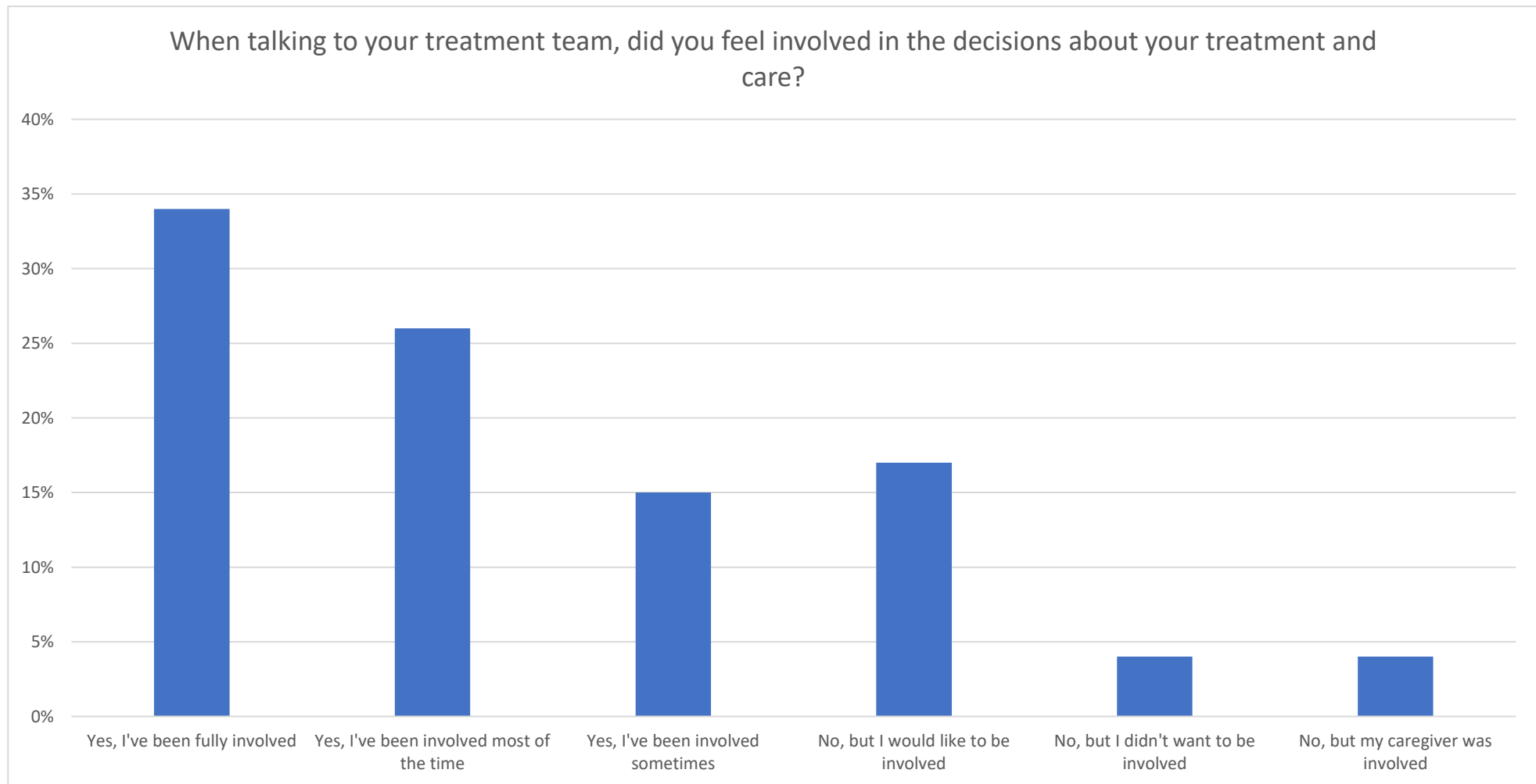


Figure 11b: Number and proportion of respondents feeling involved in decisions on their treatment and care

Answer Choices	Percentage	Number
Yes, I've been fully involved	34%	36
Yes, I've been involved most of the time	26%	27
Yes, I've been involved sometimes	15%	16
No, but I would like to be involved	17%	18
No, but I didn't want to be involved	4%	4
No, but my caregiver was involved	4%	4

Future studies or surveys could explore:

- Whether this figure reflects the experience of the wider lung cancer patient population in Italy
- Why respondents from Italy feel this way, and why some people were not involved or only involved sometimes when others felt fully or mostly involved
- Why some people do not want to be involved in decision-making, and if there are ways they could be better supported
- 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 105 respondents, one skipped this question. The majority of respondents said they were always treated with dignity and respect (68%). 14% of respondents said they were 'mostly' treated with dignity and respect, but 13% said they were only 'sometimes' treated with dignity and respect. Four respondents said that they were never treated with dignity and respect (4%) (Figure 12b).

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

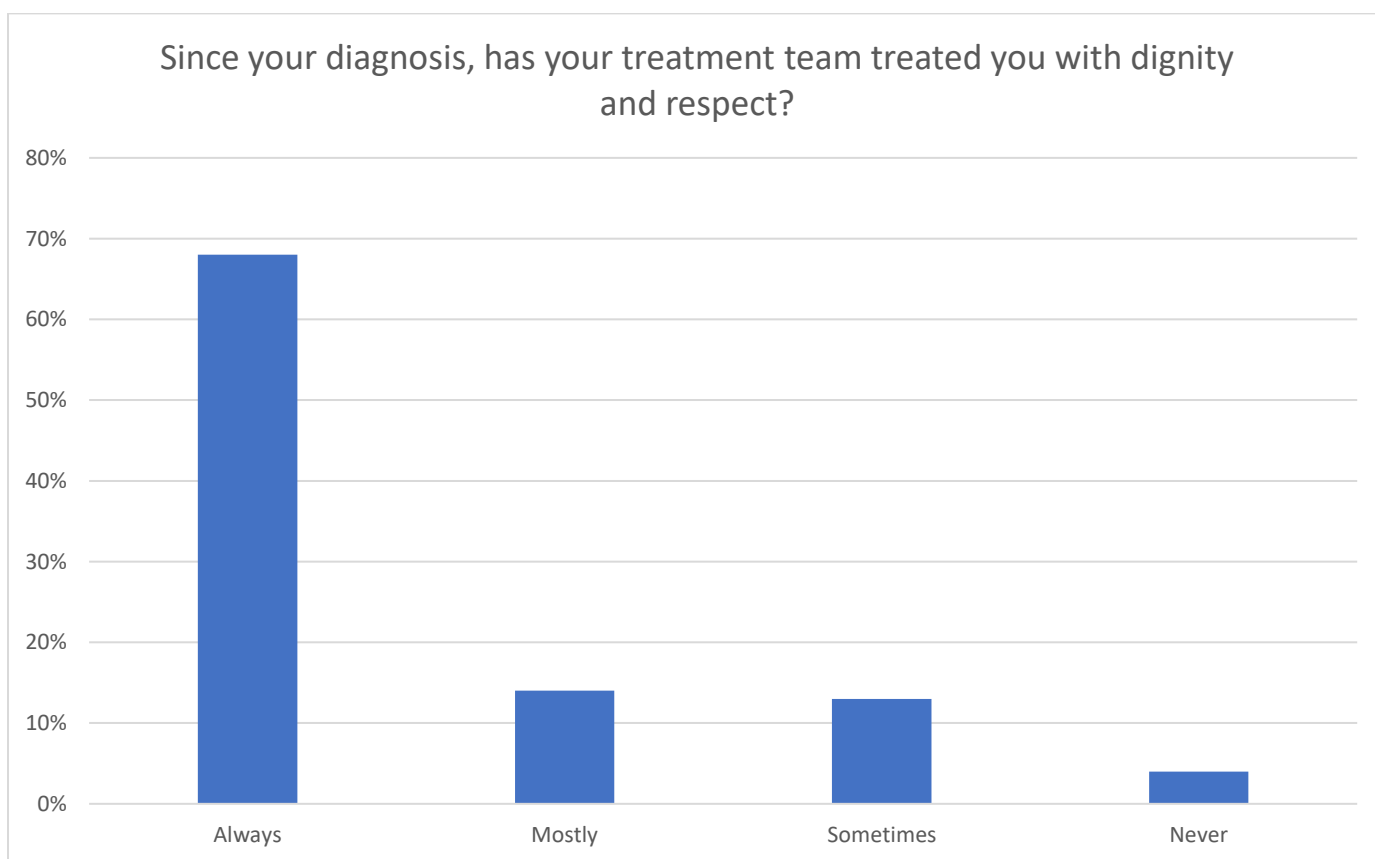


Figure 12b: Data on the number and percentage of respondents feeling treated with dignity and respect by their treatment team

	Always		Mostly		Sometimes		Never	
	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number
2021 survey	68%	71	14%	15	13%	14	4%	4

Future studies or surveys could explore:

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

How do people diagnosed with lung cancer describe themselves?

Often people with lung cancer are described simply as 'patients' but this may not be how people diagnosed with lung cancer think about themselves or want to be described. Some may describe themselves as 'patients' while having treatment, but not if their treatment stops. While there is much to be done to improve outcomes and survival from lung cancer, with earlier diagnosis and treatments improving, more people are living for longer after their diagnosis. Therefore, it is important to understand how people want to be described, and at what point do they start to identify as a 'survivor' for 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. A larger proportion of respondents described themselves as 'living with lung cancer' (24%), and 'fighting lung cancer' (22%) than a 'patient' (19%).

17% of respondents described themselves as 'surviving with lung cancer', and 15% as 'at war with lung cancer'. 12% and 10% described themselves as 'fighter' and 'warrior' respectively.

Five respondents skipped this question. Figure 13 (overleaf) shows all the responses. There was also the option to pick 'other' for people to include their own description. Five respondents (5%) selected 'other', and Figure 14 sets out some of the responses.

Figure 13: How respondents described themselves

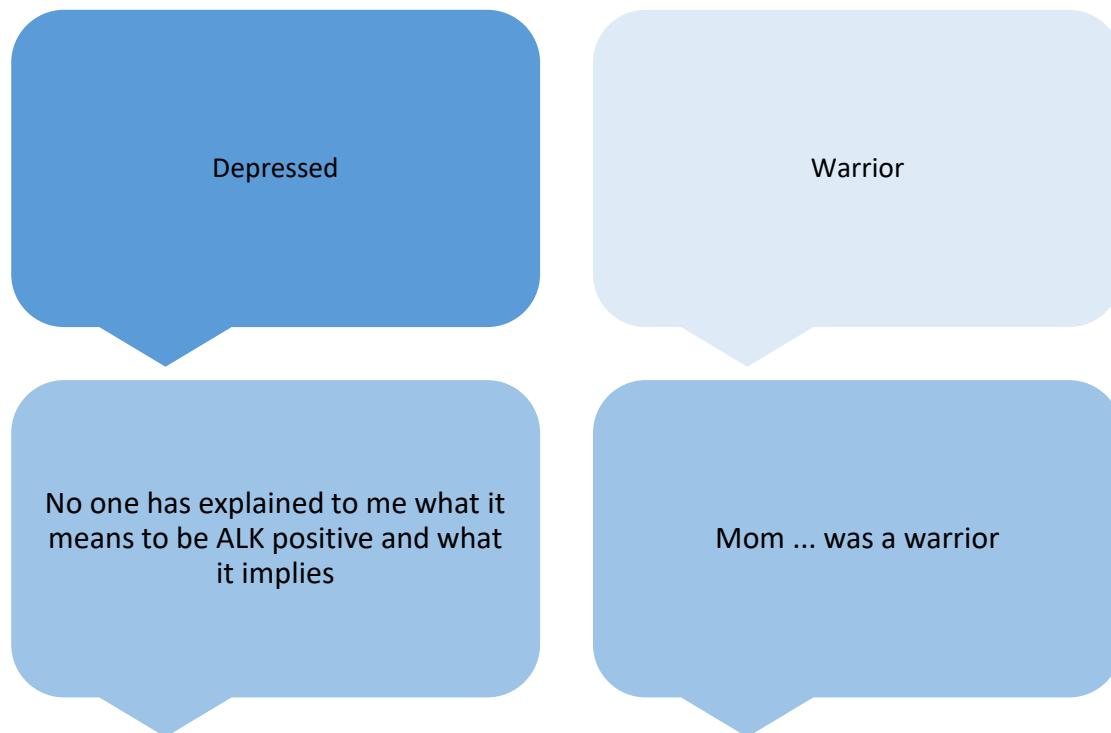
	Living with lung cancer		Patient		Surviving with lung cancer		Lung cancer survivor		Overcomer	
	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number
2021 survey	24%	24	19%	19	17%	17	6%	6	0%	0

	Survivor		Advocate		Thrifer		Other	
	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number
2021 survey	4%	4	0%	0	4%	4	5%	5

	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	6%	6	15%	15	12%	12	10%	10	22%	22

Figure 14: How would you describe yourself today? Responses from respondents who picked 'other'

Five respondents (22%) selected 'other', and some of the responses have been copied below



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 language of war, eg 'fighter' or 'warrior'

Emotional and physical wellbeing

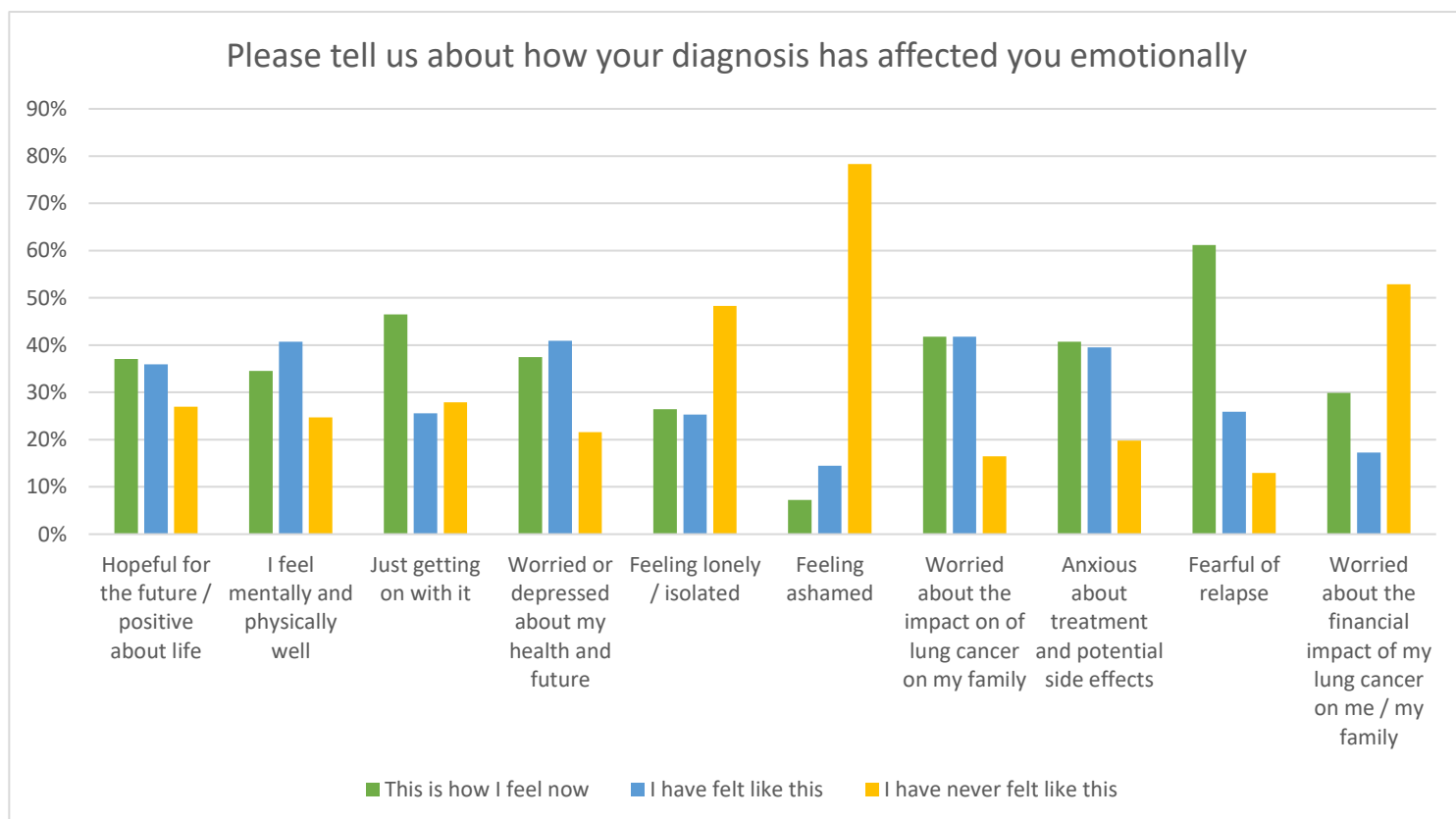
A cancer diagnosis can considerably affect the emotional health of a patient and that of their families and caregivers. Common feelings include distress, depression, anxiety and may involve loss of self-esteem and feelings of isolation. A 2019 study found that about one third of patients newly diagnosed 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. Five people skipped this question. Respondents could also choose the 'other' option and indicate other forms of support they have received. Figure 15a summarises key findings, and Figure 15b outline responses for the 'other' option.

Figure 15: How diagnosis affected respondents emotionally



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

47% of respondents said they were just getting on with their cancer. 37% feel hopeful or positive about life, but 27% of respondents never felt hopeful and 36% used to feel this way. 38% of respondents currently feel worried or depressed about their health and future, and 61% are fearful of relapse.

When it came to their mental and physical wellbeing, 35% of respondents feel well at the moment, while 41% said they have felt well and 25% never felt well.

Despite some of the stigma associated with lung cancer, 78% said they never felt ashamed although 14% had felt this way at some point.

45% of respondents said they are feeling or have felt lonely or isolated. 41% of respondents are currently anxious about treatment while 40% have felt this way. 42% of respondents are currently worried about the impact of their condition on their family, with a further 42% have felt this way.

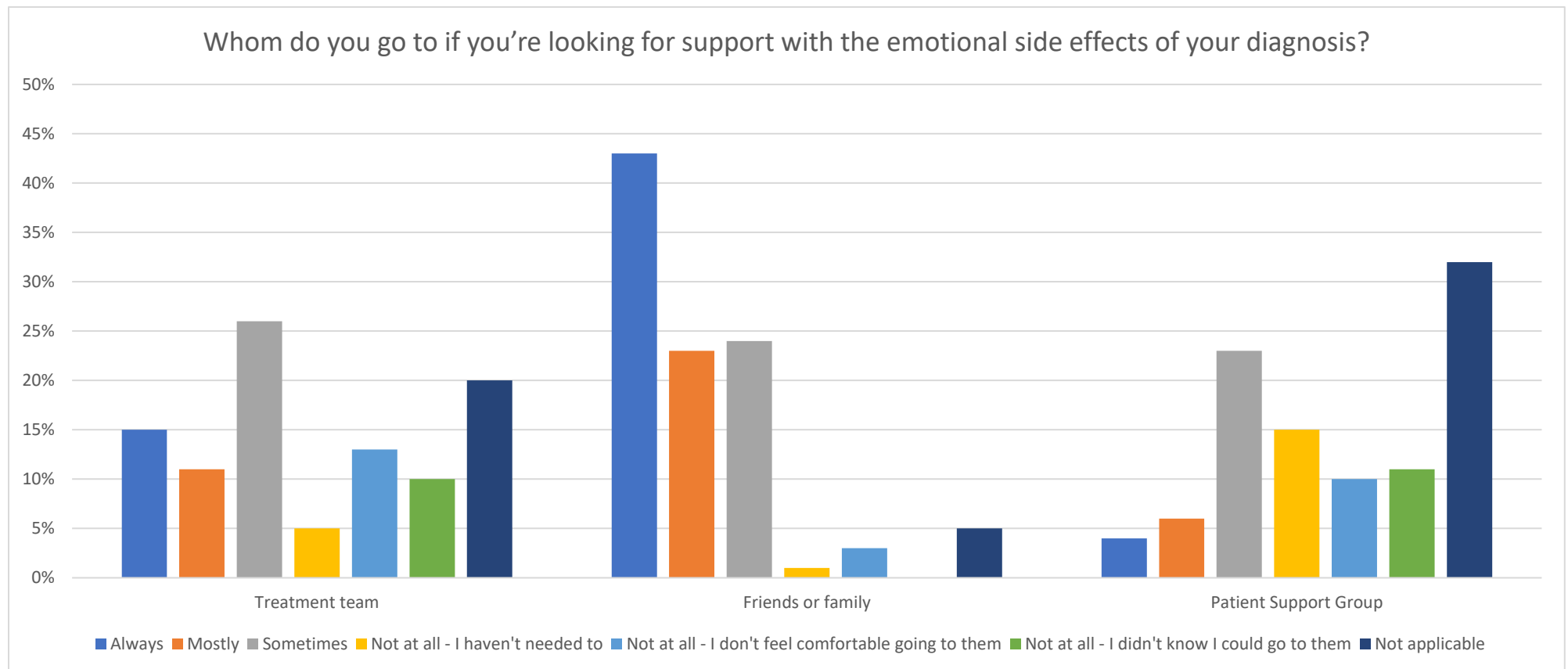
Further studies could explore:

- 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 105 respondents, 6 people skipped this question.

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



The results show that respondents primarily turned to friends and family for emotional support. 43% said they always reached out to friends and family for support, compared to a quarter (15%) saying they always reached out to their treatment team for help, and 4% saying they always reached out to patient support groups.

26% said they sometimes asked their care team for emotional support. However, one in ten respondents (10%) said they didn't know they could ask their treatment team for this kind of support, and 13% said they don't feel comfortable doing so.

23% of respondents said they sometimes asked patient support 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 10% of respondents said they would not feel comfortable to do so
- Whether treatment teams offer emotional support to people diagnosed with lung cancer, and if people are aware that their treatment team can help
- What more support can be offered to family members given 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?

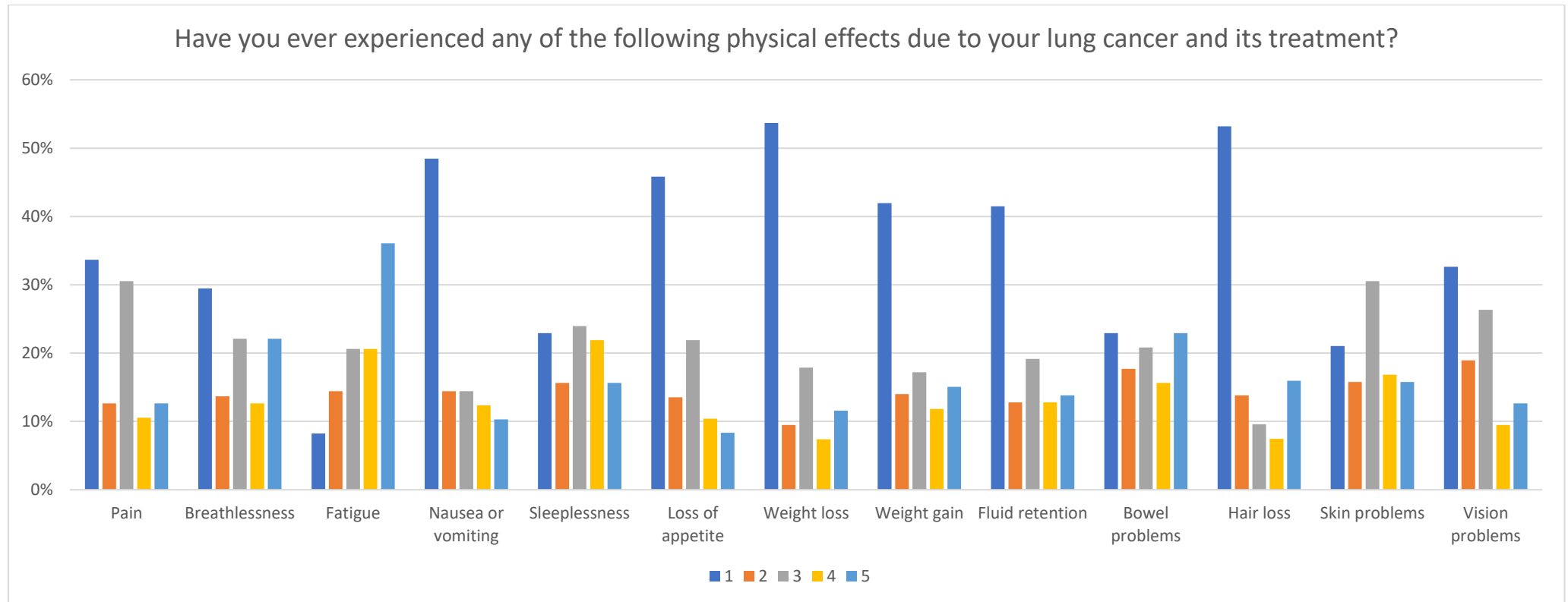
Respondents were asked about the physical effects they experienced because of their cancer and its treatment. We gave respondents 13 options and, for each option, people could select a number from 1 to 5, where 1 means this has not affected them and 5 means this has been a very serious concern. Six people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

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

	1	2	3	4	5	Total	Weighted Average
Answer Choices	Percentage	Percentage	Percentage	Percentage	Percentage	Number	Number
Pain	34%	13%	31%	11%	13%	95	2.56
Breathlessness	29%	14%	22%	13%	22%	95	2.84
Fatigue	8%	14%	21%	21%	36%	97	3.62
Nausea or vomiting	48%	14%	14%	12%	10%	97	2.22
Sleeplessness	23%	16%	24%	22%	16%	96	2.92
Loss of appetite	46%	14%	22%	10%	8%	96	2.22
Weight loss	54%	9%	18%	7%	12%	95	2.12
Weight gain	42%	14%	17%	12%	15%	93	2.44
Fluid retention	41%	13%	19%	13%	14%	94	2.45
Bowel problems	23%	18%	21%	16%	23%	96	2.98
Hair loss	53%	14%	10%	7%	16%	94	2.19
Skin problems	21%	16%	21%	17%	16%	95	2.91
Vision problems	33%	19%	26%	9%	13%	95	2.51

The weighted averages in Figure 17a give an indication of how serious the issues are for patients, compared to each other. A higher number indicates a more serious concern for the respondents. The table shows that, on average, fatigue was the most serious issue for respondents (3.62), followed by bowel problems (2.98), skin problems (2.91), and breathlessness (2.78).

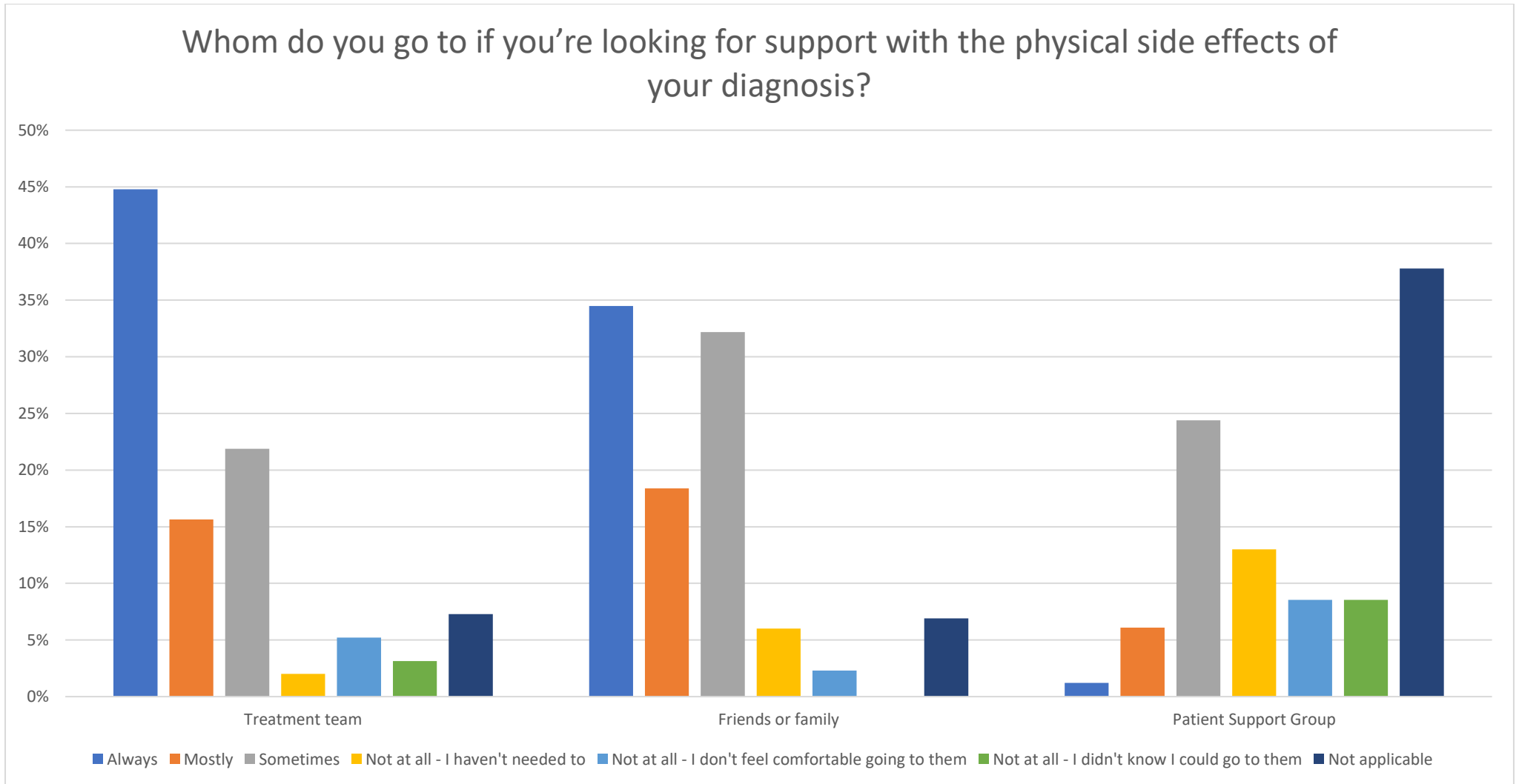
Figure 17b: Have you ever experienced any of the following physical effects due to your lung cancer and its treatment? Please choose an option from 1 – 5, where 1 means this has not affected me and 5 means this has been a very serious concern?



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

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



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 treatment team. 45% said they always contacted their care team, followed by 35% who said they always reached out to friends and family.

16% of respondents said they mostly go to their treatment team, followed by 22% of respondents who said they sometimes reach out to their treatment team for support. Of concern, 5% of respondents said they didn't feel comfortable going to their treatment team and 3% said they didn't know they could go to their treatment team. It would be useful to understand if this is representative of the wider lung cancer population and why this might be the case.

Looking at some of the findings outline above, people diagnosed with lung cancer tend to go to their treatment team for support with physical effects, but to friends and family when they need support to deal with emotional effects. Patient support groups are an important source of support for a significant proportion of patients, both with physical and emotional effects of lung cancer.

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, including services that weren't available before the crisis. 11 people skipped this question.

Figure 19: 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	7%	7
There has been no difference in how easy it has been to contact my treatment team	45%	42
I found it more difficult to speak to my treatment team	11%	10
I have held back in contacting my treatment team because they are so busy	4%	4
My treatment has continued as normal	54%	51
My treatment has been delayed / cancelled	4%	4
I don't know if my treatment has been affected	6%	6
I have carried on attending appointments during the pandemic	33%	31
I have been reluctant to attend appointments for fear of infection	6%	6
I have missed appointments for fear of infection	1%	1
My face-to-face appointments have been swapped for telephone or video calls	2%	2
I have been offered new services that weren't available to me before the pandemic	4%	4

Only 7% of respondents said it had been easier to contact their treatment team during the pandemic, with 45% of respondents saying there has been no difference and ten people (11%) finding it more difficult. 4% of respondents said they held back from contacting their team because they were so busy.

33% of respondents said they have carried on attending their appointments in person during the pandemic. Only 2% 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).

54% of respondents said their treatment has carried out as normal, but four people (4%) had experienced delays to treatment, with a further 6% unsure about the impact on their treatment. Six patients said that they had been reluctant to attend appointments for fear of infection, and one person had missed appointments because of this.

Four people said they were offered other services that weren't available to them before the pandemic, but they did not indicate what kind.

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. 13 people skipped this question.

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

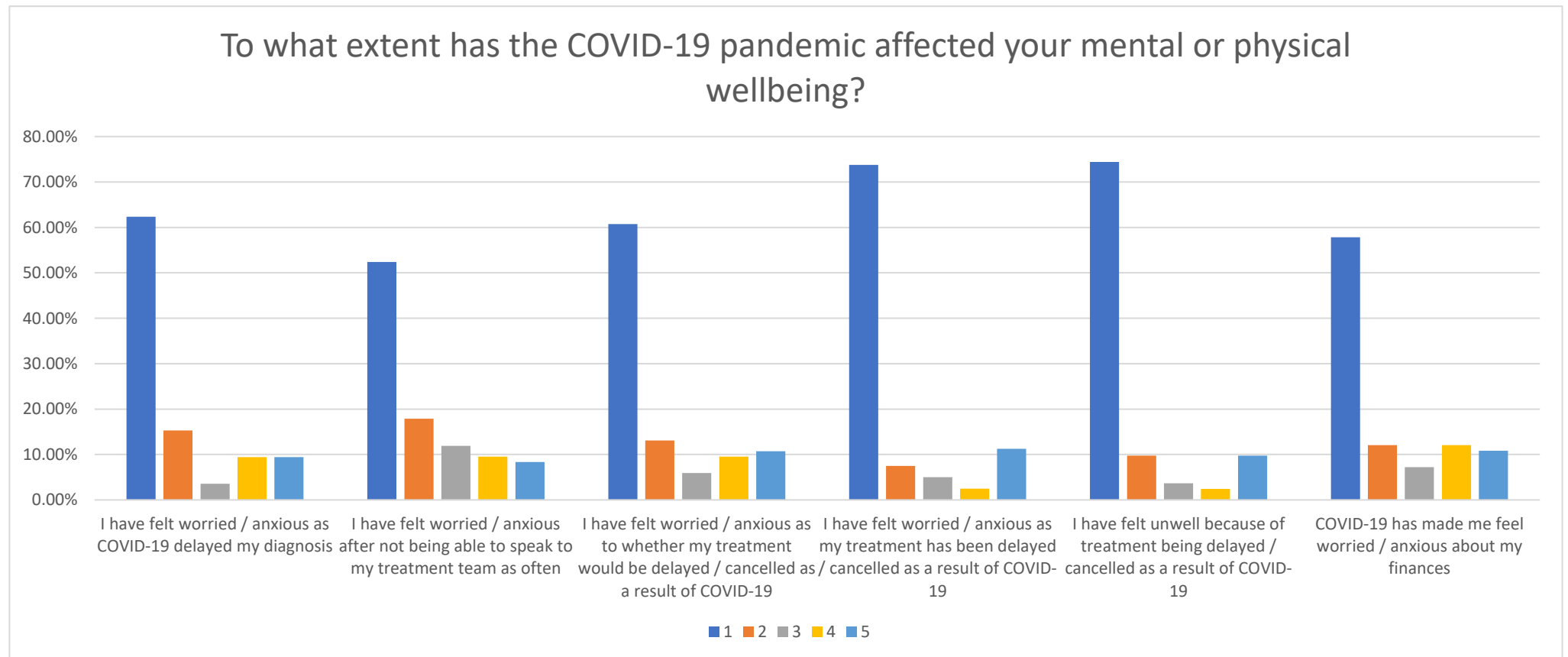


Figure 20b: To what extent has the COVID-19 pandemic affected your mental or physical wellbeing? Please choose an option from 1 – 5, where 1 means this has not affected me and 5 means this has been a very serious concern

Answer Choices	1	2	3	4	5
I have felt worried / anxious as COVID-19 delayed my diagnosis	62%	15%	4%	9%	9%
I have felt worried / anxious after not being able to speak to my treatment team as often	52%	18%	12%	10%	8%
I have felt worried / anxious as to whether my treatment would be delayed / cancelled as a result of COVID-19	61%	13%	6%	10%	11%
I have felt worried / anxious as my treatment has been delayed / cancelled as a result of COVID-19	74%	8%	5%	3%	11%
I have felt unwell because of treatment being delayed / cancelled as a result of COVID-19	74%	10%	4%	2%	10%
COVID-19 has made me feel worried / anxious about my finances	58%	12%	7%	12%	11%

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

- On feeling anxious about delays to diagnosis as a result of COVID-19, 4% of respondents scored a 3, 9% scored a 4 and 9% scored a 5
- On worries caused because treatment have been delayed or cancelled as a result of COVID-19, 10% scored it a 4 and 11% scored it a 5
- On worries about finances as a result of the pandemic, 12% scored it a 2, 12% scored a 4 and 11% 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 some countries in an effort to maintain support for patients when face-to-face options were not as easily available. New technologies and telehealth are now increasingly used as tool in lung cancer diagnosis and have enabled healthcare professionals to follow-up with patients during the pandemic when restrictions were in place.^{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. Ten people skipped this question.

Figure 21a: 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	40%	38
Video	4%	4
In person	67%	64
No, I have not been in contact with my treatment team at all, but I wanted to	11%	10
No, I have not been in contact with my treatment team at all, but I haven't needed / wanted to	6%	6

67% respondents continued to see their treatment team in person, and 40% of respondents have had conversations with their treatment team via telephone. Only four people spoke to their care team by video consultation (4%).

10 people (11%) said they have not been in contact with their treatment team at all, but wanted to. Six respondents (6%) 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. Only seven people answered this question.

Figure 22: 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	14%	1
In person is the only option and I can't travel	14%	1
A video call has been offered but I don't have a computer / smartphone	14%	1
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	6%	0
A phone call has been offered but I don't want to do a phone call	0%	0
Other (please specify)	57%	4

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. 40 people answered this question.

Results show that 45% said they found contacting their treatment team by video or telephone helpful because they didn't have to travel to hospital as much, while 25% found it quicker to have appointments by video or telephone.

However, half of respondents still preferred face-to-face appointments. 5% found it more difficult to understand the treatment team or make themselves understood if not in person. 10% of respondents said they don't like it and want to stop as soon as possible.

Figure 23a: What is your opinion on contacting your treatment team by video or telephone?

Answer Choices	Percentage	Number
I found it quicker	25%	10
I found it helpful as I don't have to travel to hospital as much	45%	18
I prefer face-to-face appointments	50%	20
I found it more difficult to understand my treatment team / make myself understood	5%	2
I don't like it and I want to stop as soon as possible	10%	4

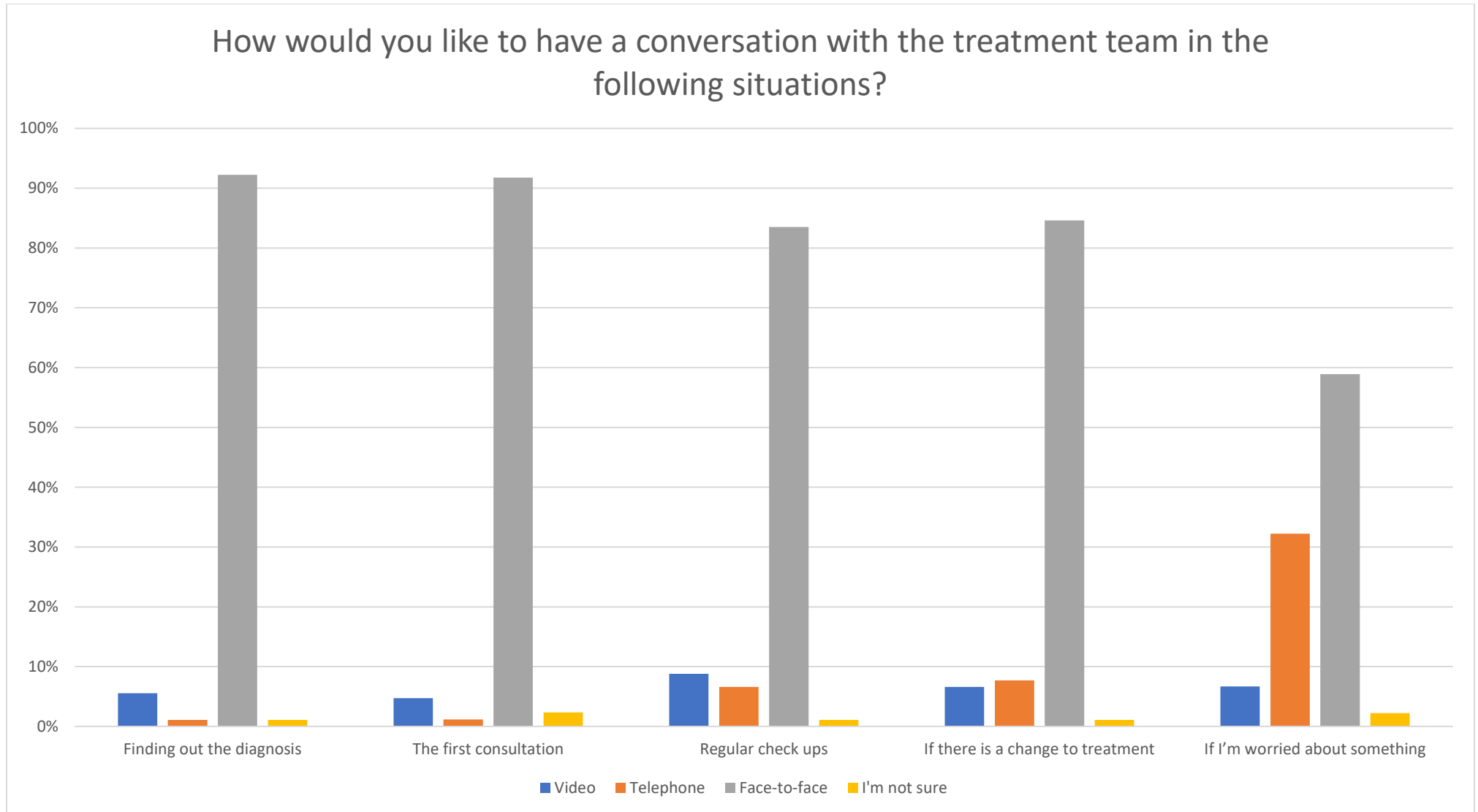
When dealing with different situations, what do people think is the best way to speak with their treatment team?

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. 11 people skipped this question.

Respondents have a preference for face-to-face appointments in all situations. 92% of respondents said that the best way to find out by a diagnosis was in person, and 92% said they preferred to have a face-to-face conversation for their first consultation. 85% felt that if there was a change in treatment it was best to have a face-to-face conversation. For regular check-ups, 84% felt it was best to have a face-to-face conversation, while 11% felt that having a telephone appointment would be appropriate. Respondents said that if they are worried about something, they would prefer to talk in person (59%) or have a telephone consultation (32%).

In future studies, it would be useful to assess whether this is representative of the wider population in Italy. 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 24: 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. 14 people skipped this question.

Figure 25: 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	73%	16%	9%	2%
Patient support organisations	30%	29%	23%	19%
Other people that have been diagnosed with lung cancer	42%	20%	17%	21%
Friends or family	63%	11%	1%	24%
The internet	68%	4%	2%	26%
Social media	59%	9%	3%	30%
Pharmaceutical company	16%	19%	30%	35%

The results show that most respondents have sought information from their treatment team (73%), with a further 16% saying they would ask their treatment team but haven't yet, and 9% saying they didn't realise they could ask their treatment team.

The internet was the next most common source of information, with 68% of respondents having looked for information on the internet and a further 4% intending to. However, 26% of respondents would not use the internet to seek out information.

Friends or family (63%) and social media (59%) were other sources of information to which respondents had already turned.

A significant proportion of respondents had already talked to other patients (42%) or to patient support groups (30%).

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. 13 people skipped this question.

Figure 26: How do you like to receive information? (Tick all that apply)

Answer Choices	Percentage	Number
A conversation in person	82%	76
A conversation over the phone	20%	18
A conversation on video call	18%	17
Something I can read e.g. a leaflet / booklet	21%	19
Something I can view online e.g. a website / social media	35%	32
Something I can listen to e.g. a podcast	7%	6
Something I can watch e.g. a video	24%	22

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

Eight in ten respondents (82%) said they like in person conversations, with telephone or video scoring lower (20% and 18% respectively). This in line with findings above where respondents expressed preference for face-to-face appointments in most situations.

However written material, which people can keep and refer to when they want, is important too. 35% of respondents said they would like something to view online and 21% said they would like to have something to read.

A quarter of respondents (24%) said they would like information by video, with only 7% saying they would like to use 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 members from Italy are [Alliance for Lung Cancer Advocacy, Support, and Education \(ALCASE Italia\)](#) and [Tribunale per i Diritti del Malato – Cittadinanzattiva](#).

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 [website](#) or email our secretariat at: glcc@roycastle.org.

References

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