



GLOBAL LUNG CANCER
COALITION

COVID-19 PANDEMIC: THE IMPACT ON LUNG CANCER PATIENTS

Insights from the United Kingdom

2021 Patient Experience Survey

Table of contents

| | |
|---|-----------|
| Introduction | 2 |
| Methodology | 3 |
| 2021 Patient Experience survey and insights from 2020 | 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? | 14 |
| Respondent experiences | 18 |
| Feeling involved in decisions about their treatment and care..... | 18 |
| Being treated with dignity and respect | 21 |
| How do people diagnosed with lung cancer describe themselves?..... | 23 |
| Insights from the 2021 patient experience survey | 26 |
| Emotional and physical wellbeing | 26 |
| How were people affected emotionally after a lung cancer diagnosis? | 26 |
| Where do people turn for emotional support?..... | 28 |
| What are the physical effects people have experienced due to their lung cancer and its treatment? | 31 |
| Where do people turn for support with physical impact of their lung cancer and its treatment? | 33 |
| The impact of the COVID-19 pandemic on people with lung cancer | 37 |
| Experience of care during the pandemic | 37 |
| Impact of the pandemic on mental and physical wellbeing..... | 40 |
| Communication with treatment team during COVID-19 | 43 |
| Why were people not able to speak with their treatment team? | 44 |
| What do people think of video or telephone consultations?..... | 45 |
| When dealing with different situations, what do people think is the best way to speak with their treatment team?..... | 46 |
| Receiving information | 48 |
| How would people diagnosed with lung cancer like to receive information? | 50 |
| More information | 51 |

Introduction

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

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

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

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

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

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

If you have any queries, please contact glcc@roycastle.org.

Methodology

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

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

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

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

This year, fewer people from the UK filled out our survey: 54 in 2021 compared to 158 in 2020.

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

2021 Patient Experience survey and insights from 2020

Demographics of respondents

Background information on respondents

Respondents were asked whether they were a patient or if they were a carer filling out the survey thinking about the experience of the person for whom they provided care. Fewer people from the UK completed the survey this year: 54 compared to 158 in 2020. Of the 54 people who answered this question, 48 people described themselves as a patient and six as a carer. All respondents answered this question.

The majority of the respondents said they had not filled out the first patient experience survey (35 respondents). Two respondents said they had completed it in 2020 and 17 respondents said they were not sure.

Gender

This year, 45 (83%) of respondents were women and 9 (17%) were men (Figure 1). As with 2020, more women than men filled out the survey (74% of respondents in 2020 were women).

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

| Female | | Male | | Gender neutral | | Prefer not to say | | None of the above, I describe myself as | |
|------------|--------|------------|--------|----------------|--------|-------------------|--------|---|--------|
| Percentage | Number | Percentage | Number | Percentage | Number | Percentage | Number | Percentage | Number |
| 83% | 45 | 17% | 9 | 0% | 0 | 0% | 0 | 0% | 0 |

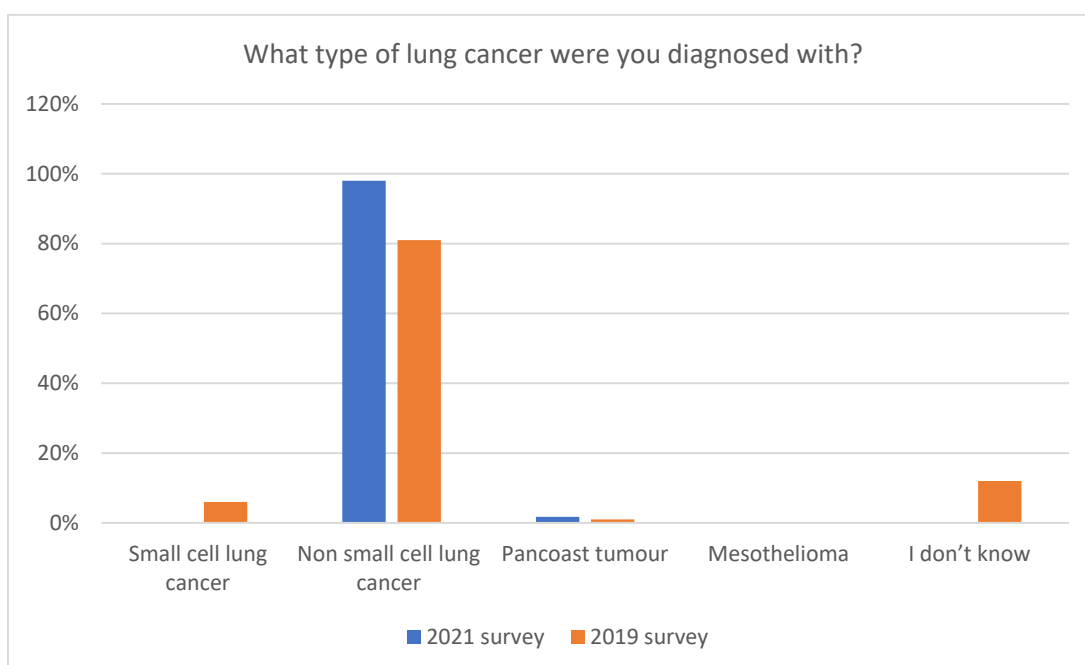
Diagnosis

Type of lung cancer

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

Non-small cell lung cancer is the most common form of cancer, accounting for 80-85% of all lung cancers.ⁱ As in 2020, the largest proportion of respondents (98% vs 81% in 2020) stated they had non-small cell lung cancer. No one said they had small cell lung cancer or mesothelioma. All respondents answered this question.

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



Some patients do not know which type of lung cancer they had or have. In 2020, 12% of UK respondents did not know what type of lung cancer, but this year none of the respondents said they did not know the type of cancer they had or have.

The type of lung cancer a patient has will affect the treatment options that are available to them. This can, in turn, can contribute to a better understanding of their treatment choices and help them feel more involved in decisions about their care. It is encouraging that all the UK respondents to this year's survey know their type of lung cancer.

Further survey work could be conducted to determine:

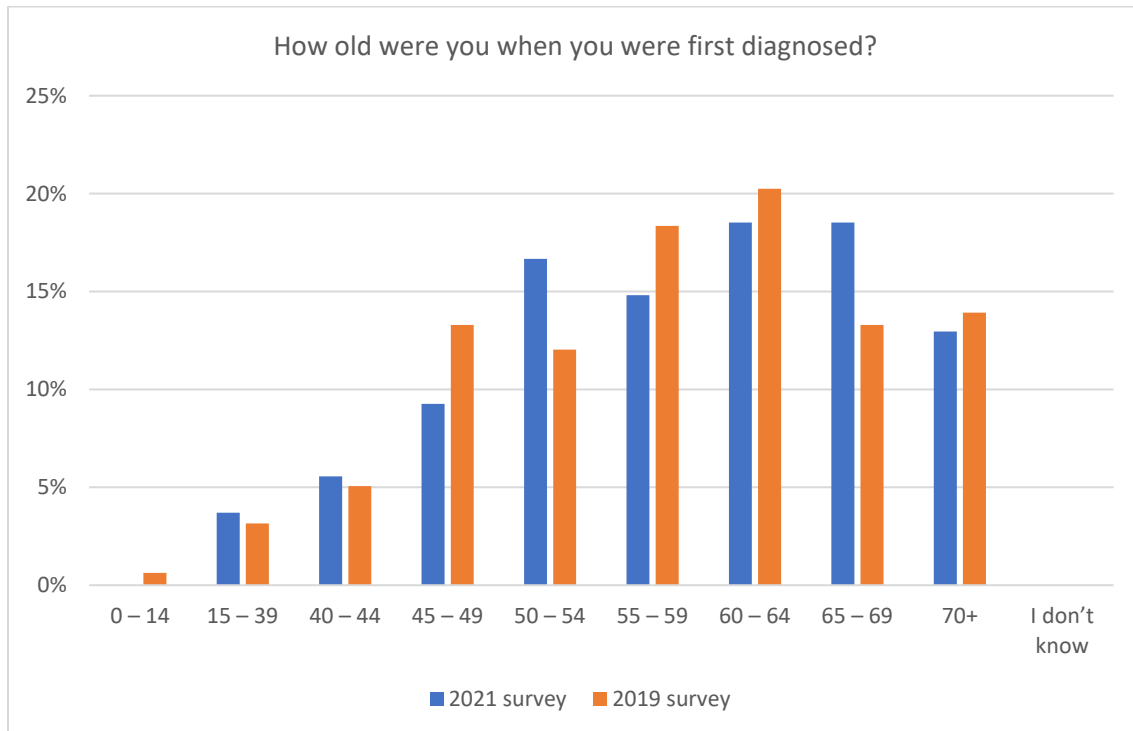
- Whether the experience of the respondents reflects that of the wider lung cancer patient population in the UK (given the relatively small sample size)

Age at diagnosis

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

In the UK, the largest proportions of respondents said they were diagnosed at age 60-64 (19%) and 65-69 (also 19%) followed by 17% at age 50-54. All 175 respondents from the UK answered this question.

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

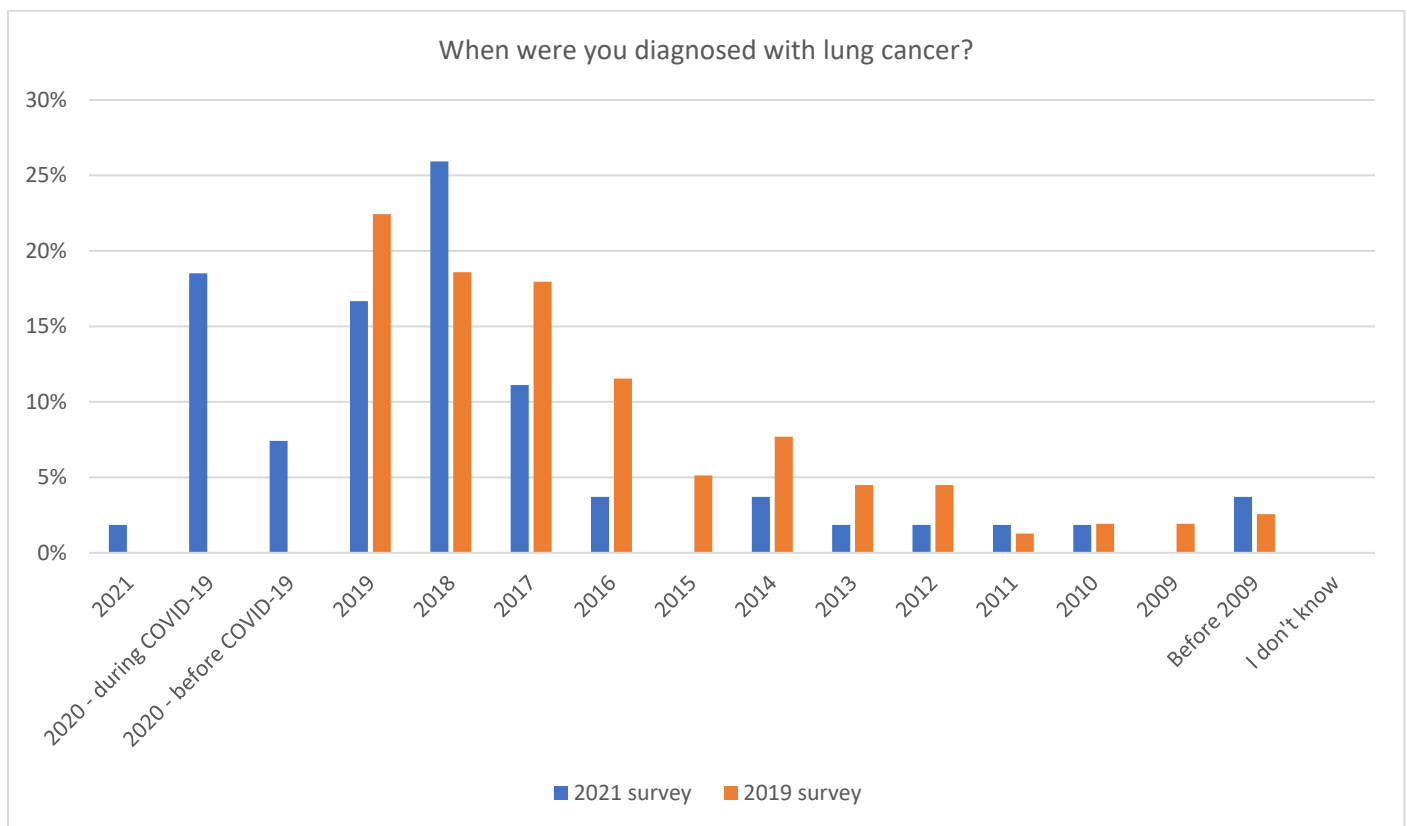


Year of diagnosis

Respondents were asked in which year they were diagnosed. Knowing how recently a patient was diagnosed may help to understand differences in their diagnostic journey, especially as delays in treatment and diagnosis have been reported during the COVID-19 pandemic.ⁱⁱ All 54 respondents from the UK answered this question.

The largest proportion of respondents to this year's survey were diagnosed in 2018 (26%) and in 2020 (also 26%; 19% during the pandemic and 7% before pandemic hit). 17% of this year's survey respondents were diagnosed in 2020. Figure 4 shows the survey responses for 2021 and 2020.

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



Delay in diagnosis

Earlier diagnosis is a key part of improving survival rates for people diagnosed with lung cancer. This year, people were asked if they felt that there was an unnecessary delay in getting their diagnosis. This question was added to learn about the potential impact that COVID-19 may have had on people who tried to get their symptoms checked out or were waiting for test results to come back. Participants could tick more than one option. All 54 respondents from the UK answered this question.

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

| Answer Choices | Percentage | Number |
|--|------------|--------|
| Yes, it took me too long to see someone to get my symptoms checked out | 19% | 10 |
| Yes, it took too long to see someone to test if I had lung cancer | 17% | 9 |
| Yes, it took too long to get my test results | 11% | 6 |
| No, I am satisfied with the time it took to get my diagnosis | 54% | 29 |
| I'm not sure | 6% | 3 |

Half (54%) of respondents from the UK said they were satisfied with the time it took to get their diagnosis. Nearly a fifth of the respondents (19%) said it took them too long to see someone to get their symptoms checked out. 17% felt it took too long to see someone to get tested to see if they had lung cancer and one in ten (11%) felt they waited too long for test results.

Late diagnosis can considerably impact a patient's chances of surviving lung cancer. NHS teams 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 are concerning and show a level of worry among respondents as to how long it took to get their diagnosis. Future analysis using a larger sample size would help determine if these statistics are representative of the wider population and to what extent they may change as services recover from COVID-19.

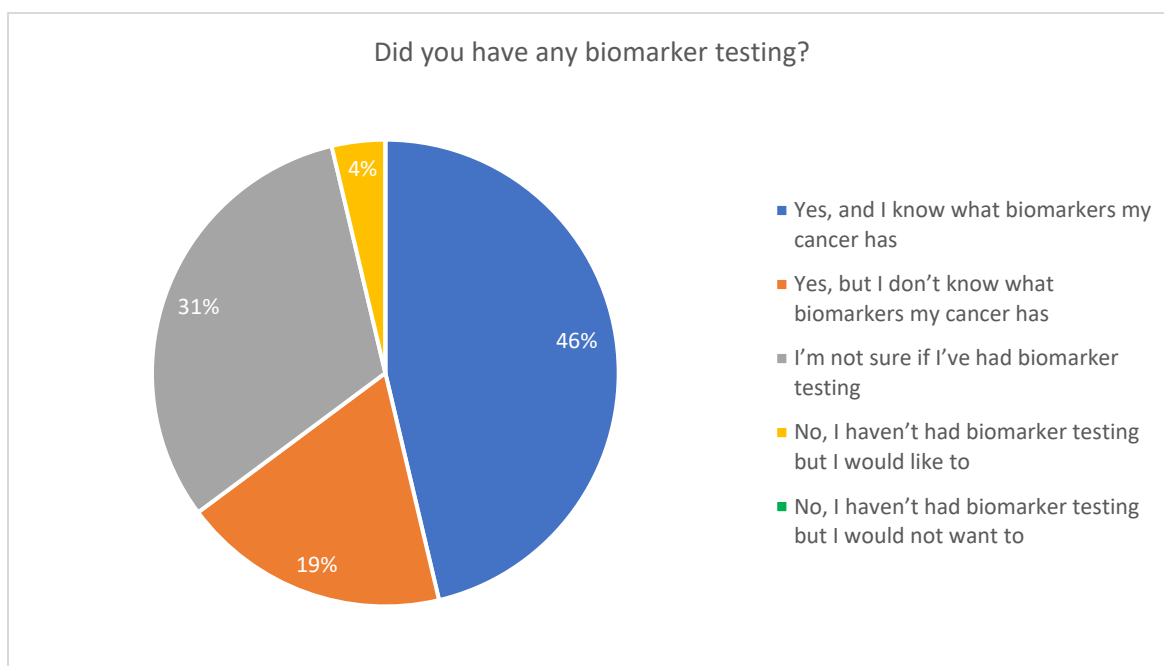
Biomarker testing

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

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

In the first survey, 60% of respondents said they had received a biomarker test, 18% said they hadn't received one, and 22% said they didn't know if they have had one. The results for this year show that, overall, a higher proportion of respondents (65%) knew they had biomarker testing but, amongst those, 19% did not know what biomarkers their cancer has. 4% of respondents said they did not get a test but would like one. One in three patients (31%) were not sure if they'd had a biomarker test.

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



Interventions

Respondent profile

Respondents were asked where they were in their cancer journey, and could choose from five options. The majority said they were currently receiving treatment (60%), followed by 34% saying they had finished treatment. 6% said that treatment was not available to them. One respondent skipped this question.

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

| Answer Choices | Percentage | Number |
|---|------------|--------|
| I have just been diagnosed with lung cancer and haven't started treatment yet | 0% | 0 |
| I am currently having treatment | 60% | 32 |
| I have finished treatment | 34% | 18 |
| I chose not to have treatment | 0% | 0 |
| Treatment wasn't available to me | 6% | 3 |

Treatment

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

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

- **Surgery:** 43% of respondents had surgery compared to 45% in 2020. Surgery is still the best curative option for patients with early-stage lung cancer (stages I and II) so identifying a larger proportion of patients at an early stage, when surgery is an option for them, should be a priority
- **Radiotherapy:** about a third (31%) of respondents said they had received radiotherapy, compared to 35% in 2020
- **Chemotherapy:** 44% of respondents from the UK had received chemotherapy compared to 56% in 2020
- **Immunotherapy:** the proportion of respondents who had received immunotherapy was greater, with 30% this year saying they had received immunotherapy, compared to 19% in 2020
- **Targeted therapies:** just over a third of respondents (35%) this year said they had received targeted therapies, compared to 33% in 2020
- **Symptom management:** a third of respondents (33%) said they had received treatment to help with symptom management, compared to a third (24%) in 2020
- **No treatment:** this year two respondents (4%) said they have not received any treatment because it was not available to them
- **Other treatments:** five respondents (9%) also told us if they had received additional forms of treatment. Figure 9b includes some of their responses

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

| | Surgery | | Radiotherapy | | Chemotherapy | | Immunotherapy | |
|-------------|------------|--------|--------------|--------|--------------|--------|---------------|--------|
| | Percentage | Number | Percentage | Number | Percentage | Number | Percentage | Number |
| 2021 survey | 43% | 23 | 31% | 17 | 44% | 24 | 30% | 16 |
| 2020 survey | 45% | 70 | 35% | 54 | 56% | 87 | 19% | 30 |

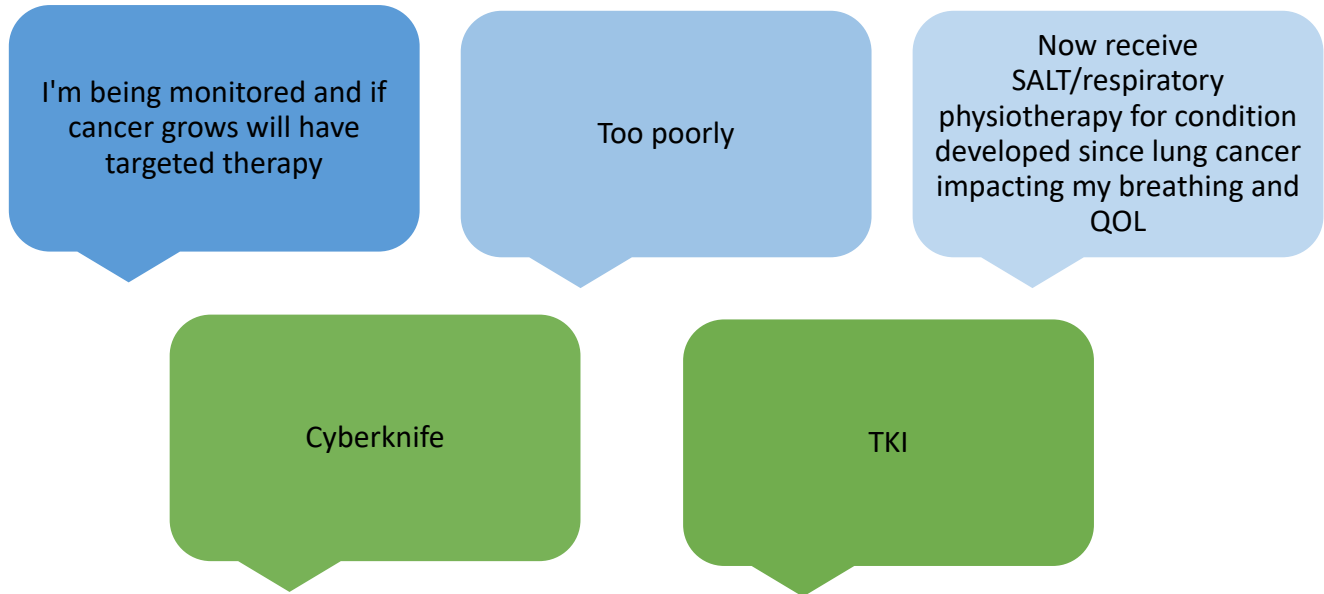
| | Targeted therapies | | Symptom management | |
|-------------|--------------------|--------|--------------------|--------|
| | Percentage | Number | Percentage | Number |
| 2021 survey | 35% | 19 | 33% | 18 |
| 2020 survey | 33% | 52 | 24% | 37 |

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

| Answer options | Percentage | Number |
|--|------------|--------|
| I have not received any treatment because I have just been diagnosed | 0% | 0 |
| I have not received any treatment, but I am due to start | 0% | 0 |
| I have not received any treatment because COVID-19 has delayed it | 0% | 0 |
| I have not received any treatment because I chose not to | 0% | 0 |
| I have not received any treatment because it is not available to me | 4% | 2 |
| Other (please specify) | 9% | 5 |

Figure 9b: Which types of treatment have you received? Results for 2021

The figure below shows 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. In this year's survey, we added in more options around stop smoking advice, and support from peer or other support groups. We also asked about the reasons why some patients had not received additional forms of support. Respondents were also given the option to select 'other' and indicate which other forms of support they had received.

Out of the 54 respondents, one person skipped this question. The survey results are summarised below and include comparisons with the 2020 patient experience survey:

- **Psychosocial support / counselling:** 38% of respondents to the 2021 survey said they had received psychosocial support and or counselling, compared to 39% in 2020
- **Physical therapy / pulmonary rehabilitation:** 17% of respondents said they had received physical therapy compared with 21% in 2020 (Figure 10a)
- **Occupational therapy:** only 4% said they had received occupational therapy, compared to 15% in 2020
- **Dietary advice:** 13% of respondents received dietary advice, down from 32% in 2020
- **Lifestyle advice:** 8% said they had they had received lifestyle advice, compared with 14% of respondents in 2020
- **Financial advice:** 11% of respondents said they had received financial advice, compared to 29% in 2020
- **Return to work advice:** 4% said they had received advice on going back to work. Three times that proportion of respondents had received this form of support in 2020 (12%)
- **Smoking cessation:** no respondents said they had received support on how to stop smoking
- **Support group:** 40% said they had received support from peer and/or support group (63 respondents)
- **No support:** two respondents said they had not received any other support because the pandemic has delayed it (4%), and three said they chose not to receive any (6%). Figure 10c contains further information on respondents' responses
- **Other type of support:** participants also shared with us other forms of support they received. Eight respondents said they had received other kinds of support for their condition (15%). In Figure 10d, we outline some of the responses

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

| | Psychosocial support / counselling | | Physical therapy / pulmonary rehabilitation | | Occupational therapy | | Dietary advice | |
|-------------|------------------------------------|--------|---|--------|----------------------|--------|----------------|--------|
| | Percentage | Number | Percentage | Number | Percentage | Number | Percentage | Number |
| 2021 survey | 38% | 20 | 17% | 9 | 4% | 2 | 13% | 7 |
| 2020 survey | 39% | 40 | 21% | 21 | 15% | 15 | 32% | 33 |

| | Lifestyle advice | | Financial advice | | Advice on going back to work | | Other | |
|-------------|------------------|--------|------------------|--------|------------------------------|--------|------------|--------|
| | Percentage | Number | Percentage | Number | Percentage | Number | Percentage | Number |
| 2021 survey | 8% | 4 | 11% | 6 | 4% | 2 | 15% | 8 |
| 2020 survey | 14% | 14 | 29% | 30 | 12% | 12 | 22% | 22 |

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

| | Support Group | | Smoking cessation | |
|-------------|---------------|--------|-------------------|--------|
| | Percentage | Number | Percentage | Number |
| 2021 survey | 40% | 21 | 0% | 0 |

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

| Answer options | Percentage | Number |
|--|------------|--------|
| I have not received any other support because I have just been diagnosed | 2% | 1 |
| I have not received any other support, but I am due to start | 0% | 0 |
| I have not received any other support because COVID-19 has delayed it | 4% | 2 |
| I have not received any other support because I chose not to | 6% | 3 |
| I have not received any other support because it is not available to me | 6% | 3 |

Figure 10d: Have you had any other types of care and support? Results for 2021

The figure below shows the responses from participants (eight 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 to and why some people (6%) chose not to take them up
- How useful people found the services they received, and if they would recommend the service to others
- Determine 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

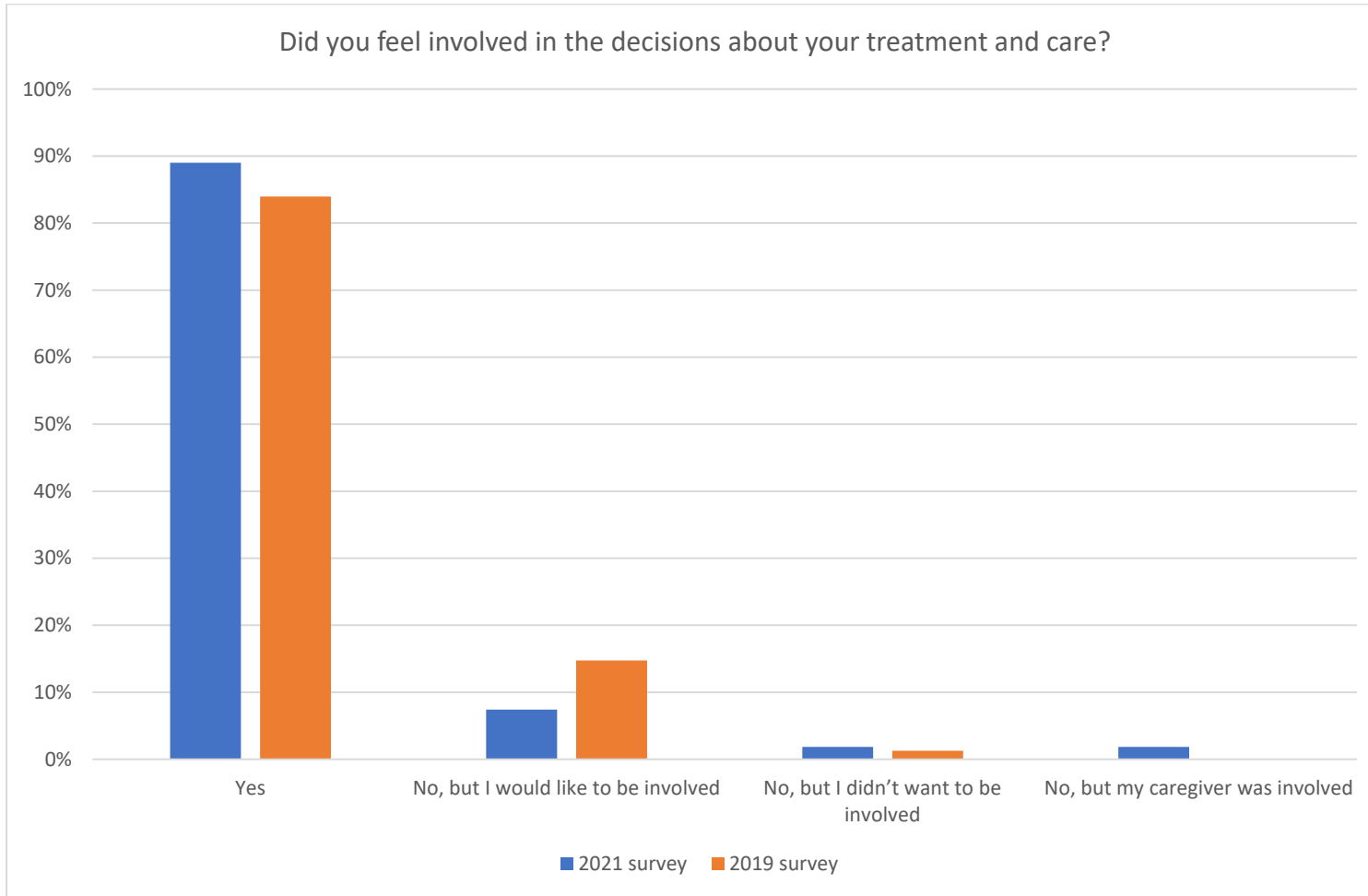
The GLCC believes that every patient has the right to be fully informed of, and involved in, decisions about their treatment and care. This right is enshrined in the GLCC's Patient Charter. The survey findings show the extent to which patients in the UK feel sufficiently involved in making decisions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

In 2020, respondents could only choose from 'Yes', 'No', 'No, but I didn't want to be involved' and 'No, but my caregiver was involved'. 85% felt involved in decision making about their care.

This year, we wanted to examine this further and gave respondents additional options to choose from: 'Yes, I've been fully involved', 'Yes, I've been involved most of the time' and 'Yes, I've been involved sometimes'. All 54 respondents answered this question. 48% of respondents felt they were fully involved in decision-making, 22% felt they were involved most of the time, and 19% felt they were only sometimes involved.

7% of respondents felt they were not involved but wanted to be, compared with 15% previously. One person said they didn't want to be involved in decision-making (two in 2020); and one respondent said their caregiver was involved in decision-making in their place (none in 2020). Figure 11a (below) compares the responses of this year's survey to that of 2020, while Figure 11b shows the breakdown of the data for 2021.

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



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

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

| Answer Choices | Percentage | Number |
|--|------------|--------|
| Yes, I've been fully involved | 48% | 26 |
| Yes, I've been involved most of the time | 22% | 12 |
| Yes, I've been involved sometimes | 19% | 10 |
| No, but I would like to be involved | 7% | 4 |
| No, but I didn't want to be involved | 2% | 1 |
| No, but my caregiver was involved | 2% | 1 |

Future studies or surveys could explore:

- Whether this figure reflects the experience of the wider lung cancer patient population in the UK (given the relatively small sample size)
- Why respondents from the UK feel this way, and why some people were only involved sometimes when others felt fully or mostly involved
- What healthcare professionals can do to ensure people 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.

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

Out of 54, one respondent skipped this question. When compared to 2020, we found a higher proportion of respondents said they were always treated with dignity and respect (72% vs 65% in 2020). 21% of respondents said they were 'mostly' treated with dignity and respect, and 6% said they were 'sometimes' treated with dignity and respect, compared with 29% and 14% respectively in 2020. One respondent said that they were never treated with dignity and respect, compared with two in 2020 (Figure 12b).

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

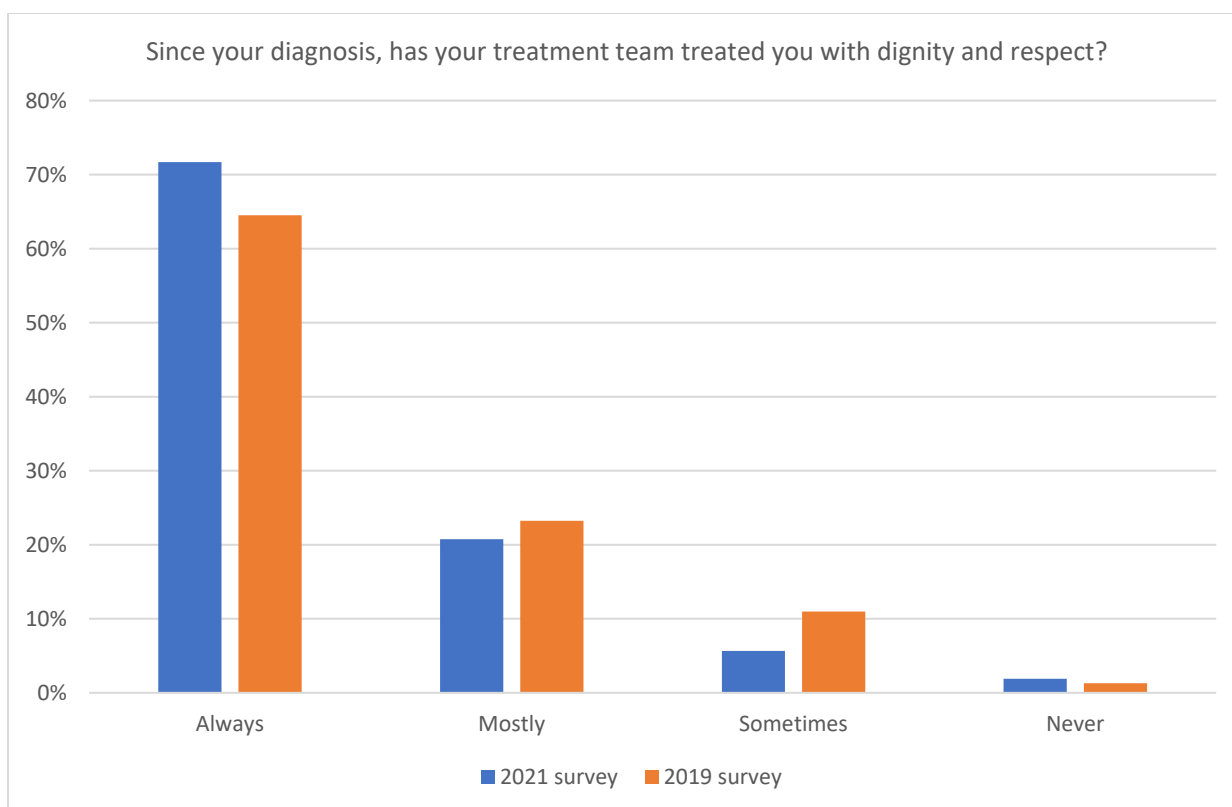


Figure 12b: Data on the number and percentage of respondents feeling treated with dignity and respect by their treatment team, results for 2021 and 2020

| | Always | | Mostly | | Sometimes | | Never | |
|-------------|------------|--------|------------|--------|------------|--------|------------|--------|
| | Percentage | Number | Percentage | Number | Percentage | Number | Percentage | Number |
| 2021 survey | 72% | 38 | 21% | 11 | 6% | 3 | 2% | 1 |
| 2020 survey | 65% | 100 | 23% | 36 | 11% | 17 | 1% | 2 |

Future studies or surveys could explore:

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

How do people diagnosed with lung cancer describe themselves?

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

In the first survey, the GLCC asked people how they describe themselves. Respondents were asked to tick as many of the different descriptions as they felt applied to them. A higher proportion of respondents described themselves as ‘living with lung cancer’ (46%) rather than as a ‘patient’ (31%).

While people were given more options to choose from this year, the most popular choice was again ‘living with lung cancer’ with 64% of respondents describing themselves this way. With a higher proportion of respondents diagnosed in the last three years (44%), it is likely that most are having treatment currently, which could explain why most described themselves as ‘living with lung cancer’. 44% described themselves as a ‘patient’ (31% in 2020). 8% and 2% described themselves as ‘fighter’ and ‘warrior’ respectively (those options were not available in 2020).

This year, four respondents skipped this question. Figure 13a (overleaf) shows all the responses and compares the results to those obtained in 2020. In Figure 13b, we show the results for the options that were only available this year, such as ‘thriller’ or ‘warrior’. There was also the option to pick ‘other’ for people to include their own description. Seven respondents (14%) selected ‘other’, and Figure 14 sets out some of the responses.

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

| | Living with lung cancer | | Patient | | Surviving with lung cancer | | Lung cancer survivor | | Overcomer | |
|-------------|-------------------------|--------|------------|--------|----------------------------|--------|----------------------|--------|------------|--------|
| | Percentage | Number | Percentage | Number | Percentage | Number | Percentage | Number | Percentage | Number |
| 2021 survey | 64% | 32 | 44% | 22 | 14% | 7 | 20% | 10 | 2% | 1 |
| 2020 survey | 46% | 71 | 31% | 47 | 16% | 24 | 28% | 43 | 4% | 6 |

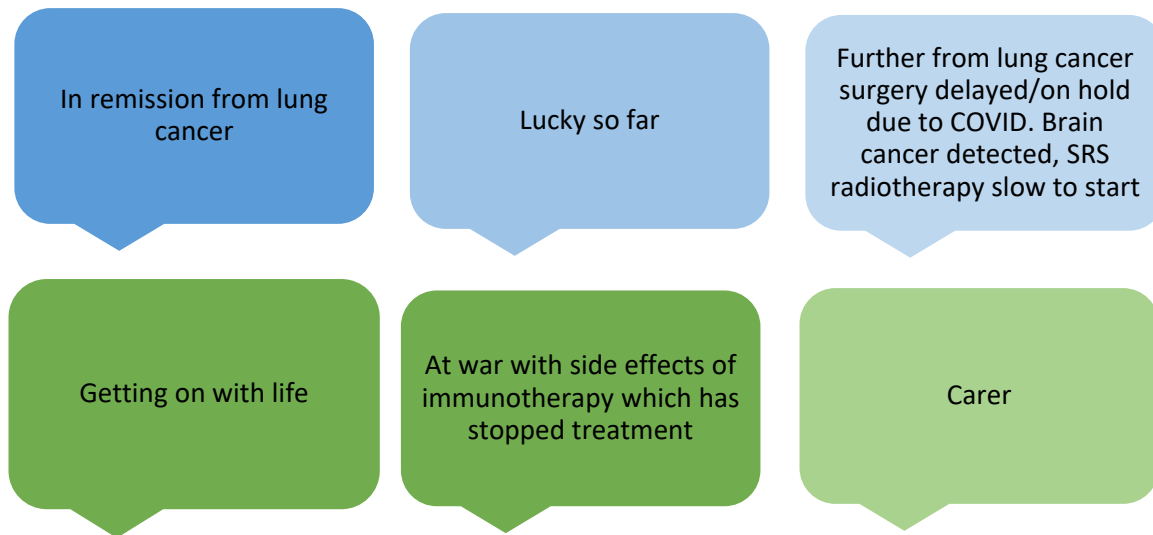
| | Survivor | | Advocate | | Thriver | | Other | |
|-------------|------------|--------|------------|--------|------------|--------|------------|--------|
| | Percentage | Number | Percentage | Number | Percentage | Number | Percentage | Number |
| 2021 survey | 10% | 5 | 22% | 11 | 4% | 2 | 14% | 7 |
| 2020 survey | 17% | 26 | 11% | 17 | 6% | 10 | 9% | 14 |

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

| | Battling lung cancer | | At war with lung cancer | | Fighter | | Warrior | | Fighting lung cancer | |
|-------------|----------------------|--------|-------------------------|--------|------------|--------|------------|--------|----------------------|--------|
| | Percentage | Number | Percentage | Number | Percentage | Number | Percentage | Number | Percentage | Number |
| 2021 survey | 4% | 2 | 4% | 2 | 8% | 4 | 2% | 1 | 12% | 6 |

Figure 14: How would you describe yourself today? Responses from respondents who picked 'other', results for 2021

Seven respondents (14%) selected 'other'. Two respondents answered 'in remission from lung cancer'



Future studies could look into:

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

Insights from the 2021 patient experience survey

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

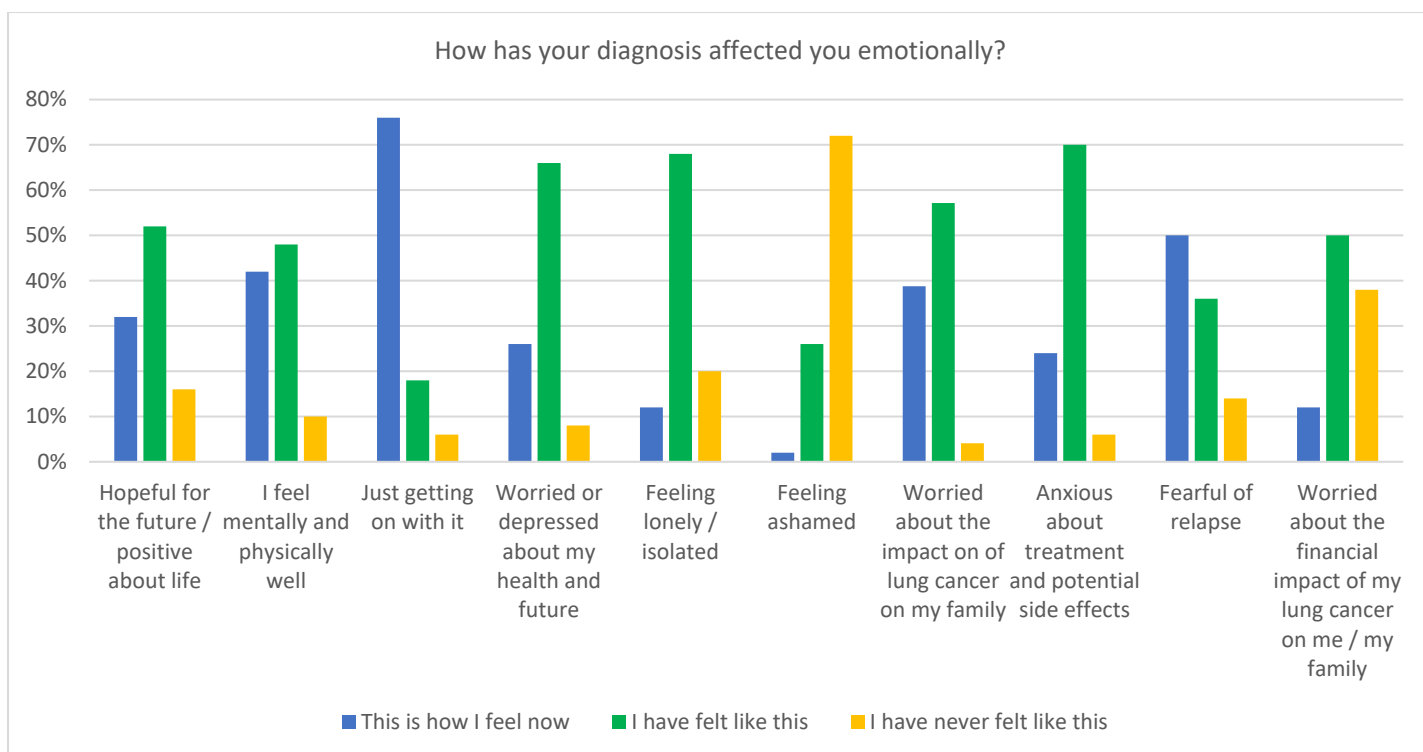
This year, the GLCC decided to ask people questions to understand how their diagnosis has affected them both emotionally and physically, and what type of support they sought.

Emotional and physical wellbeing

How were people affected emotionally after a lung cancer diagnosis?

Respondents were asked how their diagnosis has affected them emotionally. The survey included a list of ten options as well as the possibility to indicate whether the statement applied to them now, in the past, or never. Only four 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 15a: How diagnosis affected respondents emotionally, results for 2021

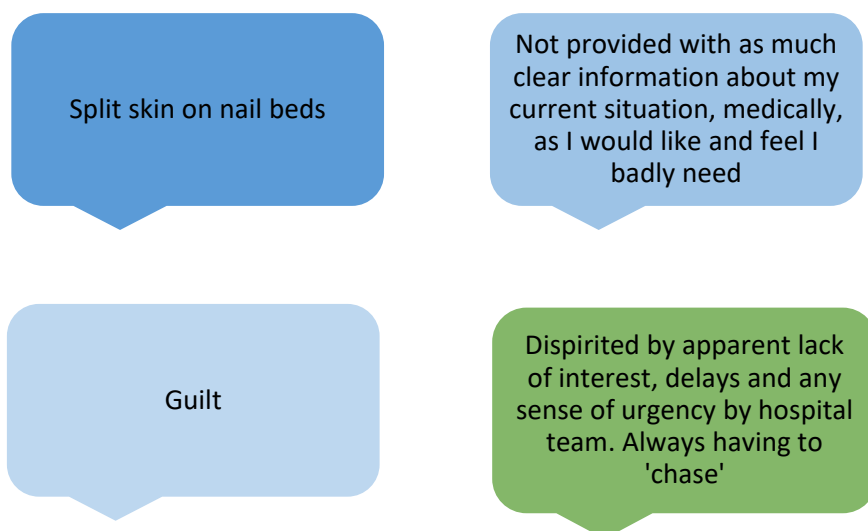


The results show that respondents experience a wide range of emotions. Despite some of the stigma associated with lung cancer, 72% said they never felt ashamed while a quarter (26%) had felt this way at some point. 80% of respondents said they are feeling or have felt lonely or isolated.

76% of UK respondents said they were just getting on with their cancer. 32% feel hopeful or positive about life, but 16% of respondents never felt hopeful and 52% used to feel this way. 26% of respondents currently feel worried or depressed about their health and future, and half (50%) are fearful of relapse.

When it came to their mental and physical wellbeing, 42% of respondents feel well at the moment, while about a half of respondents (48%) said they have felt well and 10% never felt well. Just over a fifth (24%) are currently anxious about treatment while 70% have felt this way. 39% of respondents are currently worried about the impact of their condition on their family, while a further 57% have felt this way.

Figure 15b: How diagnosis affected respondents emotionally. Responses from respondents (four respondents) who picked 'other', results for 2021



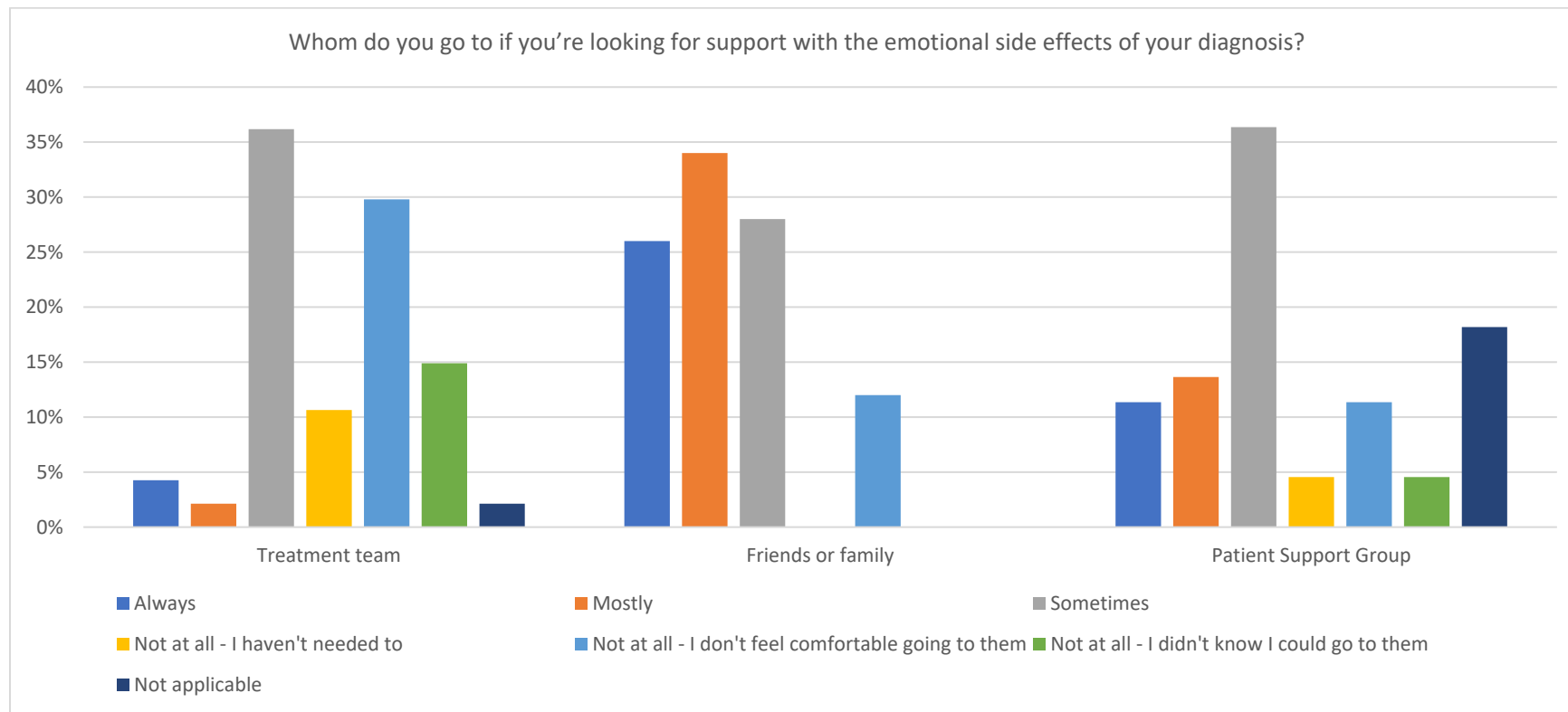
Further studies could explore:

- How experience of care and interaction with a treatment team influences the way people feel about their diagnosis as they progress through their journey
- How different forms of support and information impact people's mental and physical wellbeing, and concerns about treatment and potential impact
- Why some people felt lonely, and what can be done to support them

Where do people turn for emotional support?

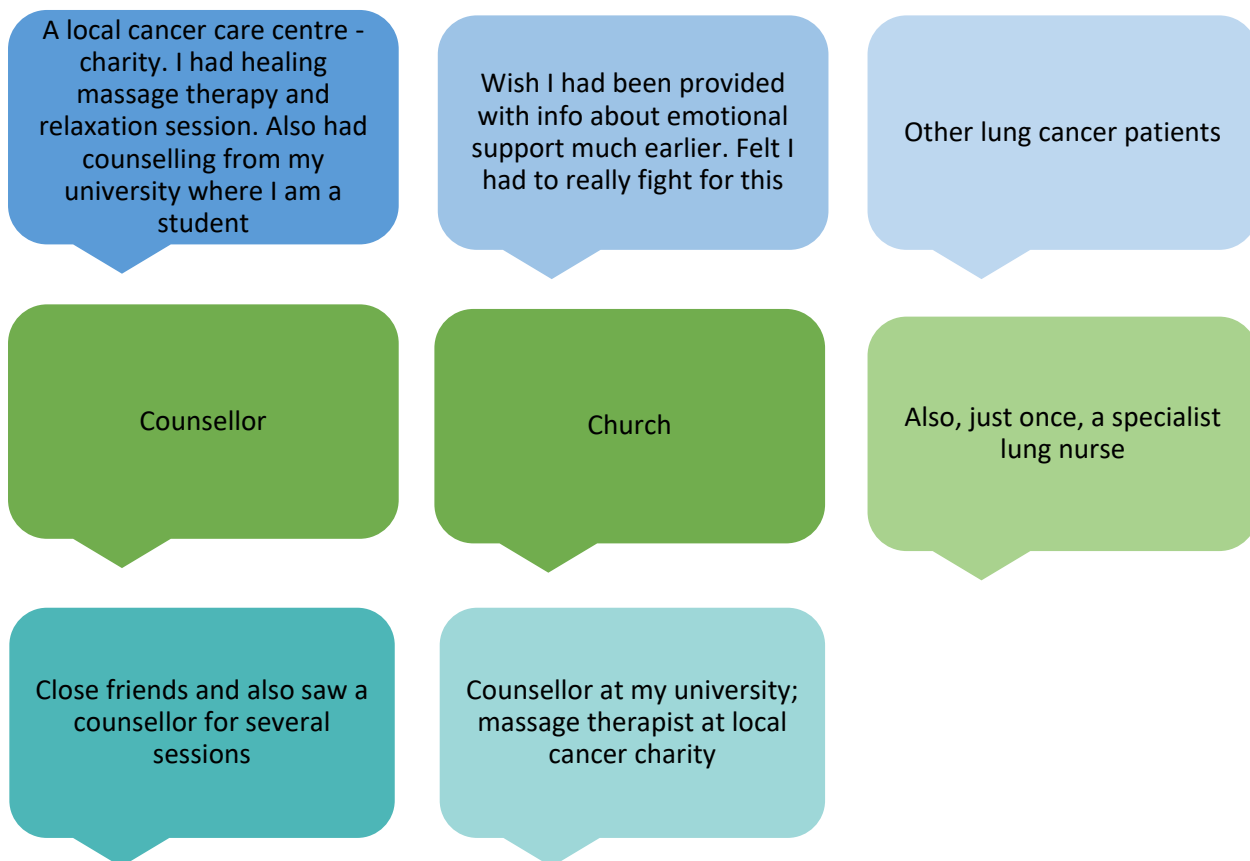
Respondents were asked about whom they go to when looking for support with the emotional impact of their diagnosis. People could choose from four options, including 'other' to which they could add information about where they would turn for help. Out of the 54 respondents, four people skipped this question, and eight respondents selected the 'other' option (Figure 16b)

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



The results show that respondents primarily turned to friends and family for emotional support. A quarter (26%) said they always reached out to friends and family for support, compared to 4% saying they always reached out to their treatment team for help, and 11% saying they always reached out to patient support groups. 36% said they sometimes asked their care team for emotional support. However, 15% of the respondents said they didn't know they could ask their treatment team for this kind of support, and 30% said they don't feel comfortable doing so. 36% of respondents said they sometimes asked patient support groups for emotional support.

Figure 16b: Where do people turn for support with the emotional impact of their diagnosis? Responses from respondents (eight respondents) who picked 'other', results for 2021



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 nearly a third 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
- Should more support be offered to family members given the fact that they are often the most important source of emotional support for people affected with cancer

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

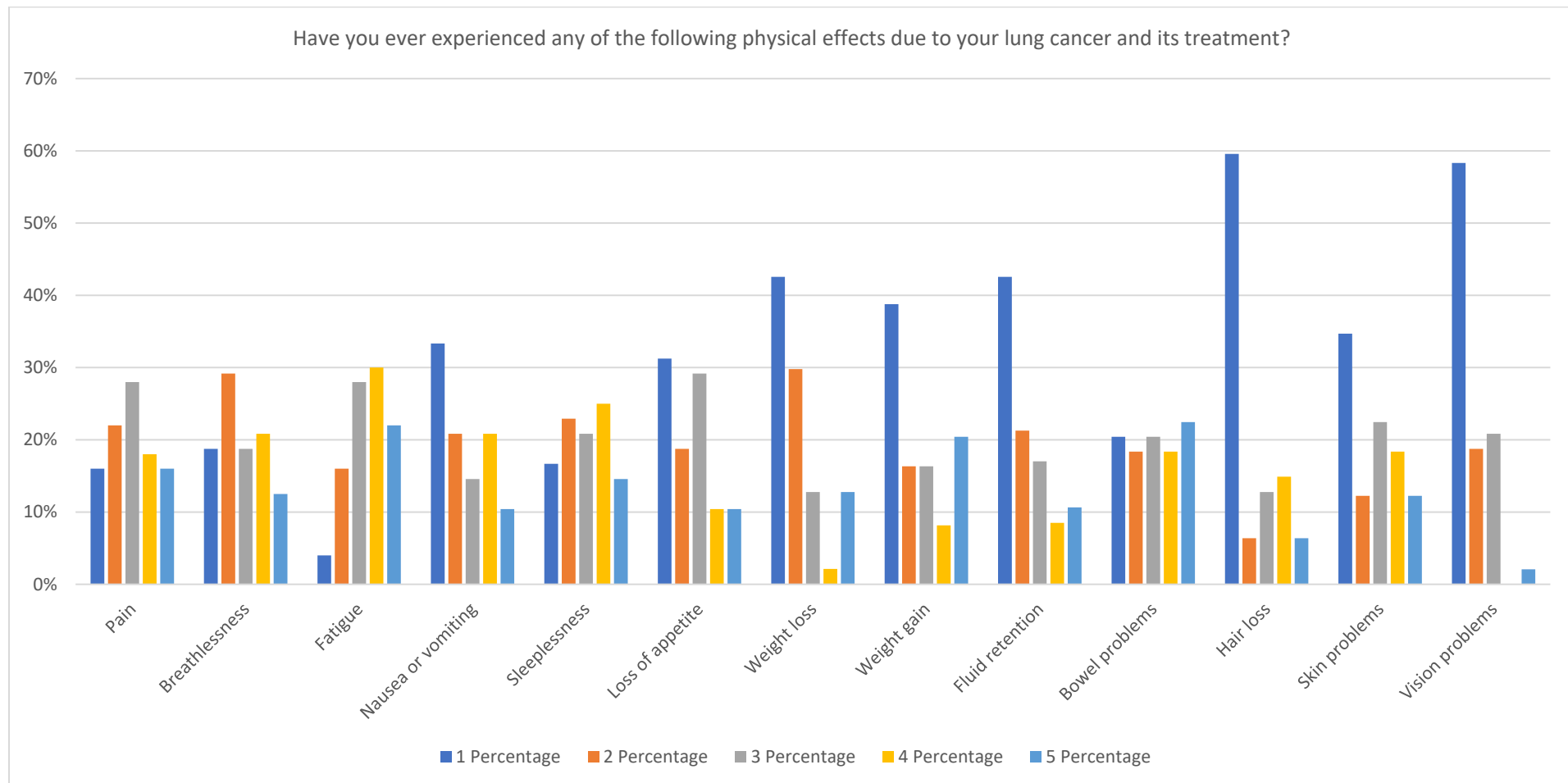
Respondents were asked about the physical effects they experienced because of their cancer and its treatment. We gave respondents 13 options and, for each option, people could select a number from 1 to 5, where 1 means this has not affected them and 5 means this has been a very serious concern. Four people skipped this question, and six 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. Results for 2021

| | 1 | 2 | 3 | 4 | 5 | Total | Weighted Average | |
|--------------------|------------|------------|------------|------------|------------|--------|------------------|------|
| Answer Choices | Percentage | Percentage | Percentage | Percentage | Percentage | Number | Number | |
| Pain | | 16% | 22% | 28% | 18% | 16% | 50 | 2.96 |
| Breathlessness | | 19% | 29% | 19% | 21% | 13% | 48 | 2.79 |
| Fatigue | | 4% | 16% | 28% | 30% | 22% | 50 | 3.5 |
| Nausea or vomiting | | 33% | 21% | 15% | 21% | 10% | 48 | 2.54 |
| Sleeplessness | | 17% | 23% | 21% | 25% | 15% | 48 | 2.98 |
| Loss of appetite | | 31% | 19% | 29% | 10% | 10% | 48 | 2.5 |
| Weight loss | | 43% | 30% | 13% | 2% | 13% | 47 | 2.13 |
| Weight gain | | 39% | 16% | 16% | 8% | 20% | 49 | 2.55 |
| Fluid retention | | 43% | 21% | 17% | 9% | 11% | 47 | 2.23 |
| Bowel problems | | 20% | 18% | 20% | 18% | 22% | 49 | 3.04 |
| Hair loss | | 60% | 6% | 13% | 15% | 6% | 47 | 2.02 |
| Skin problems | | 35% | 12% | 22% | 18% | 12% | 49 | 2.61 |
| Vision problems | | 58% | 19% | 21% | 0% | 2% | 48 | 1.69 |

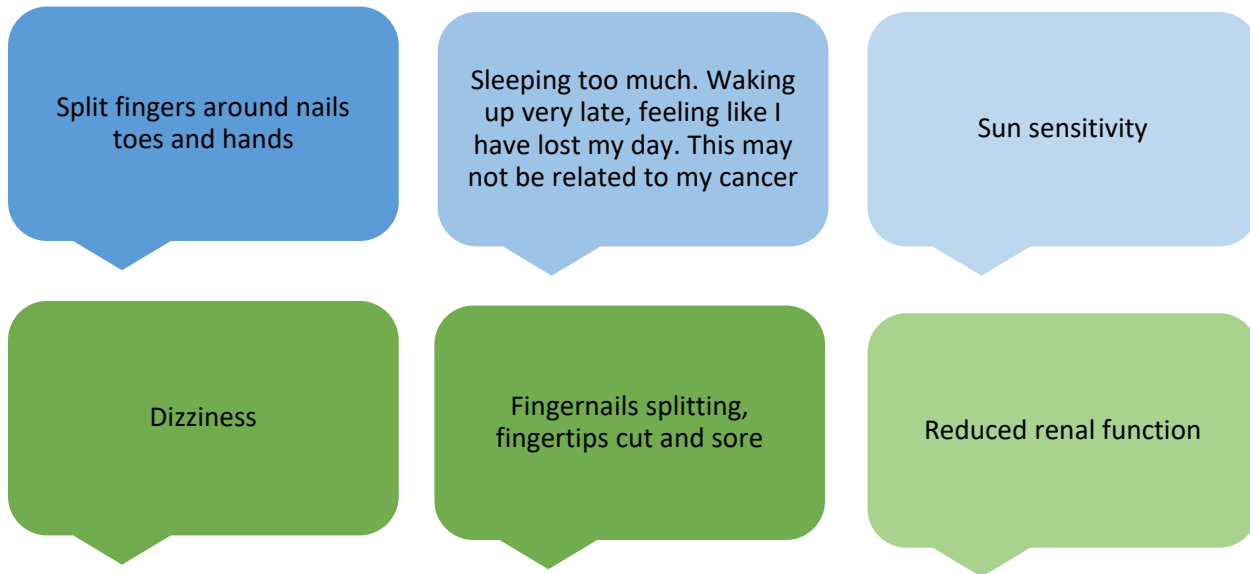
The weighted averages in Figure 17a give an indication of how serious the issues are for patients, compared to each other. A higher number indicates a more serious concern for the respondents. The table shows that, on average, fatigue (3.5) was the most serious issue for respondents, followed by bowel problems (3.04), sleeplessness (2.98) and pain (2.96).

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



22% of respondents gave a 5 when describing the impact of fatigue, and 30% scored a 4 meaning that fatigue has been a very serious concern for respondents. 22% gave a 5 to describe the impact of bowel problems and a quarter of respondents scored a 4 for sleeplessness (25%). When it came to pain, 18% of respondents scored a 4 and 16% scored a 5.

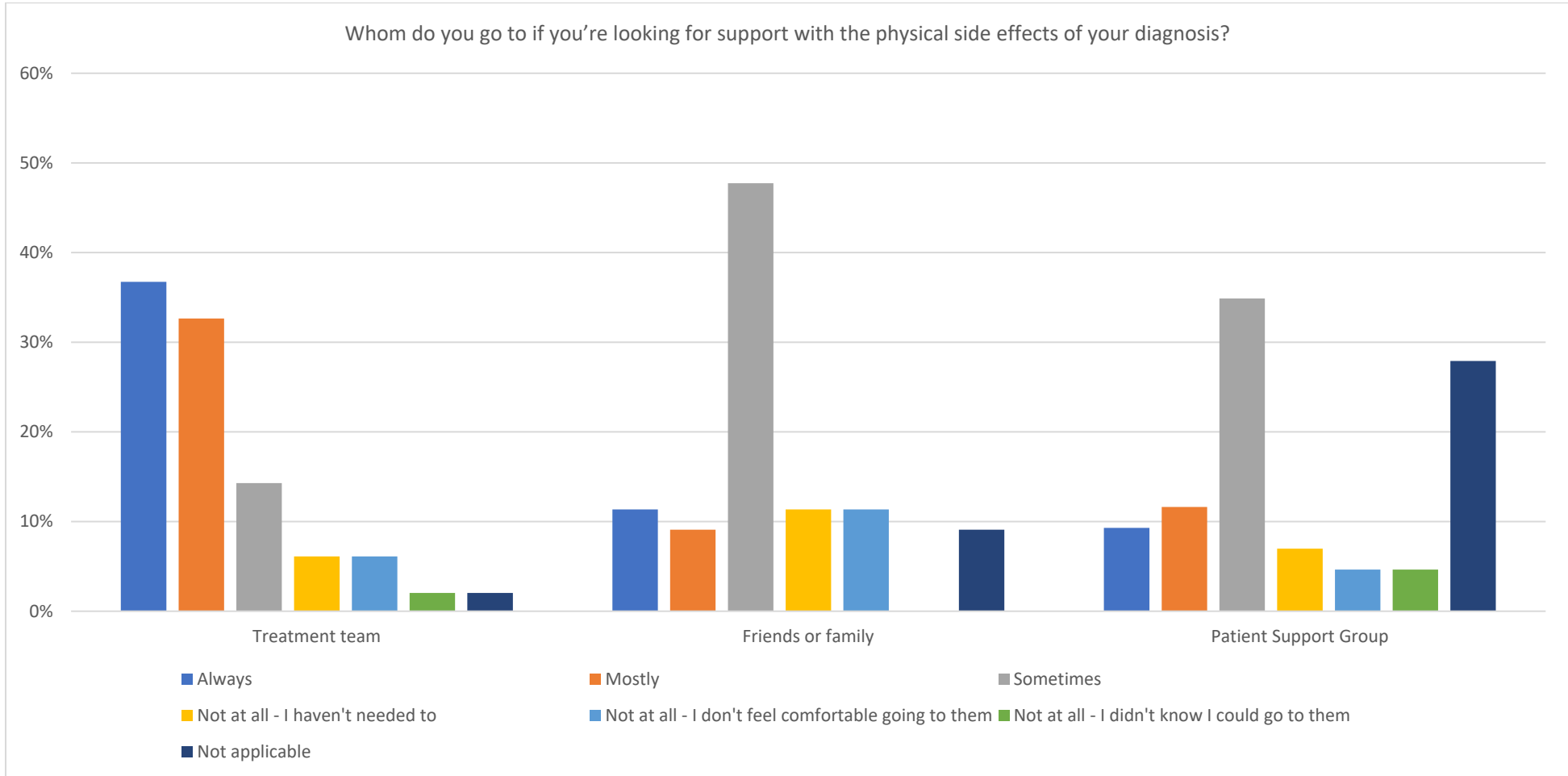
Figure 17c: Have you ever experienced any of the following physical effects due to your lung cancer and its treatment? Responses from respondents (six respondents) who picked 'other', results for 2021



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

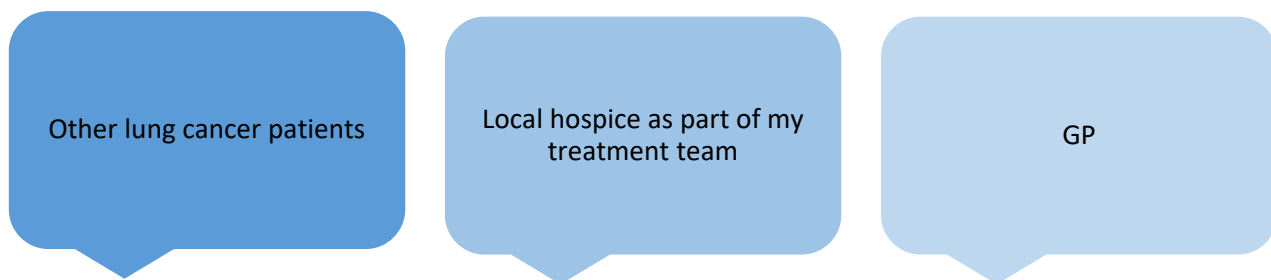
Respondents were asked whom they go to when they are looking for support with the physical effect of their diagnosis. People could choose from their treatment team, family and friends, patient support group or 'other'. In addition, patients could indicate how often they reached out to those people. Five people skipped this question. Figure 18a (overleaf) is a breakdown of all the responses, and Figure 18b shows results for the three respondents who picked 'other'.

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



When it came to asking for support with the physical impact of their diagnosis, the highest proportion of respondents said they would go to their treatment team. 37% said they always contacted their care team, and 11% said they always reached out to friends and family. 14% of respondents said they sometimes reach out to their treatment team for support when they experienced physical effects from their diagnosis. 5% of respondents said they don't feel comfortable asking for support to patient support groups, and 5% of respondents said they didn't know they could go to them. Looking at some of the findings outline above, people diagnosed with lung cancer go to their treatment team for support with physical effects, but friends and family when they need support to deal with emotional effects.

Figure 18b: Whom do you go to if you're looking for support with the physical effects of your diagnosis? Responses for respondents (three respondents) who picked 'other', results for 2021



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

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

Experience of care during the pandemic

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

Figure 19a: Which of the following describes your experience during COVID-19? (Tick all that apply). Results for 2021 check data with overall spreadsheet (ie with the ‘other’ results)

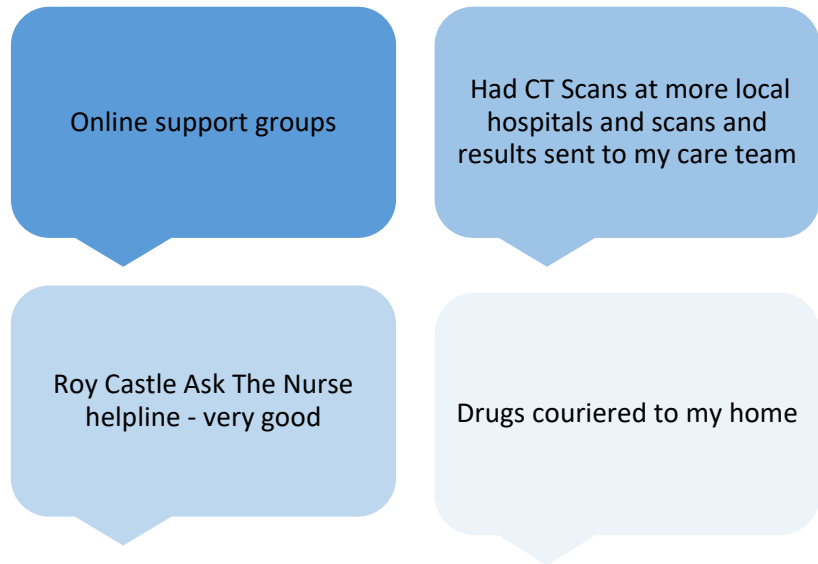
| Answer Choices | Percentage | Number |
|---|------------|--------|
| I found it easier to contact my treatment team | 2% | 1 |
| There has been no difference in how easy it has been to contact my treatment team | 43% | 20 |
| I found it more difficult to speak to my treatment team | 26% | 12 |
| I have held back in contacting my treatment team because they are so busy | 21% | 10 |
| My treatment has continued as normal | 43% | 20 |
| My treatment has been delayed / cancelled | 11% | 5 |
| I don't know if my treatment has been affected | 6% | 3 |
| I have carried on attending appointments during the pandemic | 49% | 23 |
| I have been reluctant to attend appointments for fear of infection | 4% | 2 |
| I have missed appointments for fear of infection | 4% | 2 |
| My face-to-face appointments have been swapped for telephone or video calls | 85% | 40 |
| I have been offered new services that weren't available to me before the pandemic | 9% | 4 |

Only 2% of respondents said it had been easier to contact their treatment team during the pandemic, with 43% of respondents saying there has been no difference and 26% finding it more difficult. 49% said they have carried on attending their appointments in person during the pandemic. 85% of respondents said their face-to-face appointments have been swapped for telephone or video calls (a later section looks in more detail at the impact of this). 21% of respondents said they held back from contacting their team because they were so busy.

43% of respondents said their treatment has carried out as normal, around one in ten (11%) had experienced delays to treatment, with a further 6% unsure about the impact on their treatment.

Figure 19b: Which of the following describes your experience during COVID-19? Results for 2021

Four respondents selected 'other'. Some of the responses are set out below.



Impact of the pandemic on mental and physical wellbeing

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

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

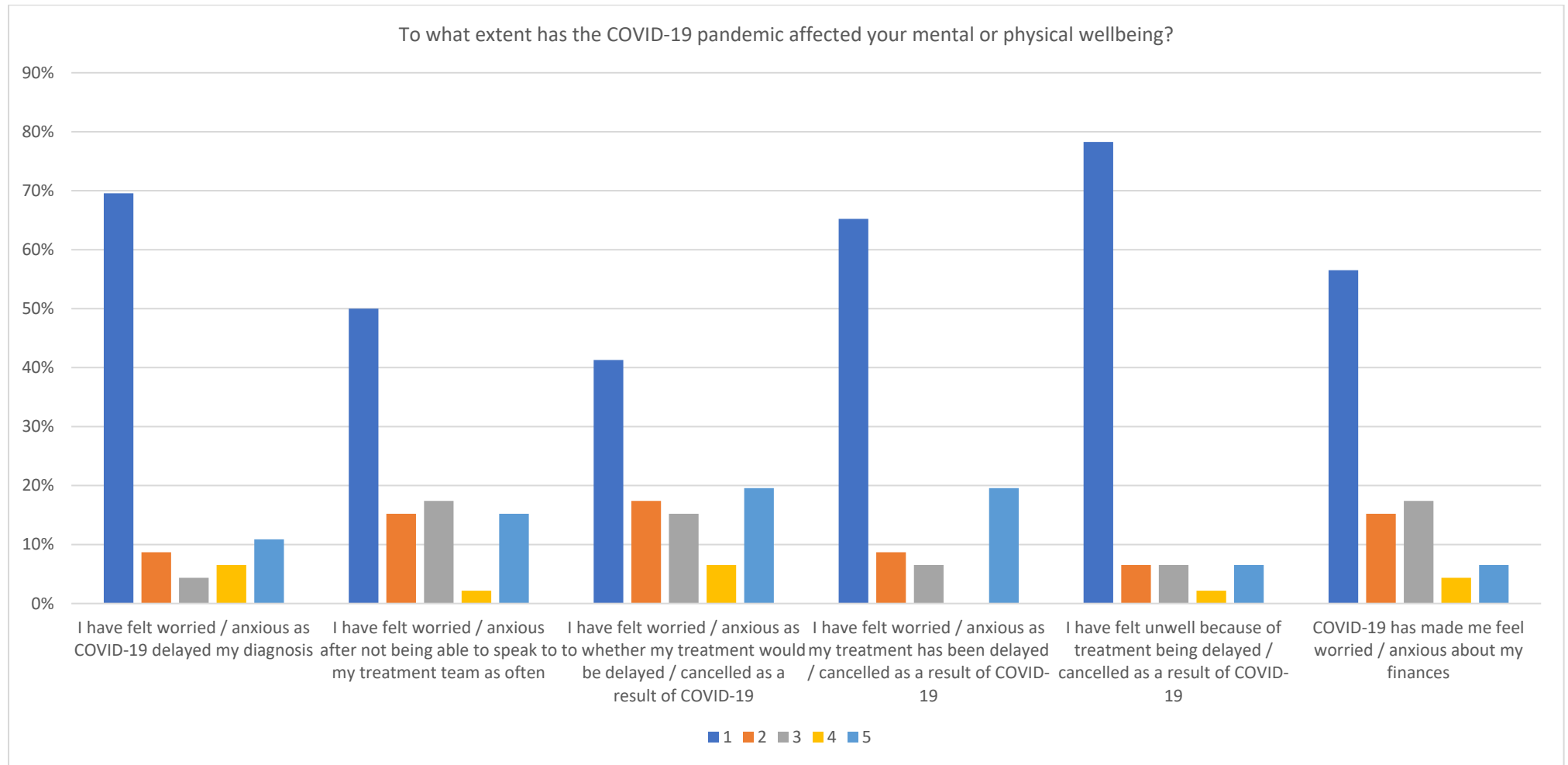


Figure 20b: To what extent has the COVID-19 pandemic affected your mental or physical wellbeing? Please choose an option from 1 – 5, where 1 means this has not affected me and 5 means this has been a very serious concern. Results for 2021

| Answer Choices | 1 | 2 | 3 | 4 | 5 |
|---|-----|-----|-----|----|-----|
| I have felt worried / anxious as COVID-19 delayed my diagnosis | 70% | 9% | 4% | 7% | 11% |
| I have felt worried / anxious after not being able to speak to my treatment team as often | 50% | 15% | 17% | 2% | 15% |
| I have felt worried / anxious as to whether my treatment would be delayed / cancelled as a result of COVID-19 | 41% | 17% | 15% | 7% | 20% |
| I have felt worried / anxious as my treatment has been delayed / cancelled as a result of COVID-19 | 65% | 9% | 7% | 0% | 20% |
| I have felt unwell because of treatment being delayed / cancelled as a result of COVID-19 | 78% | 7% | 7% | 2% | 7% |
| COVID-19 has made me feel worried / anxious about my finances | 57% | 15% | 17% | 4% | 7% |

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, more than one in ten (11%) of respondents scored a 5, and 7% scored a 4
- On worries caused because treatment have being delayed or cancelled as a result of COVID-19, 20% scored it a 5
- On worries about finances as a result of the pandemic, 11% scored it a 4 or 5

17% said they felt anxious after not being able to speak with their treatment team as often (score 4 and 5 at 2% and 15% respectively). 20% felt worried as to whether their treatment would be delayed or cancelled because of COVID-19 (20% of respondents 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 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. Six 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). Results for 2021

| Answer Choices | Percentage | Number |
|--|------------|--------|
| Telephone | 94% | 45 |
| Video | 17% | 8 |
| In person | 67% | 32 |
| 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 | 2% | 1 |

94% of respondents have had conversations with their treatment team via telephone. 67% respondents continued to see their treatment team in person, followed by video consultation (17%). 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 respondent from the UK answered this question.

Figure 22: Why were you not able to speak to your treatment team? Results for 2021

| 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. Nine people skipped this question.

Results show that 33% said they found contacting their treatment team by video or telephone helpful because they didn't have to travel to hospital as much, while 24% found it quicker to have appointments by video or telephone. However, nearly three quarters (73%) still preferred face-to-face appointments. 16% found it more difficult to understand the treatment team or make themselves understood if not in person. Four people said they don't like it and want to stop as soon as possible (9%).

Figure 23a: What is your opinion on contacting you treatment team by video or telephone? Results for 2021

| Answer Choices | Percentage | Number |
|--|------------|--------|
| I found it quicker | 24% | 11 |
| I found it helpful as I don't have to travel to hospital as much | 33% | 15 |
| I prefer face-to-face appointments | 73% | 33 |
| I found it more difficult to understand my treatment team / make myself understood | 16% | 7 |
| I don't like it and I want to stop as soon as possible | 9% | 4 |

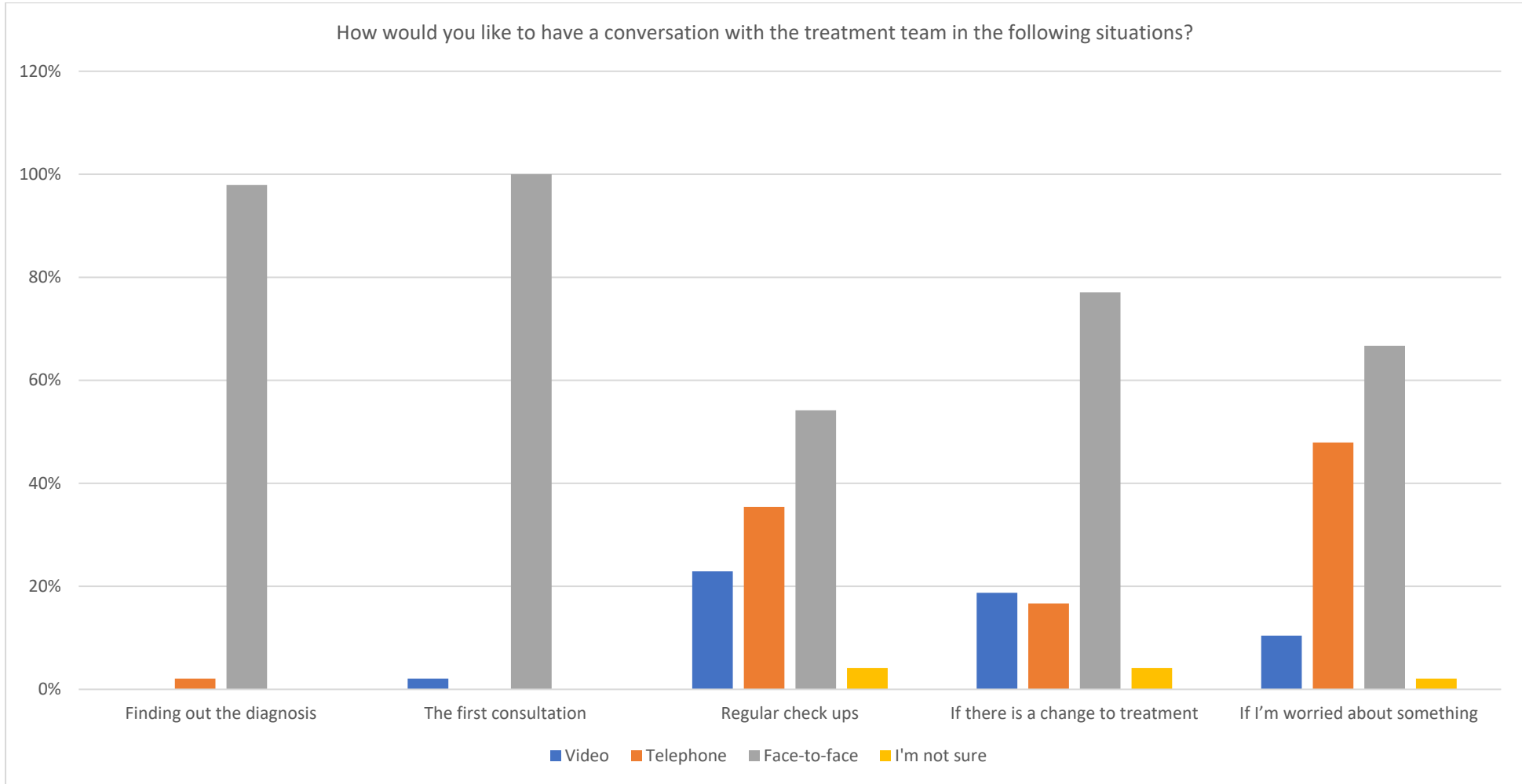
When dealing with different situations, what do people think is the best way to speak with their treatment team?

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. Six people skipped this question.

98% of respondents said that the best way to find out by a diagnosis was in person, and 100% said they preferred to have a face-to-face conversation for their first consultation. 77% felt that if there was a change in treatment it was best to have a face-to-face conversation. For regular check-ups, 54% felt it was best to have a face-to-face conversation, while 35% 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 (67%) or have a telephone consultation (48%).

Respondents have a preference for face-to-face appointments in all situations. In future studies, it would be useful to assess whether this is representative of the wider population in the UK. 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 24a: How would you like to have a conversation with the treatment team in the following situations? (Tick all that apply). Results for 2021



Receiving information

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

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

Figure 25a: If you wanted more information, would you want to get your information from any of the following? (Tick all that apply). Results for 2021

| Answer Choices | Yes, I'd like to, and I have done so already | | Yes, but I haven't done yet | | Yes, and I didn't know I could | | No, I don't want to | | Total |
|--|--|--------|-----------------------------|--------|--------------------------------|--------|---------------------|--------|--------|
| | Percentage | Number | Percentage | Number | Percentage | Number | Percentage | Number | Number |
| My treatment team | 77% | 37 | 17% | 8 | 4% | 2 | 2% | 1 | 48 |
| Patient support organisations | 60% | 28 | 21% | 10 | 4% | 2 | 15% | 7 | 47 |
| Other people that have been diagnosed with lung cancer | 58% | 26 | 22% | 10 | 4% | 2 | 16% | 7 | 45 |
| Friends or family | 36% | 16 | 13% | 6 | 2% | 1 | 49% | 22 | 45 |
| The internet | 69% | 33 | 13% | 6 | 4% | 2 | 15% | 7 | 48 |
| Social media | 40% | 19 | 13% | 6 | 0% | 0 | 47% | 22 | 47 |
| Pharmaceutical company | 13% | 6 | 17% | 8 | 26% | 12 | 43% | 20 | 46 |

The results show that the majority of respondents have sought information from their treatment team (77%), followed by the internet (69%) and patient support organisations (60%). Thinking about their treatment team, 17% said they haven't reached out to them yet, and 2% said they didn't want to. 58% of respondents said they had already contacted other people diagnosed with lung cancer for information.

49% of respondents said they wouldn't contact friends and family to seek out information, 47% wouldn't turn to social media, and 43% of said they wouldn't go to pharmaceutical companies for information. Amongst the respondents who picked 'other', one said "Leaflets given to me. Not very helpful. Too basic and don't tell me enough" and the other said they "would like additional, more objective advice and support, from independent source such as specialist charity nurse".

Further studies could explore:

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

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

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

Figure 26: How do you like to receive information? (Tick all that apply). Results for 2021

| Answer Choices | Percentage | Number |
|---|------------|--------|
| A conversation in person | 84% | 41 |
| A conversation over the phone | 61% | 30 |
| A conversation on video call | 35% | 17 |
| Something I can read e.g. a leaflet / booklet | 61% | 30 |
| Something I can view online e.g. a website / social media | 61% | 30 |
| Something I can listen to e.g. a podcast | 16% | 8 |
| Something I can watch e.g. a video | 39% | 19 |

The findings show that people with lung cancer have different preferences and needs, so information needs to be available in different formats. For conversations, 84% of respondents said they would like in person conversations, with telephone or video scoring lower (61% and 35% respectively). This 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. 61% said they would like something to view online and 61% said they would like to have something to read. Videos are popular with a third of respondents (39%) but podcasts less so (16%).

More information

The Global Lung Cancer Coalition is an alliance of patient organisations from across the world. Established in 2001, the GLCC comprises 40 non-government patient organisations from 30 nations: Argentina, Australia, Brazil, Bulgaria, Canada, Czech Republic, Denmark, Egypt, France, Germany, Greece, Ireland, Israel, Italy, Japan, Mexico, Netherlands, Norway, Peru, Portugal, Russia, Slovenia, South Africa, Spain, Sweden, Switzerland, Taiwan, Turkey, UK and USA.

The GLCC's members from the UK are:

- [British Lung Foundation](#)
- [Lung Cancer Nursing UK](#)
- [Roy Castle Lung Cancer Foundation](#)

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

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

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