



GLOBAL LUNG CANCER
COALITION

COVID-19 PANDEMIC: THE IMPACT ON LUNG CANCER PATIENTS

Insights from the Netherlands

2021 Patient Experience Survey

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Introduction

In 2019, 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. 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 Netherlands**. Patients from the Netherlands 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, 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, more people from the Netherlands filled out our survey – 175 compared to 152 in 2019. Section 1, 2, and 3 listed above were included in the first survey, and we have compared 2019 and 2021 results whenever applicable. Sections 4, 5, and 6 are new so only include 2021 data.

2021 Patient Experience survey and insights from 2019

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. More people from the Netherlands completed the survey this year, 175 compared to 152 in 2019. Out of the 175 people who answered this question, 152 people described themselves as a patient and 17 as a carer. Six people skipped this question.

The majority of the respondents said they had not filled out the first patient experience survey (118 respondents). 15 respondents said they had completed it in 2019 and 42 respondents said they were not sure.

Gender

This year, 151 (86%) of respondents were women and 24 (14%) were men (Figure 1). As with 2019, more women than men filled out the survey (74% of respondents in 2019 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	Number	Percentage	Number	Percentage	Number	Percentage
86	151	14	24	0	0	0	0	0	0

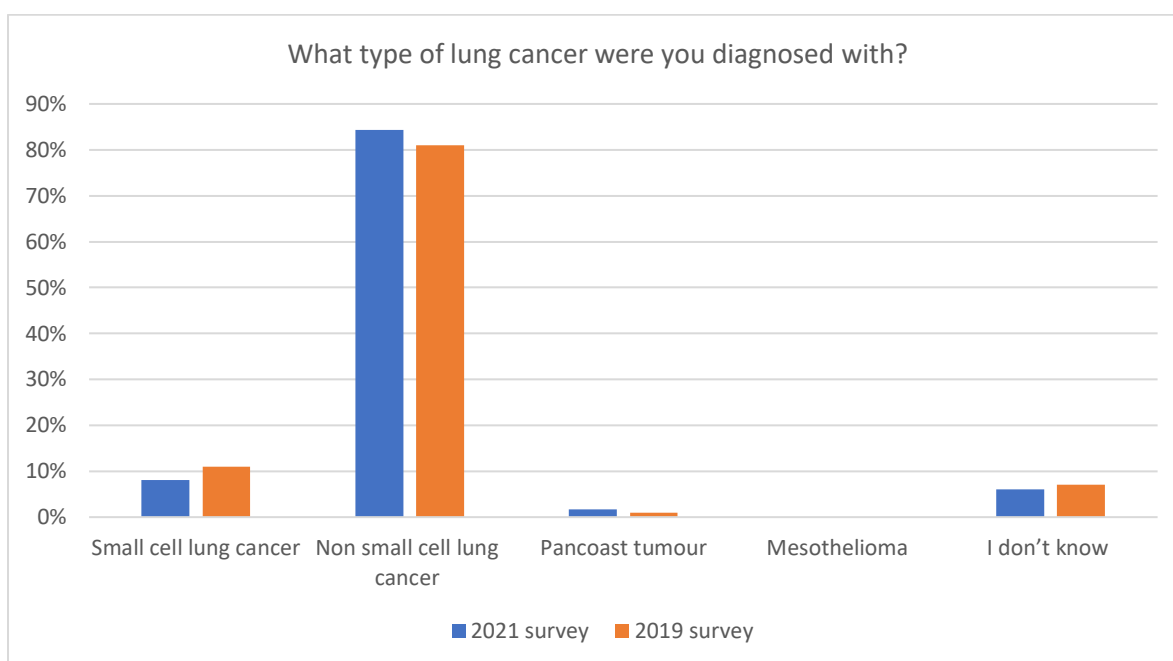
Diagnosis

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 2019, the largest proportion of respondents (84% vs 81% in 2019) stated they had non-small cell lung cancer. Only two respondents skipped this question.

Figure 2: Type of lung cancer among respondents, results for 2021 and 2019



Some patients do not know which type of lung cancer they had or have. In 2019, 7% of Netherlands respondents did not know what type of lung cancer they had compared to 6% this year. Amongst those who did not know what type of lung cancer they have, half said they did not want to know and the other half said they would like to know.

The type of lung cancer a patient has will affect the treatment options that are available to them. The results show that some people did not want to know the type of cancer they have, even though this can contribute to understanding their treatment choices and to feel more involved in decisions about their care.

Further survey work could be conducted to determine:

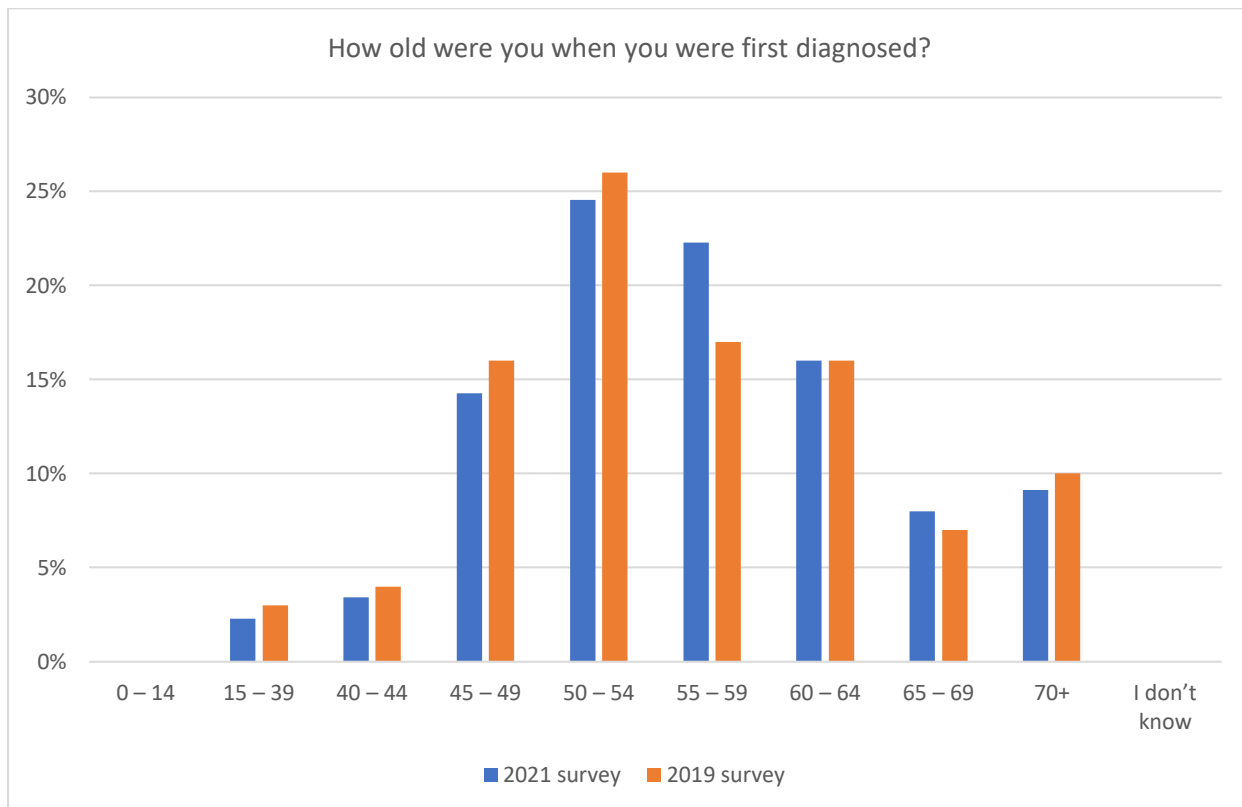
- Whether the figure of 6% of respondents who do not know what type of lung cancer they have reflects the experience of the wider lung cancer patient population in the Netherlands (given the relatively small sample size)
- The reasons why people did not want to know the type of lung cancer they have

Age at diagnosis

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

In the Netherlands, the largest proportion (25%) of respondents said they were diagnosed at age 50-54, followed by 22% at age 55-59. All 175 respondents from the Netherlands answered this question. These results are similar to those obtained in 2019, when 26% were diagnosed at age 50-54, followed by 17% at age 55-59.

Figure 3: Age profile of respondents, results for 2021 and 2019

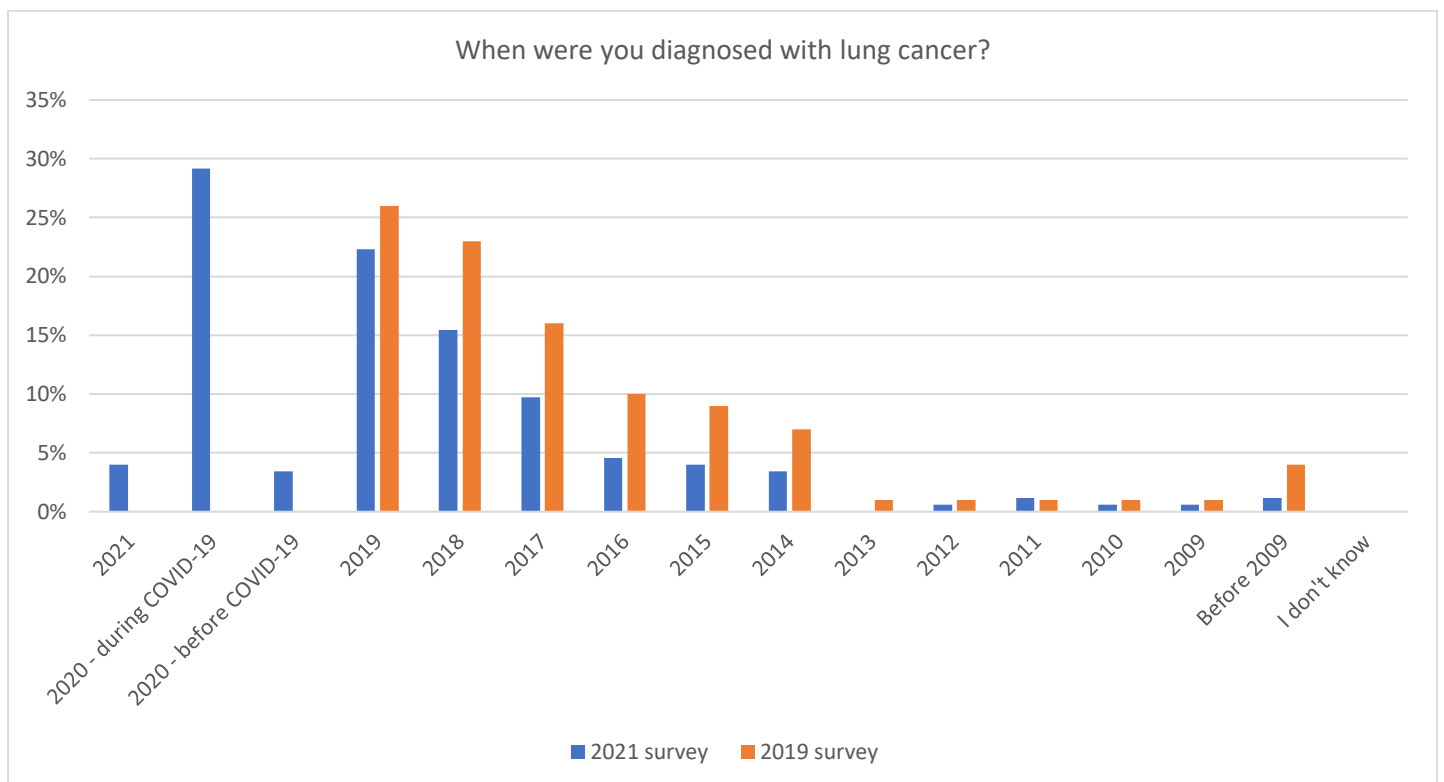


Year of diagnosis

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 175 respondents from the Netherlands answered this question.

The largest proportion of respondents were diagnosed during the pandemic (29%), followed by 22% diagnosed in 2019. Figure 4 shows the survey responses for 2021 and 2019, when most respondents were diagnosed in 2019 (26%).

Figure 4: Year of diagnosis amongst respondents, results for 2021 and 2019



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 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. All 175 respondents from the Netherlands 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	24%	42
Yes, it took too long to see someone to test if I had lung cancer	9%	16
Yes, it took too long to get my test results	9%	16
No, I am satisfied with the time it took to get my diagnosis	62%	109
I'm not sure	1%	1

62% of respondents from the Netherlands said they were satisfied with the time it took to get their diagnosis. Nearly a quarter (24%) said it took them too long to see someone to get their symptoms checked out. Nearly one in ten (9%) felt it took too long to see someone to get tested to see if they had lung cancer.

These results are concerning as late diagnosis can considerably impact a patient's chances of surviving lung cancer. 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.

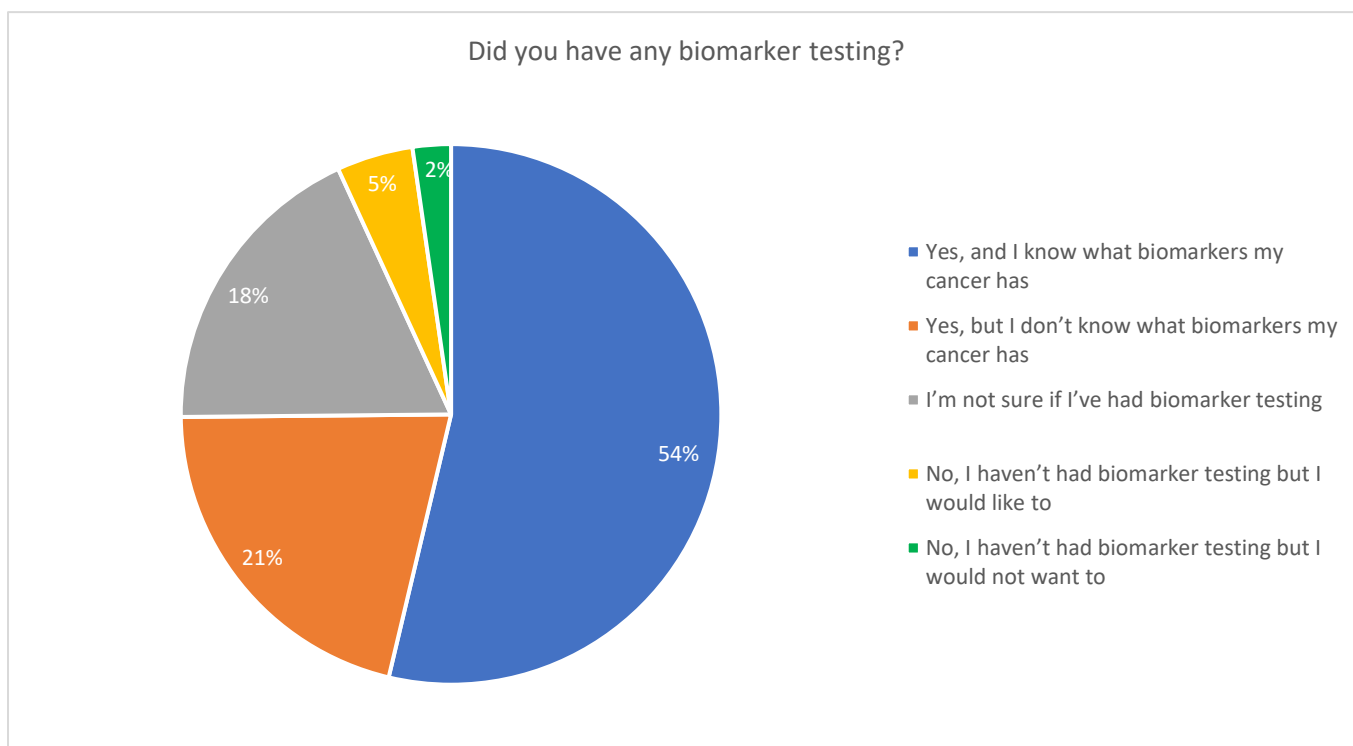
Biomarker testing

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 Netherlands answered this question.

In the first survey, 65% of respondents said they had received a biomarker test, 22% said they hadn't received one, and 13% said they didn't know if they have had one. The results for this year show that a higher number of respondents (75%) had biomarker testing but, amongst those, 21% did not know what biomarkers their cancer has. 5% of respondents said they did not get a test but would like one.

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



Interventions

Respondent profile

Respondents were asked where they were in their cancer journey, and could choose from five options. The majority said they were currently receiving treatment (62%), followed by 34% saying they had finished treatment. 1% said they chose not to have treatment, and 1% said that treatment was not available to them. All 175 respondents answered 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	2%	3
I am currently having treatment	62%	109
I have finished treatment	34%	60
I chose not to have treatment	1%	2
Treatment wasn't available to me	1%	1

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 form of treatment they had received. Only one person skipped this question.

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

- **Surgery:** almost 30% of respondents had surgery compared to 33% in 2019. Surgery is still the best curative option for patients with early-stage lung cancer (stages I and II) so identifying a larger proportion of patients at an early stage, when surgery is an option for them, should be a priority
- **Radiotherapy:** Just over half (53%) of respondents said they had received radiotherapy, compared to 50% in 2019
- **Chemotherapy:** 60% of respondents from the Netherlands had received chemotherapy compared to 53% in 2019
- **Immunotherapy:** the proportion of respondents who had received immunotherapy was much greater, with half of the respondents (50%) this year saying they had received immunotherapy, compared to 26% in 2019
- **Targeted therapies:** 29% of respondents this year said they had received targeted therapies, compared to 36% in 2019
- **Symptom management:** just over a fifth of respondents (21%) said they had received treatment to help with symptom management, compared to a third (34%) in 2019
- **No treatment:** Four respondents said they had received no treatment, but none said it was because of COVID-19. Amongst those, half (2 respondents) said this was because they were due to start treatment. Three respondents said they had received no treatment in 2019
- **Other treatments:** Seven respondents 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 2019

	Surgery		Radiotherapy		Chemotherapy		Immunotherapy	
	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number
2021 survey	29%	50	53%	93	60%	104	50%	87
2019 survey	33%	50	50%	76	53%	80	26%	40

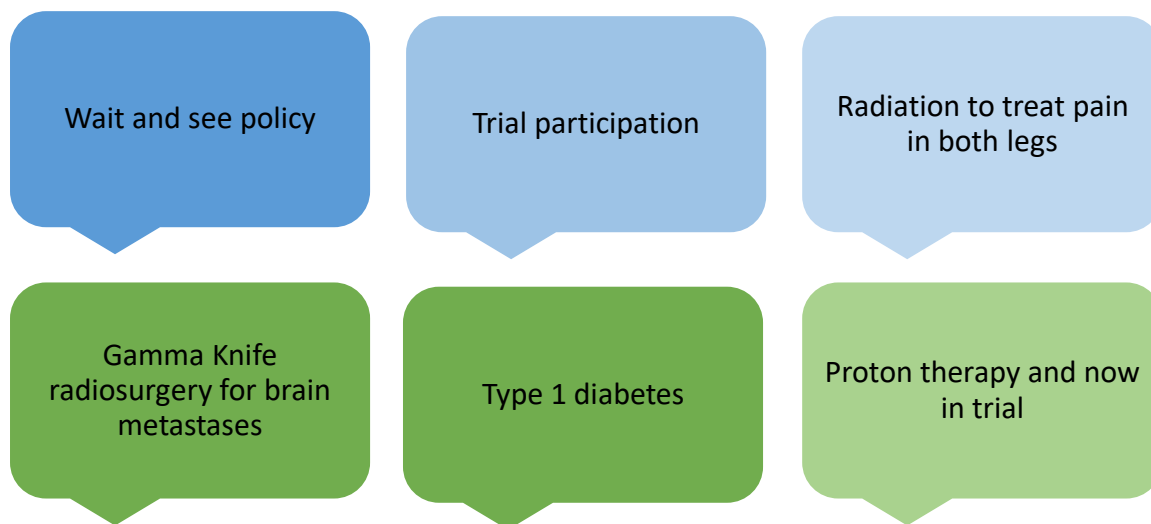
	Targeted therapies		Symptom management	
	Percentage	Number	Percentage	Number
2021 survey	29%	51	21%	36
2019 survey	36%	54	34%	52

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

Answer Choices	Percentage	Number
I have not received any treatment because I have just been diagnosed	1%	1
I have not received any treatment, but I am due to start	1%	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	1%	1
I have not received any treatment because it is not available to me	0%	0
Other (please specify)	4%	7

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

The figure below shows the responses from participants (seven respondents) who selected the 'other' option. Two respondents have said "wait and see policy".



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 175 respondents, only one person skipped this question. The survey results are summarised below and include comparisons with the 2019 patient experience survey:

- **Psychosocial support / counselling:** 30% of respondents to the 2021 survey said they had received psychosocial support and or counselling, compared to 49% in 2019
- **Physical therapy / pulmonary rehabilitation:** around a third of respondents (34%) said they had received physical therapy compared with 48% in 2019 (Figure 10a)
- **Occupational therapy:** only 5% said they had received occupational therapy, compared to 30% in 2019
- **Dietary advice:** 24% of respondents received dietary advice, up from 6% in 2019
- **Lifestyle advice:** 2% said they had they had received lifestyle advice, compared with 6% of respondents in 2019
- **Financial advice:** 1% of respondents said they had received financial advice, compared to 2% in 2019
- **Return to work advice:** 3% said they had received advice on going back to work. More than double that proportion of respondents had received that form of support in 2019 (7%)
- **Smoking cessation:** 4 respondents said they had received support on how to stop smoking (2%)
- **Support group:** 36% said they had received support from peer and/or support group (63 respondents)
- **No support:** 2 respondents said they had not received any other support because the pandemic has delayed it, and 32 said they chose not to receive any (18%). Figure 10c contains further information on respondents' responses
- **Other type of support:** participants also shared with us other forms of support they received. 30 respondents said they had received other kinds of support for their condition (17%). In Figure 10d, we outline some of the responses

Figure 10a: Types of support respondents received, results for 2021 and 2019

	Psychosocial support / counselling		Physical therapy / pulmonary rehabilitation		Occupational therapy		Dietary advice	
	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number
2021 survey	30%	52	34%	59	5%	8	24%	41
2019 survey	49%	56	48%	55	30%	35	6%	7

	Lifestyle advice		Financial advice		Advice on going back to work	
	Percentage	Number	Percentage	Number	Percentage	Number
2021 survey	2%	3	1%	1	3%	6
2019 survey	6%	7	2%	2	7%	8

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

	Support Group		Smoking cessation		Other	
	Percentage	Number	Percentage	Number	Percentage	Number
2021 survey	36%	63	2%	4	17%	30

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

Answer Choices	Percentage	Number
I have not received any other support because I have just been diagnosed	2%	3
I have not received any other support, but I am due to start	2%	4
I have not received any other support because COVID-19 has delayed it	1%	2
I have not received any other support because I chose not to	18%	32
I have not received any other support because it is not available to me	1%	2

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

The figure below shows the responses from participants (30 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 chose not to take them up (18%)
- 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

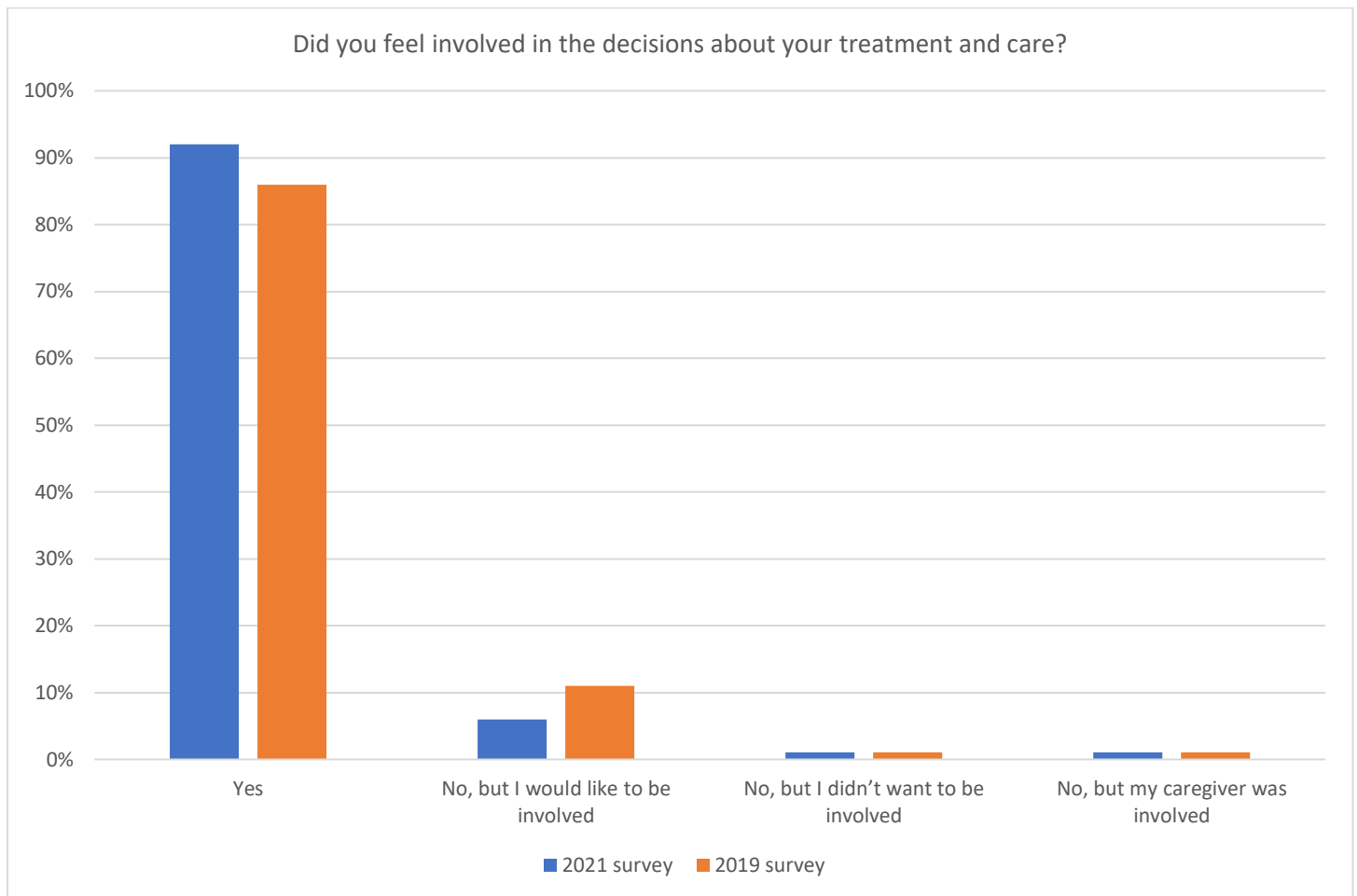
The GLCC believes that every patient has the right to be fully informed of, and involved in, decisions about their treatment and care. This right is enshrined in the GLCC's Patient Charter. The survey findings show the extent to which patients in the Netherlands feel sufficiently involved in making decisions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

In 2019, respondents could only choose from 'Yes', 'No', 'No, but I didn't want to be involved' and 'No, but my caregiver was involved'. 86% 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 175 respondents answered this question. 75% of respondents felt they were fully involved in decision-making, 13% felt they were most of the time involved, and 5% felt they were only sometimes involved.

6% of respondents felt they were not sufficiently involved but wanted to be, compared with 11% a couple of years ago. One person said they didn't want to be involved (two in 2019); and two people said their caregiver was involved in decision-making in their place (two in 2019). Figure 11a (below) compares the responses of this year's survey to that of 2019, 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 2019



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 2019, respondents could only choose from 'Yes', 'No', 'No, but I didn't want to be involved' and 'No, but my caregiver was involved'. For 2019, 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	75%	131
Yes, I've been involved most of the time	13%	22
Yes, I've been involved sometimes	5%	8
No, but I would like to be involved	6%	11
No, but I didn't want to be involved	1%	1
No, but my caregiver was involved	1%	2

Additional analysis of responses shows that 75% of respondents felt fully involved and 13% of respondents have been involved most of the time. However, eight respondents felt they were only involved sometimes.

Future studies or surveys could explore:

- Whether this figure reflects the experience of the wider lung cancer patient population in the Netherlands (given the relatively small sample size)
- Why respondents from the Netherlands 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 175, only one respondent skipped this question this year. When compared to 2019, we found a higher number of respondents said they were always treated with dignity and respect (83% vs 70% in 2019). 11% of respondents said they were ‘mostly’ treated with dignity and respect, and 5% said they were ‘sometimes’ treated with dignity and respect, compared with 23% and 5% respectively in 2019. As in 2019, two patients said that they were never treated with dignity and respect (Figure 12b).

Figure 12a: Proportion of patients feeling treated with dignity and respect by their treatment team, results for 2021 and 2019

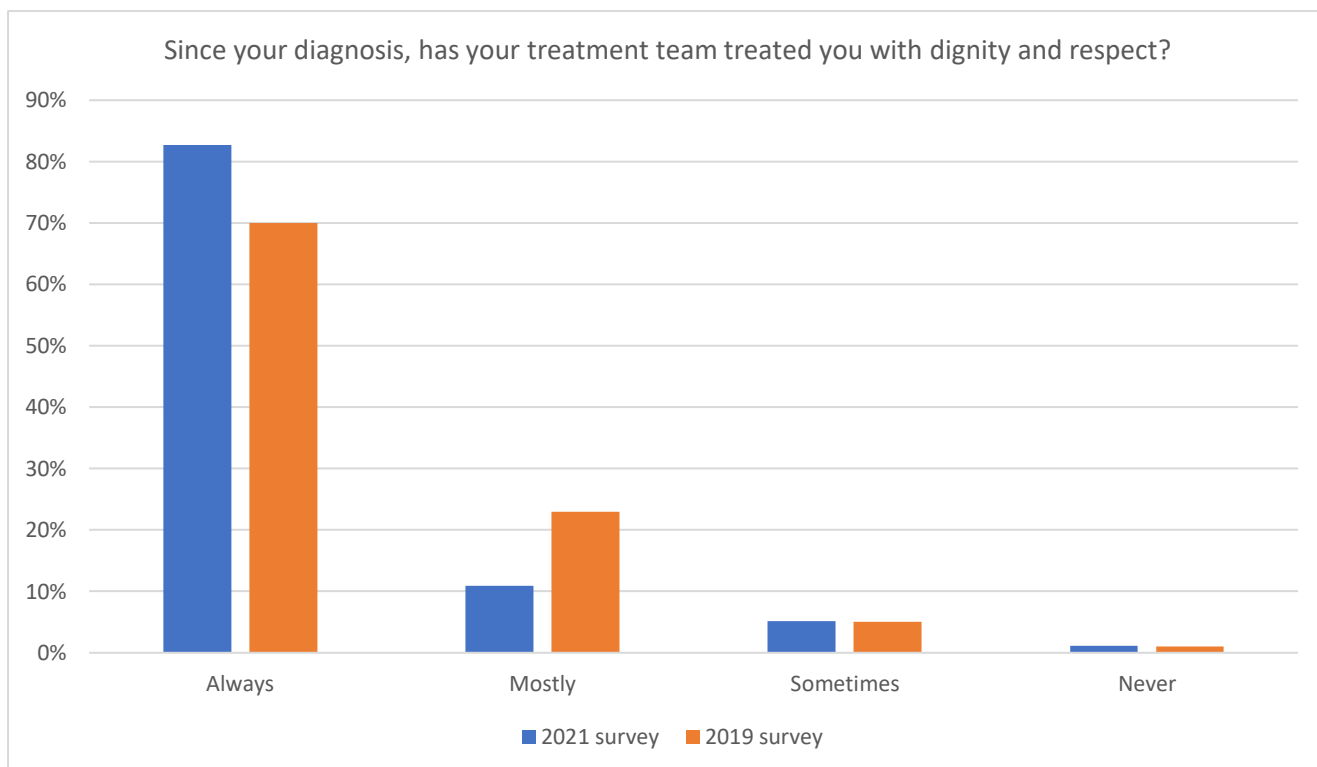


Figure 12b: Data on the number and percentage of patients feeling treated with dignity and respect by their treatment team, results for 2021 and 2019

	Always		Mostly		Sometimes		Never	
	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number
2021 survey	83%	144	11%	19	5%	9	1%	2
2019 survey	70%	105	23%	34	5%	8	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’ (66%) rather than as a ‘patient’ (44%).

While people were given more options to choose from this year, the most popular choice was again ‘living with lung cancer’ with 45% of respondents describing themselves this way. With a higher proportion of respondents diagnosed in the last three years (59%), it is likely that most are having treatment currently, which could explain why most described themselves as ‘living with lung cancer’. About a fifth of respondents (21%) described themselves as a ‘patient’ (44% in 2019). 14% and 9% described themselves as ‘fighter’ and ‘warrior’ respectively, but those options were not available in 2019.

This year, six respondents skipped this question. Figure 13a (overleaf) shows all the responses and compares the results to those obtained in 2019. 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. 17 respondents (10%) selected ‘other’, and Figure 14 sets out some of the responses.

Figure 13a: How respondents described themselves, results for 2021 and 2019

	Living with lung cancer		Patient		Surviving with lung cancer		Lung cancer survivor		Overcomer	
	Percentage	Number	Number	Percentage	Number	Percentage	Number	Percentage	Number	Percentage
2021 survey	46%	77	35	21%	17	10%	16	9%	5	3%
2019 survey	66%	97	65	44%	17	12%	30	20%	5	3%

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

	Fighter		Survivor		Warrior		Fighting lung cancer	
	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number
2021 survey	14%	24	10%	17	9%	16	8%	13

	Battling lung cancer		Advocate		Thrifer		At war with lung cancer	
	Percentage	Number	Percentage	Number	Percentage	Number	Percentage	Number
2021 survey	7%	12	4%	6	3%	5	3%	5

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



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 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.

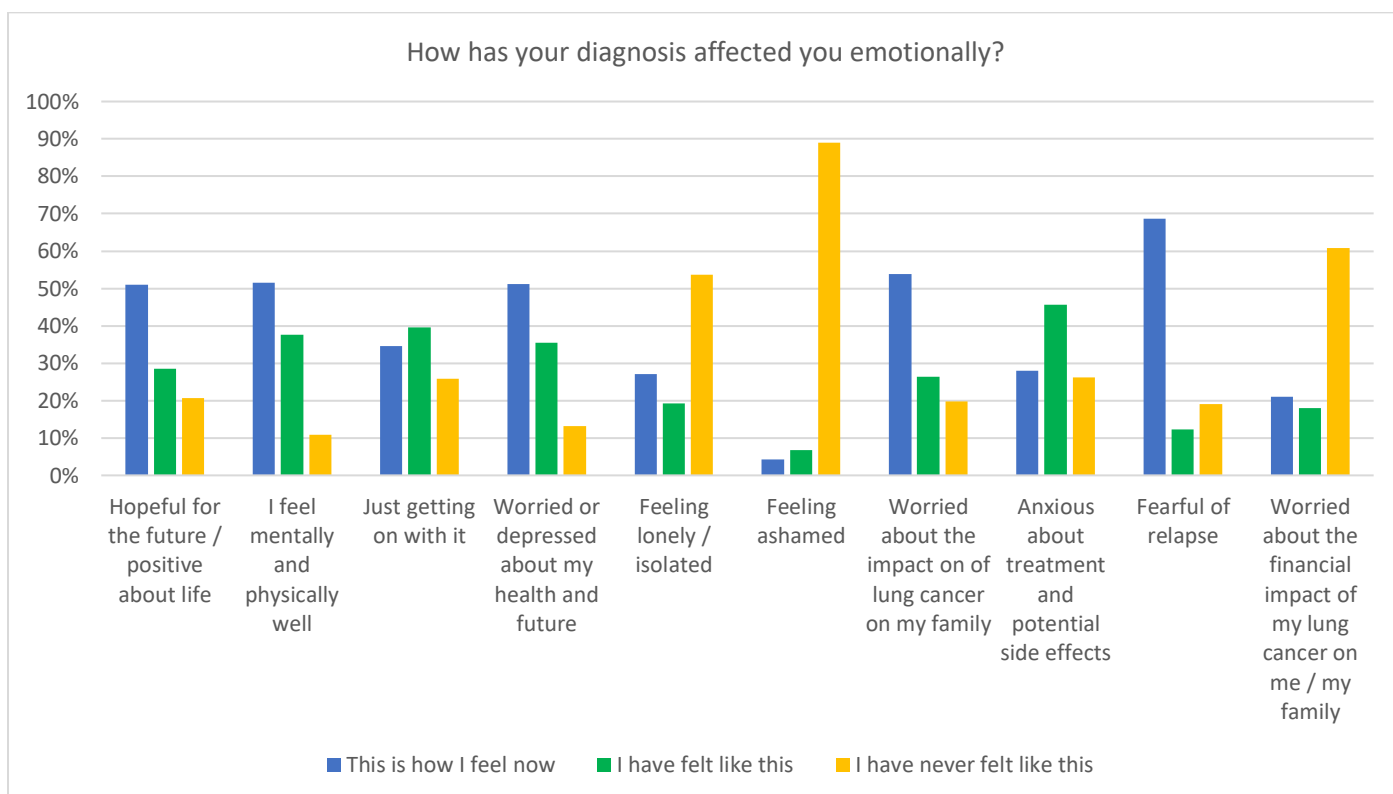
This year, the GLCC decided to ask people questions to understand how their diagnosis has affected them emotionally and physically, and what type of support they sought.

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 five people skipped this question. Figure 15 summarises key findings for respondents from the Netherlands.

Figure 15: 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, 89% said they never felt ashamed. 54% never felt lonely or isolated.

More than half of respondents (51%) feel hopeful or positive about life, but 21% of respondents never felt hopeful and 28% used to feel this way. 51% of respondents currently feel worried or depressed about their health and future, and 69% are fearful of relapse. When it came to their mental and physical wellbeing, more half (52%) feel well at the moment, while 38% of respondents said they have felt well and 11% never felt well. Nearly one in three (28%) are currently anxious about treatment while a further 46% have felt this way. More than half (54%) of respondents are currently worried about the impact of their condition on their family.

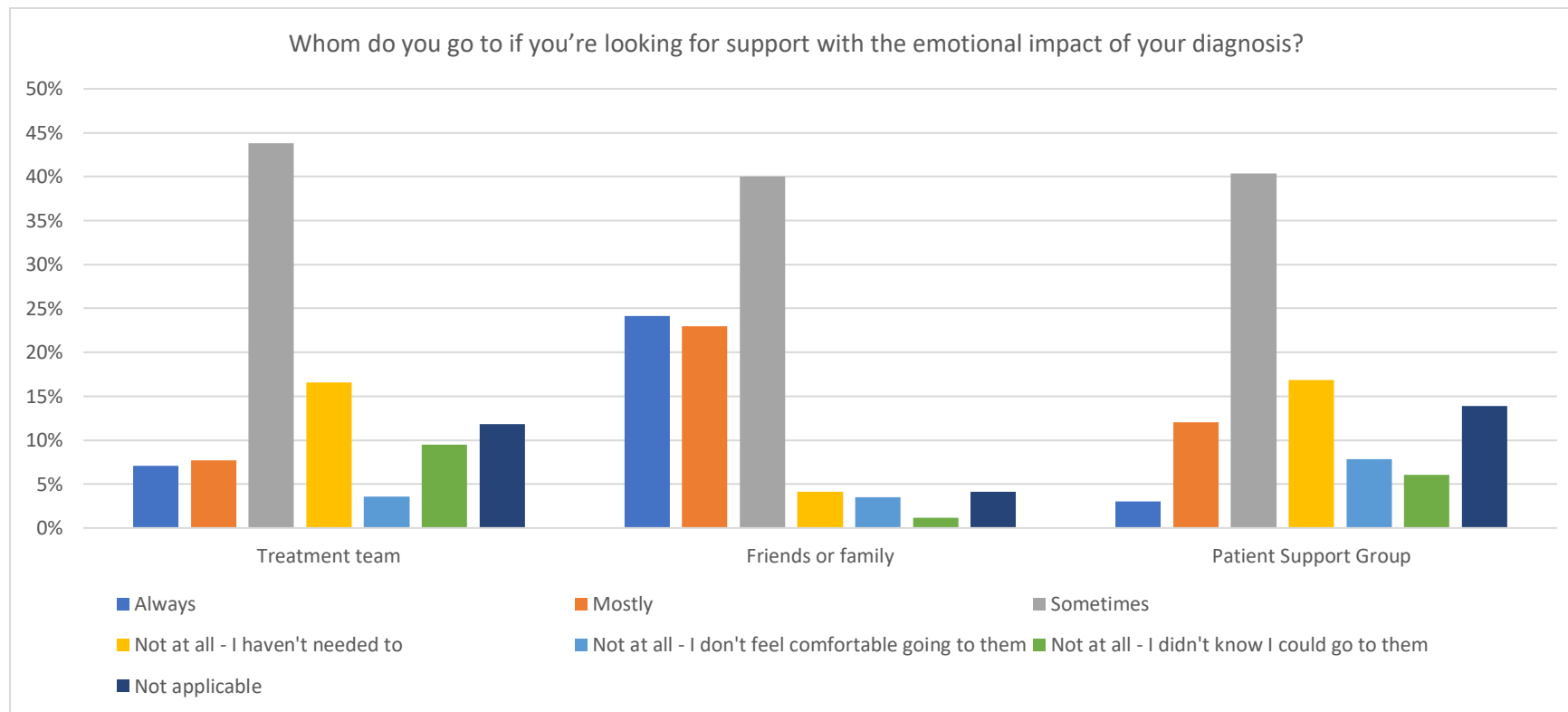
Further studies could explore:

- How experience of care and interaction with a treatment team influence 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 patients 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. Five people skipped this question, and no respondents selected the 'other' option.

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



The results show that patients primarily turned to friends and family for emotional support. 24% of respondents said they always reached out to friends and family for support, compared to 7% saying they always reached out to their treatment team for help (less than 15% of respondents always or mostly reached out to their treatment team for emotional support). 44% said they sometimes asked their care team for emotional support. However, around one in ten (9%) of the respondents said they didn't know they could ask their treatment team for this kind of support, and 4% said they don't feel comfortable doing so. 40% 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
- 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 emotional support for people affected with cancer

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

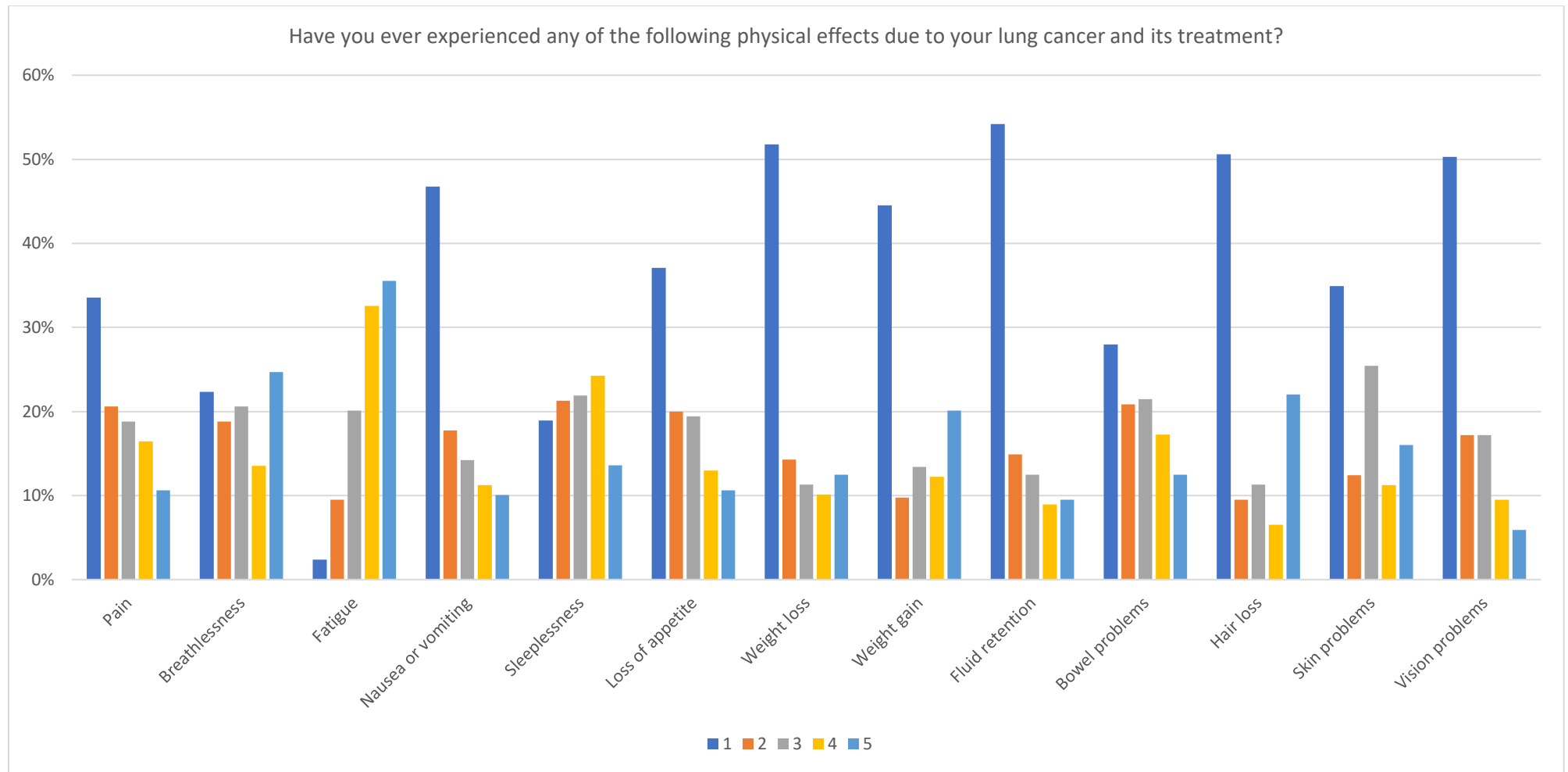
Respondents were asked about the physical effects they experienced because of their cancer and its treatment. We gave respondents 13 options and, for each option, people could select a number from 1 to 5, where 1 means this has not affected them and 5 means this has been a very serious concern. Five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

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

	1	2	3	4	5	Total	Weighted Average
Answer Choices	Percentage	Percentage	Percentage	Percentage	Percentage	Number	Number
Pain	34%	21%	19%	16%	11%	170	2.5
Breathlessness	22%	19%	21%	14%	25%	170	2.99
Fatigue	2%	9%	20%	33%	36%	169	3.89
Nausea or vomiting	47%	18%	14%	11%	10%	169	2.2
Sleeplessness	19%	21%	22%	24%	14%	169	2.92
Loss of appetite	37%	20%	19%	13%	11%	170	2.4
Weight loss	52%	14%	11%	10%	13%	168	2.17
Weight gain	45%	10%	13%	12%	20%	164	2.54
Fluid retention	54%	15%	13%	9%	10%	168	2.05
Bowel problems	28%	21%	21%	17%	13%	168	2.65
Hair loss	51%	10%	11%	7%	22%	168	2.4
Skin problems	35%	12%	25%	11%	16%	169	2.61
Vision problems	50%	17%	17%	9%	6%	169	2.04

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 (3.89) was the most serious issue for respondents, followed by breathlessness (2.99) and sleeplessness (2.92).

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

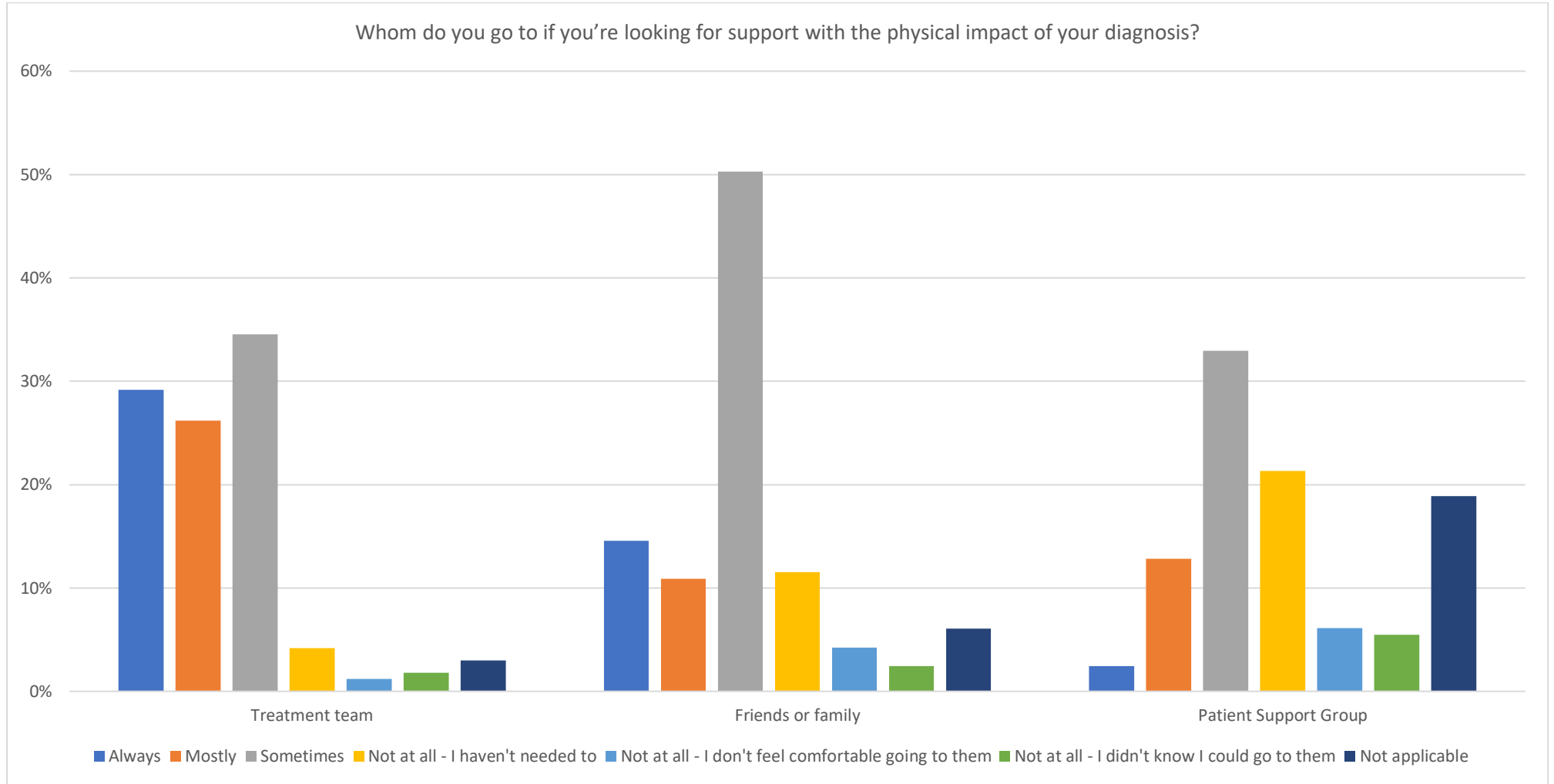


36% of respondents gave a 5 when describing the impact of fatigue, and 33% scored a 4 meaning that fatigue has been a very serious concern for respondents. 25% gave a 5 to describe the impact of breathlessness and 24% of respondents scored a 4 for sleeplessness. When it came to weight gain, around a fifth of respondents said this was a serious concern (20%).

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.

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, most respondents said they would go to their treatment team. 29% said they always contacted their care team, and 15% said they always reached out to friends and family. 35% of respondents said they sometimes reach out to their treatment team for support when they experienced physical effects from their diagnosis. 6% 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.

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. Six people skipped this question.

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

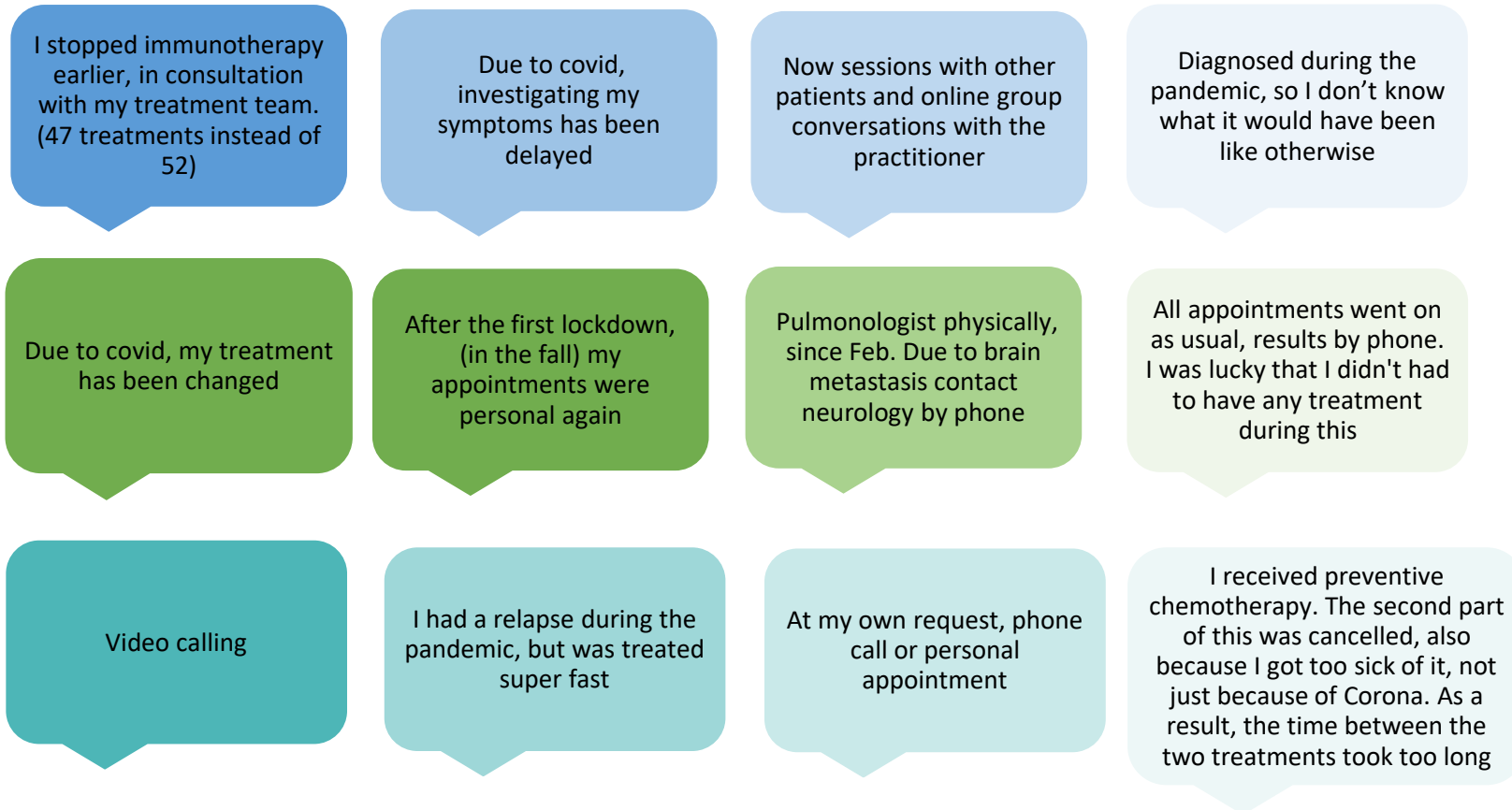
Answer Choices	Percentage	Number
I found it easier to contact my treatment team	10%	17
There has been no difference in how easy it has been to contact my treatment team	55%	93
I found it more difficult to speak to my treatment team	5%	8
I have held back in contacting my treatment team because they are so busy	5%	8
My treatment has continued as normal	37%	62
My treatment has been delayed / cancelled	9%	16
I don't know if my treatment has been affected	10%	17
I have carried on attending appointments during the pandemic	54%	92
I have been reluctant to attend appointments for fear of infection	1%	2
I have missed appointments for fear of infection	2%	3
My face-to-face appointments have been swapped for telephone or video calls	24%	40
I have been offered new services that weren't available to me before the pandemic	3%	5
Other	11%	19

10% of respondents said it had been easier to contact their treatment team during the pandemic, with 55% of respondents saying there has been no difference and 5% finding it more difficult. 54% said they have carried on attending their appointments in person during the pandemic. 24% 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). 5% of respondents said they found it more difficult to speak to their treatment team and a similar proportion had actively held back from contacting their team because they were so busy.

37% of respondents said their treatment has carried out as normal, nearly one in ten (9%) had experienced delays to treatment, with a further 10% unsure about the impact on their treatment.

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

19 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. Six people skipped this question.

Most respondents scored a 1 for each of the available options, meaning that they did not feel that the pandemic had 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 (12%) of respondents scored a 4 or 5
- On worries about treatment being delayed or cancelled as a result of COVID-19, 15% scored it a 4 or 5
- On worries about finances as a result of the pandemic, 12% scored it a 4 or 5

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

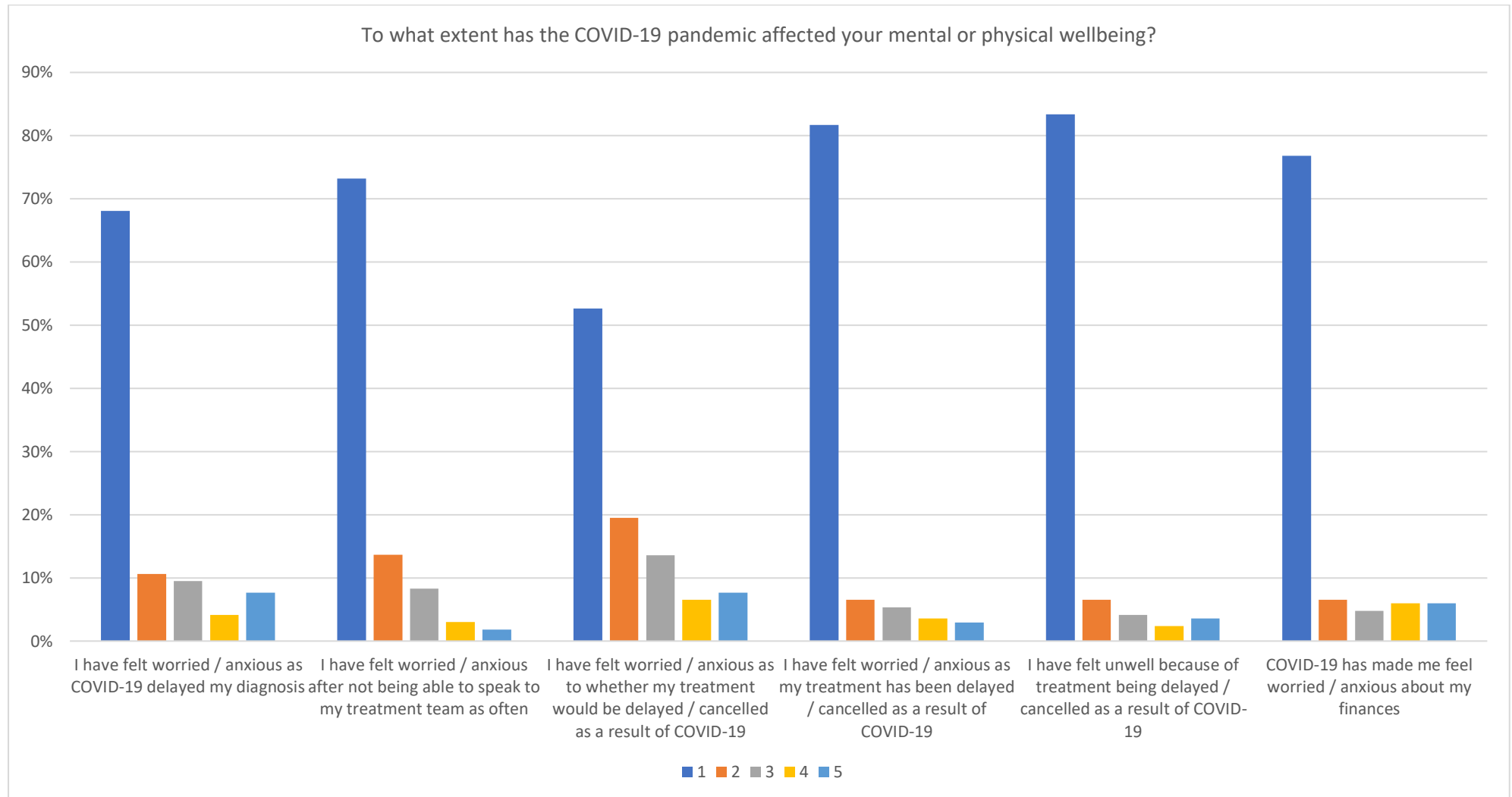


Figure 20b: To what extent has the COVID-19 pandemic affected your mental or physical wellbeing? Please choose an option from 1 – 5, where 1 means this has not affected me and 5 means this has been a very serious concern. Results for 2021

Answer choices	1	2	3	4	5	
I have felt worried / anxious as COVID-19 delayed my diagnosis		68%	11%	9%	4%	8%
I have felt worried / anxious after not being able to speak to my treatment team as often		73%	14%	8%	3%	2%
I have felt worried / anxious as to whether my treatment would be delayed / cancelled as a result of COVID-19		53%	20%	14%	7%	8%
I have felt worried / anxious as my treatment has been delayed / cancelled as a result of COVID-19		82%	7%	5%	4%	3%
I have felt unwell because of treatment being delayed / cancelled as a result of COVID-19		83%	7%	4%	2%	4%
COVID-19 has made me feel worried / anxious about my finances		77%	7%	5%	6%	6%

The results show that 12% of respondents felt worried and anxious because COVID-19 has delayed their diagnosis (score 4,5 at 4% and 8% respectively). 5% said they felt anxious after not being able to speak with their treatment team as often (score 4 and 5 at 3% and 2% respectively). 15% felt worried as to whether their treatment would be delayed or cancelled because of COVID-19.

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. Seven 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	75%	126
Video	14%	23
In person	86%	145
No, I have not been in contact with my treatment team at all, but I wanted to	1%	1
No, I have not been in contact with my treatment team at all, but I haven't needed / wanted to	3%	5

86% respondents continued to see their treatment team in person, followed by telephone (75%) and video consultation (14%). 3% said they have not been in contact with their treatment team at all but haven't needed to. One person said they haven't been in contact with their care team but they wanted to be in contact.

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. Two people said they couldn't speak to their treatment team. One said the only option available was in person visits and they were worried about infection, the other person picked 'other' and said: "There was little contact. You had to contact yourself. That's a bad thing". The results can be seen on Figure 22 below.

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	50%	1
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)	50%	1

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. 48 people skipped this question.

Results show that 50% said they found contacting their treatment team by video or telephone helpful because they didn't have to travel to hospital as much, while 13% found it quicker to have appointments by video or telephone. However, nearly six in ten (57%) still preferred face-to-face appointments. A small number (6%) found it more difficult to understand the treatment team or make themselves understood if not in person.

Figure 23a: Why were you not able to speak to your treatment team? Results for 2021

Answer Choices	Percentage	Number
I found it quicker	13%	16
I found it helpful as I don't have to travel to hospital as much	50%	63
I prefer face-to-face appointments	57%	72
I found it more difficult to understand my treatment team / make myself understood	6%	8
I don't like it and I want to stop as soon as possible	3%	4

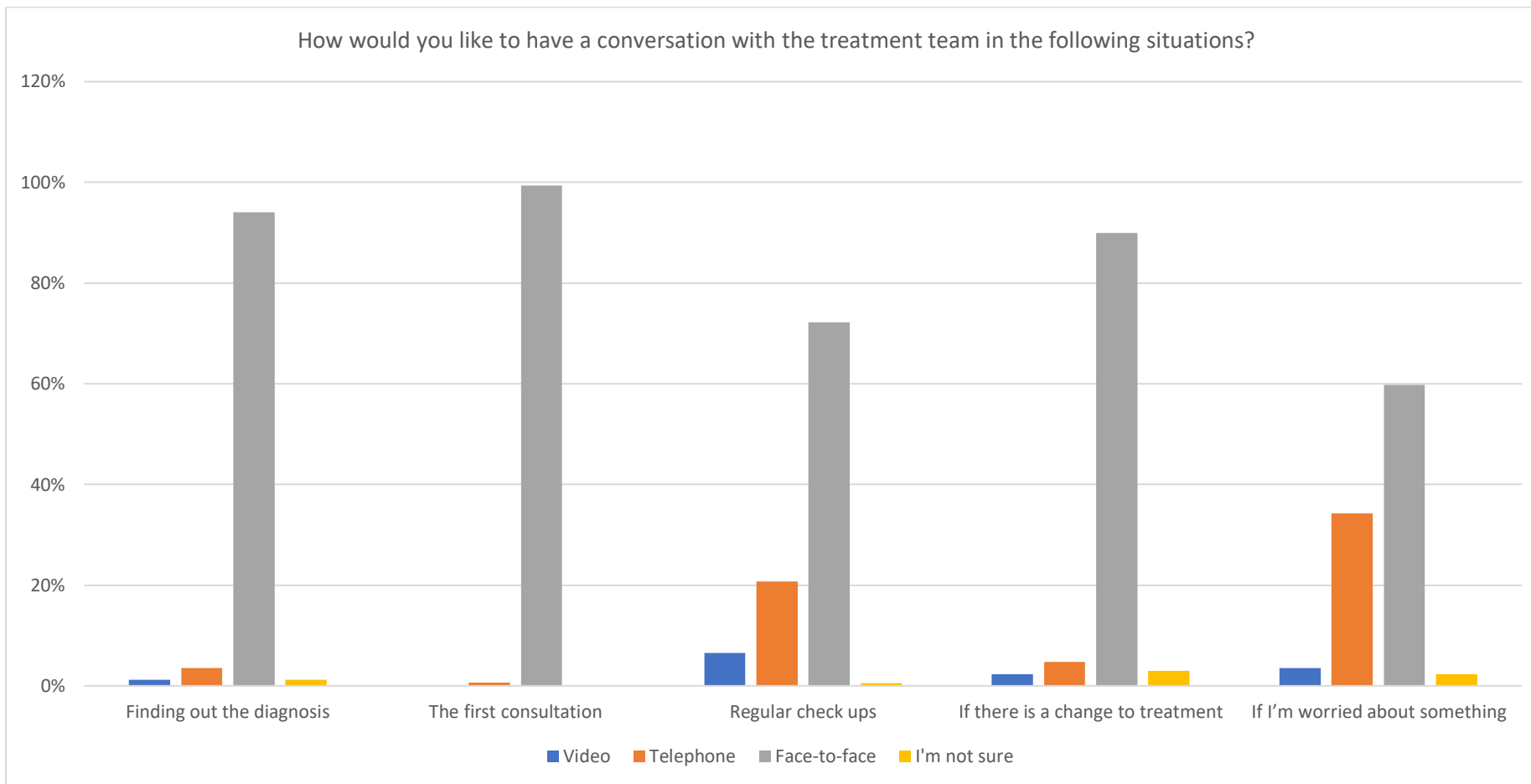
When dealing with different situations, what do people think is the best way to speak with their treatment team?

Respondents were asked how they would like to have a conversation with their treatment team when finding out their diagnosis, 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.

94% of respondents said that the best way to find out by a diagnosis was in person, and 99% said they preferred to have a face-to-face for their first consultation. 90% felt that if there was a change in treatment it was best to have a face-to-face conversation. For regular check-ups, 72% felt it was best to have a face-to-face, while 21% 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 (60%) or a telephone consultation (34%).

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 Netherlands. 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 – even in the midst of a crisis at a time of great uncertainty.

The GLCC wanted to find out where patients 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.

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	69%	116	18%	31	5%	9	7%	12	168
Patient support organisations	33%	53	31%	49	12%	19	24%	39	160
Other people that have been diagnosed with lung cancer	49%	82	20%	34	7%	11	23%	39	166
Friends or family	56%	91	7%	12	0%	0	37%	60	163
The internet	71%	117	8%	13	0%	0	21%	35	165
Social media	50%	82	7%	12	2%	3	40%	66	163
Pharmaceutical company	11%	17	11%	17	17%	28	61%	99	161

The results show that more patients have sought information from the internet than from their treatment team (71% vs 69%). When contacting their treatment team, 18% said they haven't reached out to them yet, and 7% said they didn't want to. 56% of respondents said they had reached out to friends and family, and 49% of respondents said they had already contacted other people diagnosed with lung cancer for information. 61% of people said they don't want to reach out to pharmaceutical companies for information about their cancer, and 40% said they didn't want to look for further information on social media.

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 organisation 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. Eight 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	62%	103
A conversation over the phone	23%	38
A conversation on video call	13%	22
Something I can read e.g. a leaflet / booklet	54%	90
Something I can view online e.g. a website / social media	59%	98
Something I can listen to e.g. a podcast	10%	17
Something I can watch e.g. a video	30%	50

The findings show that patients have different preferences and needs, so information needs to be available in different formats. For conversations, 62% of respondents said they would like in person conversations, with telephone or video scoring lower (in line with findings above where respondents expressed preference for face-to-face appointments in most situations).

Written material, to which people can refer when they want, is important too. 59% said they would like something to view online and 54% said they would like to have something to read. Videos are popular with a third of respondents (30%) but podcasts less so (10%).

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 member from the Netherlands is [Longkanker Nederland](#)

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

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

References

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