

Understanding lung cancer patients' experiences throughout the COVID-19 pandemic

Insights from the Global Lung Cancer Coalition's 2022 global patient experience survey

Introduction

Two years in, COVID-19 continues to impact healthcare systems and the treatment and care all patients receive, including those living with lung cancer.

The Global Lung Cancer Coalition (GLCC) wanted to understand how patients' experiences of lung cancer have been affected amid the pandemic, to inform our global and national campaigning priorities.

This report sets out the global findings from our third annual global survey. We are grateful to all the patients who took the time to share their experiences via the survey. We hope the findings will be useful to policymakers in their post-COVID-19 recovery planning, as well as to campaigners advocating for lung cancer patients' needs.

Methodology

The steering group drafted questions on a range of topics, including:

- **Demographics, diagnosis, and treatment** – to identify patient populations by gender, type of lung cancer, age at diagnosis, time since diagnosis, biomarker testing status, treatments received
- **Screening** – to assess patients' awareness of the availability of a lung cancer screening programme/lung health check in their country and willingness to attend an appointment if offered
- **Involvement in care** – to understand how involved patients felt in decisions about their treatment and care
- **Emotional impact of a lung cancer diagnosis** – to determine how patients' lung cancer diagnosis has affected them emotionally, what they've found most helpful in dealing with their emotions, and how COVID-19 has impacted their mental well-being
- **Impact of COVID-19** – to understand if lung cancer patients have had the virus, if they've received the vaccine, how the pandemic has impacted their treatment appointments, and their preferences for contacting their treatment team
- **Seeking information** – to determine whether lung cancer patients believe they received high quality information at the right time for them

Questions were translated so that patients could complete the survey in their native language. It was distributed by members through their networks and on social media.

The survey was open for eight weeks between December 2021 and January 2022.

Key insights

The global survey received 555 responses from patients across 21 countries. Countries with an asterisk (*) denote responses submitted to a general survey which was open to patients from around the world that did not have a national survey.

A full breakdown of the responses by country, gender, and lung cancer type, treatments received, age and year of diagnosis can be found in the appendix.

Diagnosis

Evidence indicates that diagnosing lung cancer earlier, when there is a higher chance of treatment being successful, will reduce the burden currently imposed on the individuals affected, their families, the country, and the healthcare system as a whole, and also improve survival rates. We wanted to understand how COVID-19 has impacted on the time it takes to diagnose lung cancer patients, and if patients received a biomarker test.

As Table 1 below shows, when asked if there was an unnecessary delay in getting their diagnosis, half of respondents (51%, 282/548) stated that they were satisfied with the time it took. However, 16% (87/548) believed it took too long to see someone to get their symptoms checked out, 10% felt it took too long to see someone to test if they had lung cancer, and 8% said it took too long to get their test results. 5% (31/548) were unsure if there was an unnecessary delay.

Table 1: Would you say there was an unnecessary delay in getting your diagnosis? Responses from 2022

Country	Yes, it took me too long to see someone to get my symptoms checked out	Yes, it took too long to see someone to test if I had lung cancer	Yes, it took too long to get my test results	No, I am satisfied with the time it took to get my diagnosis	I'm not sure	Not applicable
Global (n=548)	16%	10%	8%	51%	6%	9%
Australia (n=10)	20%	30%	0%	40%	10%	0%
Brazil (n=18)	22%	6%	6%	67%	0%	0%
Bulgaria (n=2)	0%	50%	0%	50%	0%	0%
Canada (n=28)	14%	14%	14%	54%	4%	0%
Denmark (n=45)	16%	7%	2%	73%	2%	0%
Ireland (n=11)	45%	18%	0%	27%	9%	0%
Italy (n=133)	11%	9%	15%	61%	4%	0%
Netherlands (n=44)	20%	5%	11%	61%	2%	0%
Portugal (n=17)	12%	6%	6%	71%	6%	0%
Spain (n=55)	24%	9%	2%	60%	5%	0%
Taiwan (n=74)	12%	8%	3%	3%	16%	58%
UK (n=71)	13%	14%	11%	58%	1%	3%
USA (n=30)	27%	10%	0%	53%	7%	3%
Germany* (n=1)	0%	100%	0%	0%	0%	0%
Greece* (n=1)	0%	100%	0%	0%	0%	0%
India* (n=1)	0%	0%	0%	0%	100%	0%
Isle of Man* (n=1)	0%	100%	0%	0%	0%	0%
Mexico* (n=1)	0%	0%	100%	0%	0%	0%
New Zealand* (n=1)	0%	0%	0%	100%	0%	0%
Sweden* (n=3)	0%	0%	0%	33%	33%	33%

Respondents were also asked if they received a biomarker test – which involves taking a small tissue sample of a tumour to test, to help their treatment team decide which treatment to give.

Table 2: Doctors can take a sample of a tumour to test for biomarkers (also known as mutation, genomic or molecular testing). This helps the treatment team decide which treatment to give. Did you have any biomarker testing? Responses from 2022

Country	Yes, and I know what biomarkers my cancer has	Yes, but I don't know what biomarkers my cancer has	I'm not sure if I've had biomarker testing	No, I haven't had biomarker testing but I would like to	No, I haven't had biomarker testing but I would not want to
Global (n=549)	52%	19%	20%	7%	2%
Australia (n=10)	50%	10%	20%	20%	0%
Brazil (n=18)	61%	17%	17%	6%	0%
Bulgaria (n=2)	50%	50%	0%	0%	0%
Canada (n=28)	57%	25%	7%	11%	0%
Denmark (n=44)	23%	48%	18%	5%	7%
Ireland (n=11)	45%	9%	36%	9%	0%
Italy (n=134)	69%	13%	9%	8%	1%
Netherlands (n=44)	48%	25%	23%	2%	2%
Portugal (n=16)	50%	0%	31%	13%	6%
Spain (n=55)	47%	22%	29%	2%	0%
Taiwan (n=75)	52%	20%	19%	7%	3%
UK (n=72)	33%	14%	38%	11%	4%
USA (n=30)	63%	10%	17%	10%	0%
Germany* (n=1)	0%	0%	0%	100%	0%
Greece* (n=1)	0%	0%	100%	0%	0%
India* (n=1)	100%	0%	0%	0%	0%
Isle of Man* (n=1)	100%	0%	0%	0%	0%
Mexico* (n=1)	0%	0%	100%	0%	0%
New Zealand* (n=1)	100%	0%	0%	0%	0%
Sweden* (n=3)	67%	0%	33%	0%	0%

As Table 2 shows, just over half of respondents (52%, 283/549) had a biomarker test and knew what biomarkers their cancer has, whilst 19% had a biomarker test but didn't know the biomarkers their cancer has. Notably, one-fifth of respondents (20%, 111/549) did not know if they've had a biomarker test. 9% (52/549) did not have a biomarker test, but of those, 79% (41/52) would like to have had a test.

Screening

In a small number of countries, there are national programmes that invite people who may be at a higher risk of lung cancer to have a lung screening appointment or health check. The GLCC wanted to understand if patients would attend a screening appointment if a national programme was available in their country and they were invited.

As Table 3 below shows, when asked, the majority of patients (85%, 449/526) stated that they would attend a lung cancer screening or health check if they were invited. However, one in ten (54/526) said they were unsure if they would attend a screening appointment and 4% (23/526) said they would not attend.

Of note, whilst a national lung cancer screening programme is available in the USA, the highest proportion of patients from the USA (30%, 8/27) stated that they were not sure if they would attend if they were invited to a screening appointment.

Table 3: If you were invited to attend a lung health check or screening appointment, would you attend? Responses from 2022

Country	Yes – I would attend	No – I wouldn't attend	I'm not sure
Global (n=526)	85%	4%	10%
Australia (n=10)	90%	0%	10%
Brazil (n=18)	83%	6%	11%
Bulgaria (n=2)	100%	0%	0%
Canada (n=25)	88%	8%	4%
Denmark (n=42)	81%	0%	19%
Ireland (n=10)	100%	0%	0%
Italy (n=129)	83%	5%	12%
Netherlands (n=44)	80%	11%	9%
Portugal (n=17)	82%	0%	18%
Spain (n=54)	100%	0%	0%
Taiwan (n=71)	83%	6%	11%
UK (n=68)	91%	4%	4%
USA (n=27)	63%	7%	30%
Germany* (n=1)	100%	0%	0%
Greece* (n=1)	100%	0%	0%
India* (n=1)	100%	0%	0%
Isle of Man* (n=1)	100%	0%	0%
Mexico* (n=1)	100%	0%	0%
New Zealand* (n=1)	100%	0%	0%
Sweden* (n=3)	100%	0%	0%

Involvement in 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. We wanted to understand the extent to which lung cancer patients feel involved in decisions made about their treatment and care.

Table 4: When talking to your treatment team, did you feel involved in the decisions about your treatment and care? Please choose the option that best describes you. Responses from 2022

Country	Yes, I've been fully involved	Yes, I've been involved mostly	Yes, I've been involved sometimes	No, but I would like to be involved	No, but I didn't want to be involved	No, but my caregiver was involved
Global (n=533)	52%	23%	13%	9%	2%	2%
Australia (n=10)	20%	50%	10%	0%	20%	0%
Brazil (n=18)	33%	56%	6%	0%	0%	6%
Bulgaria (n=2)	0%	0%	50%	50%	0%	0%
Canada (n=27)	48%	26%	22%	4%	0%	0%
Denmark (n=42)	67%	19%	5%	7%	0%	0%
Ireland (n=11)	36%	36%	18%	0%	0%	9%
Italy (n=128)	41%	27%	17%	9%	2%	4%
Netherlands (n=41)	76%	17%	5%	2%	0%	0%
Portugal (n=16)	63%	0%	25%	6%	6%	0%
Spain (n=55)	33%	22%	18%	20%	4%	4%
Taiwan (n=73)	64%	15%	10%	8%	1%	1%
UK (n=70)	53%	30%	6%	9%	3%	0%
USA (n=30)	73%	7%	7%	13%	0%	0%
Germany* (n=1)	0%	0%	0%	100%	0%	0%
Greece* (n=1)	0%	0%	100%	0%	0%	0%
India* (n=1)	0%	0%	100%	0%	0%	0%
Isle of Man* (n=1)	100%	0%	0%	0%	0%	0%
Mexico* (n=1)	0%	0%	100%	0%	0%	0%
New Zealand* (n=1)	100%	0%	0%	0%	0%	0%
Sweden* (n=3)	33%	0%	0%	67%	0%	0%

As Table 4 shows, just over half of respondents (52%, 275/533) felt that they had been fully involved in the decisions about their treatment and care. A further 23% (122/533) felt mostly involved, and 13% (67/533) felt involved sometimes. Only 10 respondents (2%) stated that their caregiver was involved. Notably, almost 1 in 10 (9%) stated that they weren't involved in decisions but would have liked to have been.

Emotional impact of a lung cancer diagnosis

A lung cancer diagnosis can have a profound impact on patients' emotional health and wellbeing, as well as affecting their caregivers and loved ones. We wanted to understand how patients' diagnosis has affected them emotionally, the stages that had the biggest emotional impact, and what they have found to be most helpful in dealing with their emotions.

Respondents were given a range of statements and asked to select which best describes how their diagnosis has affected them emotionally.

Table 5: Please tell us about how your diagnosis has affected you emotionally. Please tick the box which describes how the following statements apply to you. Responses from 2022

Country	Hopeful for the future / positive about life			I feel mentally and physically well			Just getting on with it			Fearful of relapse			Worried about the financial impact of my lung cancer on me / my family		
	This is how I feel now	I have felt like this	I have never felt like this	This is how I feel now	I have felt like this	I have never felt like this	This is how I feel now	I have felt like this	I have never felt like this	This is how I feel now	I have felt like this	I have never felt like this	This is how I feel now	I have felt like this	I have never felt like this
Global (n=430)	57%	30%	13%	51%	36%	13%	51%	32%	17%	60%	31%	10%	27%	28%	45%
Australia (n=9)	33%	56%	11%	22%	56%	22%	100%	0%	0%	56%	22%	11%	11%	33%	56%
Brazil (n=16)	56%	19%	0%	63%	31%	0%	25%	31%	19%	75%	0%	6%	31%	25%	19%
Bulgaria (n=1)	0%	0%	100%	0%	0%	100%	100%	0%	0%	100%	0%	0%	100%	0%	0%
Canada (n=27)	52%	26%	15%	52%	30%	7%	41%	48%	4%	48%	19%	26%	19%	44%	30%
Denmark (n=37)	68%	24%	5%	59%	27%	8%	57%	32%	5%	68%	22%	8%	11%	11%	68%
Ireland (n=10)	60%	30%	10%	30%	60%	10%	70%	20%	10%	60%	30%	10%	20%	70%	10%
Italy (n=110)	49%	21%	20%	43%	25%	20%	23%	25%	30%	52%	24%	4%	15%	11%	52%
Netherlands (n=36)	47%	28%	22%	44%	36%	14%	33%	33%	31%	72%	17%	8%	33%	19%	44%



	This is how I feel now	I have felt like this	I have never felt like this	This is how I feel now	I have felt like this	I have never felt like this	This is how I feel now	I have felt like this	I have never felt like this	This is how I feel now	I have felt like this	I have never felt like this	This is how I feel now	I have felt like this	I have never felt like this
Portugal (n=14)	43%	36%	7%	57%	21%	7%	36%	21%	14%	57%	21%	7%	36%	7%	36%
Spain (n=50)	58%	30%	6%	54%	34%	2%	70%	18%	4%	48%	40%	10%	10%	40%	46%
Taiwan (n=58)	53%	24%	12%	41%	36%	9%	31%	48%	9%	34%	38%	22%	45%	26%	17%
UK (n=63)	51%	33%	11%	49%	35%	13%	78%	16%	5%	46%	41%	13%	19%	40%	38%
USA (n=28)	52%	44%	4%	38%	54%	8%	39%	39%	21%	64%	32%	4%	35%	31%	35%
Greece* (n=1)	0%	0%	0%	0%	0%	0%	0%	0%	0%	100%	0%	0%	0%	0%	100%
India* (n=1)	100%	0%	0%	0%	100%	0%	0%	0%	100%	0%	0%	100%	0%	0%	100%
Isle of Man* (n=1)	0%	0%	0%	0%	0%	0%	100%	0%	0%	0%	0%	0%	0%	0%	0%
Mexico* (n=1)	100%	0%	0%	0%	100%	0%	100%	0%	0%	100%	0%	0%	100%	0%	0%
New Zealand* (n=1)	100%	0%	0%	100%	0%	0%	100%	0%	0%	100%	0%	0%	0%	100%	0%
Sweden* (n=3)	67%	33%	0%	33%	33%	33%	33%	67%	0%	33%	33%	0%	0%	33%	33%

Table 5 continued: Please tell us about how your diagnosis has affected you emotionally. Please tick the box which describes how the following statements apply to you. Responses from 2022

Country	Worried or depressed about my health and future			Feeling lonely / isolated			Feeling ashamed			Worried about the impact of lung cancer on my family			Anxious about treatment and potential side effects		
	This is how I feel now	I have felt like this	I have never felt like this	This is how I feel now	I have felt like this	I have never felt like this	This is how I feel now	I have felt like this	I have never felt like this	This is how I feel now	I have felt like this	I have never felt like this	This is how I feel now	I have felt like this	I have never felt like this
Global (n=430)	33%	52%	15%	16%	33%	50%	6%	24%	70%	40%	47%	13%	27%	58%	14%
Australia (n=9)	56%	33%	11%	33%	33%	33%	0%	11%	78%	44%	44%	11%	44%	33%	22%
Brazil (n=16)	25%	44%	13%	6%	13%	56%	6%	13%	56%	19%	44%	13%	38%	38%	0%
Bulgaria (n=1)	100%	0%	0%	100%	0%	0%	0%	0%	100%	100%	0%	0%	100%	0%	0%
Canada (n=27)	26%	63%	4%	11%	48%	33%	11%	26%	56%	41%	48%	15%	15%	56%	26%
Denmark (n=37)	41%	46%	11%	14%	24%	57%	3%	14%	78%	41%	41%	19%	22%	49%	27%
Ireland (n=10)	40%	40%	20%	20%	70%	10%	10%	20%	70%	40%	60%	0%	30%	60%	10%
Italy (n=110)	31%	38%	15%	11%	27%	42%	1%	15%	61%	26%	45%	15%	21%	51%	14%
Netherlands (n=36)	39%	44%	17%	22%	19%	50%	6%	6%	86%	42%	39%	17%	17%	56%	25%



	This is how I feel now	I have felt like this	I have never felt like this	This is how I feel now	I have felt like this	I have never felt like this	This is how I feel now	I have felt like this	I have never felt like this	This is how I feel now	I have felt like this	I have never felt like this	This is how I feel now	I have felt like this	I have never felt like this
Portugal (n=14)	21%	36%	21%	0%	0%	79%	7%	7%	64%	43%	21%	14%	36%	43%	7%
Spain (n=50)	28%	58%	12%	8%	16%	68%	2%	10%	82%	38%	46%	10%	24%	52%	18%
Taiwan (n=58)	38%	38%	21%	28%	26%	36%	22%	47%	14%	45%	26%	14%	38%	43%	9%
UK (n=63)	19%	62%	14%	14%	48%	35%	2%	27%	65%	33%	54%	11%	19%	67%	13%
USA (n=28)	21%	37%	56%	7%	23%	50%	27%	0%	36%	64%	48%	52%	0%	38%	58%
Greece* (n=1)	100%	0%	0%	0%	0%	0%	0%	0%	0%	100%	0%	0%	100%	0%	0%
India* (n=1)	0%	0%	100%	0%	100%	0%	0%	0%	100%	0%	0%	100%	0%	100%	0%
Isle of Man* (n=1)	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	100%	0%	0%	100%	0%
Mexico* (n=1)	0%	100%	0%	0%	0%	100%	0%	0%	100%	0%	100%	0%	0%	100%	0%
New Zealand* (n=1)	0%	100%	0%	0%	100%	0%	0%	0%	100%	0%	100%	0%	0%	100%	0%
Sweden* (n=3)	0%	100%	0%	0%	67%	33%	0%	67%	33%	0%	67%	0%	0%	67%	0%

As Table 5 shows, three in five respondents (253/425) said that they are fearful of relapse, with 31% (131/425) said they have felt like this. Only one in ten (41/425) said they have never felt like this.



57% (245/430) said they felt hopeful for the future or positive about life; 51% (216/424) said they feel mentally and physically well; and 51% (212/415) said they are just getting on with it.

85% of responding patients (364/430) said they have felt or currently feel worried or depressed about their health and future, and a similar percentage (87%, 372/430) have felt or currently feel worried about the impact of lung cancer on their family.

Table 6: Which of the following had the biggest impact on you emotionally? Depending on your lung cancer diagnosis, not all options will be relevant. Please select the top three options that are most relevant to you. Responses from 2022

Country	Worrying about symptoms before seeing a healthcare professional	Waiting to have an initial consultation with a healthcare professional	Waiting to find out test results	Getting the lung cancer diagnosis	Having to tell family and friends about my diagnosis	Waiting to start treatment	Having the first treatment session	Waiting to see if treatment is working	Waiting to find out scan results	Being told treatment was not available to you	Being told that treatment had stopped working	Being told your lung cancer had returned	Feeling physically unwell	Something else
Global (n=473)	8%	9%	28%	60%	28%	18%	7%	30%	27%	7%	11%	15%	15%	5%
Australia (n=9)	11%	11%	11%	78%	22%	0%	0%	44%	22%	11%	0%	22%	22%	22%
Brazil (n=16)	6%	6%	31%	69%	13%	25%	44%	31%	0%	0%	6%	6%	25%	19%
Bulgaria (n=1)	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	100%	0%	0%	0%
Canada (n=27)	4%	22%	30%	56%	30%	30%	4%	15%	41%	15%	7%	4%	7%	4%
Denmark (n=37)	5%	11%	24%	38%	35%	8%	3%	22%	30%	11%	19%	32%	11%	3%
Ireland (n=10)	0%	20%	40%	60%	40%	40%	0%	20%	50%	0%	0%	10%	20%	0%
Italy (n=113)	6%	9%	23%	75%	21%	21%	9%	46%	18%	6%	11%	11%	9%	0%



	Worrying about symptoms before seeing a healthcare professional	Waiting to have an initial consultation with a healthcare professional	Waiting to find out test results	Getting the lung cancer diagnosis	Having to tell family and friends about my diagnosis	Waiting to start treatment	Having the first treatment session	Waiting to see if treatment is working	Waiting to find out scan results	Being told treatment was not available to you	Being told that treatment had stopped working	Being told your lung cancer had returned	Feeling physically unwell	Something else
Netherlands (n=36)	19%	0%	17%	53%	39%	8%	6%	36%	42%	11%	14%	17%	22%	0%
Portugal (n=14)	0%	0%	7%	57%	50%	21%	7%	36%	7%	0%	0%	7%	14%	0%
Spain (n=50)	4%	12%	22%	70%	24%	26%	6%	20%	30%	0%	24%	10%	6%	4%
Taiwan (n=58)	10%	9%	41%	47%	12%	10%	7%	28%	19%	10%	3%	31%	21%	3%
UK (n=64)	9%	8%	39%	61%	41%	22%	0%	27%	42%	6%	6%	11%	14%	0%
USA (n=30)	10%	3%	30%	60%	40%	17%	7%	23%	27%	10%	7%	10%	23%	7%
Greece* (n=1)	0%	0%	0%	100%	0%	0%	0%	0%	0%	0%	0%	100%	100%	0%
India* (n=1)	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	100%	100%
Isle of Man* (n=1)	0%	0%	0%	0%	100%	0%	0%	0%	0%	0%	0%	100%	100%	0%
Mexico* (n=1)	0%	0%	0%	100%	0%	0%	0%	0%	100%	0%	0%	0%	0%	100%
New Zealand* (n=1)	0%	0%	0%	0%	100%	0%	0%	100%	0%	0%	0%	0%	100%	0%
Sweden* (n=3)	33%	0%	67%	0%	33%	0%	0%	0%	0%	0%	67%	33%	67%	0%

When asked about the emotional impact of their lung cancer, respondents stated that getting a lung cancer diagnosis (60%, 286/473), waiting to see if treatment is working (30%, 144/473), and having to tell family and friends about their diagnosis (28%, 134/473) had the biggest impact on them (Table 6).

We wanted to understand what respondents found most helpful in dealing with their emotions. As Table 7 below shows, approximately half (49%, 232/471) stated speaking to family and friends was most helpful. Many respondents (39%, 186/471) said that their treatment team helped them deal with their emotions, however, some (12%, 58/471) stated that they are yet to find anything that helps them.

Table 7: What have you found most helpful in dealing with these emotions? Please tick all that apply. Responses from 2022

Country	Speaking to my treatment team	Speaking to friends or family	Getting support from a patient advocacy group or charity	Speaking to other people with lung cancer in-person	Speaking to other people with lung cancer online or by telephone	Attending a support group for people with lung cancer in-person	Attending a support group for people with lung cancer online or by telephone	Receiving support from a therapist or counsellor	I am yet to find anything that helps me	Other
Global (n=467)	40%	50%	19%	17%	15%	10%	9%	18%	12%	10%
Australia (n=9)	22%	56%	22%	22%	11%	0%	0%	33%	11%	22%
Brazil (n=16)	63%	75%	13%	25%	25%	19%	6%	0%	0%	31%
Bulgaria (n=1)	0%	0%	0%	0%	100%	100%	0%	0%	0%	0%
Canada (n=25)	52%	52%	36%	20%	40%	4%	24%	28%	4%	16%
Denmark (n=37)	49%	68%	19%	8%	8%	11%	5%	14%	14%	11%
Ireland (n=10)	50%	50%	20%	10%	20%	0%	0%	30%	10%	0%
Italy (n=112)	27%	34%	2%	11%	4%	0%	3%	6%	13%	0%
Netherlands (n=36)	28%	81%	14%	19%	6%	6%	6%	25%	25%	11%
Portugal (n=13)	38%	38%	0%	0%	0%	0%	0%	8%	15%	8%
Spain (n=50)	40%	60%	10%	10%	16%	8%	8%	28%	12%	18%
Taiwan (n=57)	46%	32%	37%	30%	11%	26%	16%	32%	7%	5%
UK (n=64)	48%	48%	34%	22%	33%	16%	14%	25%	9%	0%
USA (n=30)	40%	53%	27%	20%	33%	17%	23%	7%	23%	10%
Greece* (n=1)	0%	100%	0%	0%	0%	0%	0%	0%	100%	0%
India* (n=1)	0%	100%	0%	0%	0%	0%	0%	0%	0%	0%
Isle of Man* (n=1)	100%	100%	0%	0%	0%	0%	0%	0%	0%	0%
Mexico* (n=1)	100%	100%	0%	0%	0%	0%	0%	0%	0%	0%
New Zealand* (n=1)	100%	0%	100%	0%	0%	0%	0%	0%	0%	0%
Sweden* (n=2)	50%	100%	50%	0%	0%	0%	0%	0%	50%	0%

Impact of COVID-19

During the COVID-19 pandemic, many patients have seen appointments being delayed or cancelled, and face-to-face appointments being swapped for telephone or video calls. We wanted to understand how the pandemic had impacted the treatment and care patients receive, and how they prefer to communicate with the treatment team in a range of situations.

Table 8: Which of the following describes your experience during COVID-19? Please check all that apply. Responses from 2022

Country	I found it easier to contact my treatment team	There has been no difference in how easy it has been to contact my treatment team	I found it more difficult to speak to my treatment team	I have held back in contacting my treatment team because they are so busy	My treatment has continued as normal	My treatment has been delayed / cancelled	I don't know if my treatment has been affected	I have carried on attending appointments during the pandemic	I have been reluctant to attend appointments for fear of infection	I have missed appointments for fear of infection	My face-to-face appointments have been swapped for telephone or video calls	I have been offered new services that weren't available to me before the pandemic
Global (n=446)	7%	47%	8%	9%	50%	6%	7%	45%	3%	1%	22%	6%
Australia (n=9)	0%	44%	0%	0%	67%	0%	11%	44%	0%	0%	33%	0%
Brazil (n=16)	13%	56%	6%	0%	63%	0%	6%	38%	0%	0%	31%	13%
Bulgaria (n=1)	0%	0%	0%	0%	0%	100%	0%	0%	0%	0%	0%	0%
Canada (n=25)	8%	44%	20%	12%	52%	12%	8%	48%	0%	0%	56%	4%
Denmark (n=31)	6%	61%	3%	3%	61%	3%	3%	58%	3%	0%	23%	3%
Ireland (n=10)	0%	60%	0%	50%	50%	0%	10%	70%	10%	0%	40%	10%
Italy (n=109)	5%	52%	7%	5%	56%	7%	8%	35%	2%	3%	4%	0%
Netherlands (n=34)	15%	50%	6%	18%	38%	9%	9%	29%	3%	3%	35%	6%
Portugal (n=13)	8%	69%	0%	0%	62%	0%	0%	69%	0%	0%	8%	0%



	I found it easier to contact my treatment team	There has been no difference in how easy it has been to contact my treatment team	I found it more difficult to speak to my treatment team	I have held back in contacting my treatment team because they are so busy	My treatment has continued as normal	My treatment has been delayed / cancelled	I don't know if my treatment has been affected	I have carried on attending the appointments during the pandemic	I have been reluctant to attend appointments for fear of infection	I have missed appointments for fear of infection	My face-to-face appointments have been swapped for telephone or video calls	I have been offered new services that weren't available to me before the pandemic
Spain (n=49)	4%	41%	22%	10%	45%	4%	6%	53%	0%	0%	14%	14%
Taiwan (n=54)	4%	28%	2%	6%	56%	4%	2%	46%	6%	2%	0%	0%
UK (n=59)	8%	44%	8%	14%	36%	7%	14%	53%	0%	0%	54%	0%
USA (n=29)	7%	41%	7%	7%	41%	7%	10%	34%	17%	0%	24%	3%
Greece* (n=1)	0%	0%	100%	0%	0%	100%	0%	0%	0%	100%	0%	100%
India* (n=1)	0%	100%	100%	0%	0%	100%	0%	0%	0%	0%	0%	0%
Isle of Man* (n=1)	0%	0%	100%	0%	0%	0%	0%	0%	100%	0%	0%	100%
Mexico* (n=1)	0%	0%	0%	0%	0%	0%	100%	0%	0%	100%	100%	0%
New Zealand* (n=1)	0%	100%	100%	0%	0%	100%	0%	0%	100%	0%	0%	100%
Sweden* (n=2)	0%	100%	0%	0%	50%	0%	0%	50%	0%	0%	0%	0%

As Table 8 shows, the majority of responding patients (47%, 211/446) stated that there has been no difference in how easy it has been to contact their treatment team. However, some (9%, 38/446) stated that they have held back in contacting their treatment team because they are so busy.

Half of the responding patients (50%, 224/446) said that their treatment has continued as normal, and many (45%, 199/446) had continued to attend appointments during the pandemic. Only a small minority (5%, 21/446) stated that they were reluctant to attend, or missed, appointments due to fear of infection.

Approximately one-fifth of respondents noted that their face-to-face appointments had been swapped to virtual appointments. However, as Table 9 below shows, the majority of respondents would prefer to see their treatment in person when: finding out their diagnosis (91%, 406/444); having their first consultation (94% 412/438); having regular check-ups (78%, 349/450); and there is a change to their treatment (84%, 374/444). Some respondents did note that if they were worried about something, they would also be willing to have a telephone consultation (32%, 146/452).

Table 9: How would you like to have a conversation with the treatment team in the following situations? Responses from 2022

Country	Finding out the diagnosis				The first consultation				Regular check ups				If there is a change to treatment				If I'm worried about something			
	Video	Telephone	Face-to-face	Not sure	Video	Telephone	Face-to-face	Not sure	Video	Telephone	Face-to-face	Not sure	Video	Telephone	Face-to-face	Not sure	Video	Telephone	Face-to-face	Not sure
Global (n=452)	2%	5%	91%	2%	2%	3%	94%	2%	8%	13%	78%	1%	5%	10%	84%	2%	7%	32%	59%	2%
Australia (n=9)	0%	0%	100%	0%	0%	0%	100%	0%	11%	33%	56%	0%	0%	13%	88%	0%	0%	44%	56%	0%
Brazil (n=16)	6%	0%	88%	6%	0%	0%	100%	0%	0%	0%	100%	0%	0%	6%	94%	0%	13%	19%	69%	0%
Bulgaria (n=1)	0%	100%	0%	0%	0%	100%	0%	0%	0%	100%	0%	0%	0%	100%	0%	0%	0%	100%	0%	0%
Canada (n=25)	0%	12%	85%	0%	4%	4%	92%	0%	12%	23%	62%	0%	12%	23%	62%	0%	8%	35%	54%	0%
Denmark (n=33)	0%	9%	91%	0%	0%	3%	97%	0%	9%	26%	66%	0%	3%	12%	82%	3%	3%	37%	60%	0%
Ireland (n=10)	0%	9%	91%	0%	0%	3%	97%	0%	9%	26%	66%	0%	3%	12%	82%	3%	3%	37%	60%	0%



	Video	Telephone	Face-to-face	Not sure	Video	Telephone	Face-to-face	Not sure	Video	Telephone	Face-to-face	Not sure	Video	Telephone	Face-to-face	Not sure	Video	Telephone	Face-to-face	Not sure
Italy (n=105)	1%	4%	93%	2%	2%	0%	95%	3%	4%	7%	90%	0%	2%	12%	84%	2%	7%	38%	53%	2%
Netherlands (n=33)	0%	3%	97%	0%	0%	3%	97%	0%	9%	19%	71%	0%	3%	3%	94%	0%	0%	30%	67%	3%
Portugal (n=12)	0%	0%	100%	0%	0%	0%	100%	0%	0%	0%	12%	0%	0%	0%	100%	0%	0%	31%	69%	0%
Spain (n=47)	2%	2%	91%	4%	0%	7%	89%	5%	12%	12%	74%	2%	0%	4%	94%	2%	12%	24%	64%	0%
Taiwan (n=54)	6%	7%	85%	2%	4%	8%	89%	2%	4%	9%	83%	4%	11%	6%	83%	0%	6%	21%	70%	4%
UK (n=62)	2%	3%	95%	0%	2%	2%	97%	0%	11%	19%	70%	0%	6%	13%	81%	0%	11%	36%	48%	5%
USA (n=29)	3%	7%	83%	7%	3%	0%	90%	7%	21%	7%	69%	3%	3%	3%	83%	10%	3%	31%	59%	7%
Mexico* (n=1)	0%	0%	100%	0%	0%	0%	100%	0%	0%	0%	100%	0%	0%	0%	100%	0%	0%	0%	100%	0%
Greece* (n=1)	0%	0%	100%	0%	0%	0%	100%	0%	0%	0%	100%	0%	0%	100%	0%	0%	0%	0%	100	0%
Germany* (n=1)	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
India* (n=1)	0%	0%	100%	0%	0%	0%	100%	0%	100%	0%	0%	0%	0%	0%	100%	0%	100%	0%	0%	0%
Isle of Man* (n=1)	0%	0%	100%	0%	0%	0%	100%	0%	0%	0%	100%	0%	0%	0%	100%	0%	0%	0%	100%	0%
New Zealand* (n=1)	0%	0%	100%	0%	0%	0%	100%	0%	100%	0%	0%	0%	100%	0%	0%	0%	0%	100%	0%	0%
Sweden* (n=2)	0%	0%	100%	0%	0%	0%	100%	0%	0%	0%	100%	0%	0%	0%	100%	0%	0%	50%	50%	0%

Seeking information

During the pandemic, many patient 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. We wanted to understand the ways in which patients like to receive information, from having conversations to being given materials to read or watch.

Table 10: The GLCC believes that lung cancer patients should receive high quality information, which tells you what you want to know and at the right time for you. Which of the following best describes how you feel about the information you received from your treatment team about your lung cancer? Responses from 2022 survey

Country	I got the information I needed at the right time	The information wasn't helpful	The information came too late	The information wasn't helpful and it was also given too late	I had to look for other information on my own	I didn't want to know any information
Global (n=459)	70%	3%	3%	2%	20%	2%
Australia (n=9)	22%	0%	11%	0%	67%	0%
Brazil (n=16)	88%	0%	0%	0%	13%	0%
Bulgaria (n=1)	0%	0%	100%	0%	0%	0%
Canada (n=26)	54%	0%	8%	0%	38%	0%
Denmark (n=36)	86%	0%	3%	3%	8%	0%
Ireland (n=10)	70%	0%	0%	0%	30%	0%
Italy (n=110)	75%	5%	4%	1%	15%	1%
Netherlands (n=34)	82%	0%	3%	3%	6%	6%
Portugal (n=13)	69%	0%	0%	8%	15%	8%
Spain (n=50)	72%	2%	2%	2%	20%	2%
Taiwan (n=54)	57%	6%	2%	2%	31%	2%
UK (n=63)	67%	5%	6%	2%	17%	3%
USA (n=29)	69%	0%	0%	7%	24%	0%
Greece* (n=1)	0%	0%	0%	0%	0%	100%
India* (n=1)	0%	0%	0%	0%	100%	0%
Isle of Man* (n=1)	100%	0%	0%	0%	0%	0%
Mexico* (n=1)	100%	0%	0%	0%	0%	0%
New Zealand* (n=1)	100%	0%	0%	0%	0%	0%
Sweden* (n=2)	50%	0%	0%	0%	50%	0%

As Table 10 shows, 7 in 10 respondents (320/459) believed that they got the information they needed at the right time. However, 20% (92/459) stated that they had to look for other information on their own. 8% of respondents (38/459) stated that the information they received wasn't helpful, came too late, or was both not helpful and came too late. Only 2% of respondents (9/459) didn't want to know any information.

Conclusions

The survey findings show that whilst each patient's experience during their lung cancer journey is different, there are some common themes that transcend different geographies and health systems:

- The majority of patients would be willing to attend a lung health check or screening appointment if it was available to them in their country and if they were invited. Screening is available in very few countries worldwide, despite evidence suggests that screening programmes support earlier detection and diagnosis and better patient outcomes. The GLCC advocates for the implementation of lung cancer screening pilots by all governments to test targeting of strategies in preparation for national roll out
- Many patients felt they had not always been involved in decisions about their treatment and care, and so there is scope to increase the extent to which patients feel involved in decision-making in all countries. Research is needed to identify best practice from countries where larger proportions of respondents felt fully involved in decision-making, so that it can be replicated elsewhere
- Every lung cancer patient has felt a range of emotions since receiving their diagnosis. To support with the emotional impact of their lung cancer, many have turned to family and friends, their treatment teams, and patient organisations for support. Policymakers should review the emotional support in place for lung cancer patients, to ensure that adequate support that meets the needs of patients is available when they need it
- For many patients, treatment has continued during the pandemic. However, some stated that face-to-face appointments have been swapped to virtual appointments. The majority of patients prefer to speak to their treatment teams in person, so provisions should be put in place to ensure that treatment teams can offer a hybrid model to patients, based on the patient's preference
- A proportion of patients felt that they did not receive the information that they needed and had to look for it themselves. Treatment teams should regularly ask patients if they have all the information they need at the time they need it, as well as be equipped with a range of resources to offer based on their needs, and be able to refer them to patient organisations for further support as required

As stated in our patient charter, the GLCC believes that every patient has the right to have access to quality health care; informed self-determination; physical and mental integrity; and confidentiality and privacy, and to be treated with dignity and respect. We are therefore calling on policymakers to ensure that policies implemented meet these standards.

More information

The Global Lung Cancer Coalition is an alliance of patient organisations from across the world. Established in 2001, the GLCC comprises 42 non-government patient organisations from 30 nations: Argentina, Australia, Brazil, Bulgaria, Canada, Czech Republic, Denmark, Egypt, France, Germany, Greece, Ireland, Israel, Italy, Japan, Mexico, Netherlands, Norway, Peru, Portugal, Russia, Slovenia, South Africa, Spain, Sweden, Switzerland, Taiwan, Turkey, UK, and USA.

The GLCC 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 year's survey, the findings from previous global patient experience surveys, or the work of the GLCC, please visit our website at www.lungcancercoalition.org or email our secretariat at: glcc@roycastle.org.

Appendix – data tables

The following tables present a breakdown of the number of responses by country, as well as the global findings to the demographic questions asked in the survey.

Breakdown of survey responses by country

Country	Total responses	Percentage of global responses
Argentina	1	0.2%
Australia	10	1.8%
Brazil	18	3.2%
Bulgaria	2	0.4%
Canada	29	5.2%
Denmark	45	8.1%
General*	9	1.6%
Ireland	11	2%
Italy	136	24.5%
Netherlands	44	7.9%
Portugal	17	3.1%
Spain	56	10.1%
Taiwan	75	13.5%
UK	72	13%
USA	30	5.4%

*Respondents to the general survey were from Germany (1), Greece (1), India (1), the Isle of Man (1), Mexico (1), New Zealand (1), and Sweden (3)

Global responses to demographic questions

What is your gender?

	Female	Male	Gender neutral / gender non- conforming	Prefer not to say	None of the above, I describe myself as
Total	408	143	2	0	0
Percentage	74%	26%	0.4%	0%	0%

What type of lung cancer were you diagnosed with?

	Small cell lung cancer	Non-small cell lung cancer: adenocarc inoma	Non-small cell lung cancer: squamous cell cancer	Non-small cell lung cancer: large cell carcinoma	Non-small cell lung cancer: undiffere ntiated	Non-small cell lung cancer – but I’m not sure which type	Pancoast tumour	Mesotheli oma	I don’t know what type of lung cancer I have, and I didn’t want to know	I don’t know what type of lung cancer I have, but I would like to know
Total	48	380	29	11	13	39	2	2	5	15
Percentage	9%	70%	5%	2%	2%	7%	0	0	1%	3%

How old were you when you were diagnosed with lung cancer?

	0 – 14	15 – 39	40 – 44	45 – 49	50 – 54	55 – 59	60 – 64	65 – 69	70+	I don’t know
Total	1	24	37	69	80	99	92	81	68	1
Percentage	0%	4%	7%	13%	14%	18%	17%	15%	12%	0%



When were you diagnosed with lung cancer?

	2022	2021	2020	2019	2018	2017	2016	2015	2014	2013	2012	2011	2010	2009	Before 2009	I don't know
Total	3	118	98	97	54	54	40	15	23	8	7	9	3	6	15	1
Percentage	1%	21%	18%	18%	10%	10%	7%	3%	4%	1%	1%	2%	1%	1%	3%	0%

Which of the following best describes you?

	I have just been diagnosed with lung cancer and haven't started treatment yet	I am currently having treatment	I have finished treatment	I chose not to have treatment	Treatment wasn't available to me
Total	16	348	159	5	5
Percentage	3%	65%	30%	1%	1%

Which types of treatment have you received? Please tick all that apply

	Surgery	Radiotherapy	Chemotherapy	Immunotherapy	Targeted therapies	Symptom management e.g. pain, nausea, constipation, or other side effects	I have not received any treatment because I have just been diagnosed	I have not received any treatment, but I am due to start	I have not received any treatment because COVID-19 has delayed it	I have not received any treatment because I chose not to	I have not received any treatment because it is not available to me	Other treatment
Total	213	224	284	164	217	135	4	3	1	2	1	40
Percentage	38%	40%	51%	30%	39%	24%	1%	1%	0%	0%	0%	7%

Global responses to questions about the availability of national lung cancer screening programmes

In some countries there are national programmes which invite groups of people who may be a higher risk of lung cancer to have a lung screening appointment or lung health check. Are you aware of a lung health check or screening programme in your country?

	Yes	No	I don't know
Total	109	385	57
Percentage	20%	70%	10%

Have you been invited to a lung health check or screening appointment? (This question was only asked to respondents who stated that they were aware of a national lung cancer screening programme/lung health check in their country).

	Yes – I attended a screening appointment and was diagnosed with lung cancer because of this	Yes – I attended a screening appointment, but my lung cancer was diagnosed by another route	Yes – but I chose not to attend	No – I have never been invited to a lung screening appointment	I'm not sure
Total	12	8	1	84	4
Percentage	11%	7%	1%	77%	4%

Global responses to questions asking about the emotional impacts of lung cancer diagnosis

To what extent has the COVID-19 pandemic affected your mental 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.

	I have felt worried / anxious as COVID-19 delayed my diagnosis					I have felt worried / anxious after not being able to speak to my treatment team as often					I have felt worried / anxious as to whether my treatment would be delayed / cancelled as a result of COVID-19					I have felt worried / anxious as my treatment has been delayed / cancelled as a result of COVID-19				
	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
Total	253	43	52	46	46	240	69	66	34	28	230	63	60	35	50	308	38	33	17	31
Percentage	57%	10%	12%	10%	10%	54%	16%	15%	8%	6%	52%	14%	14%	8%	11%	70%	9%	7%	4%	7%

	I have felt unwell because of treatment being delayed / cancelled as a result of COVID-19					COVID-19 has made me feel worried / anxious about my finances					I have felt isolated as I haven't been able to see my friends / family					I have felt worried / anxious attending appointments without my friends / family				
	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
Total	332	31	25	10	25	284	42	49	22	33	151	55	80	67	88	202	59	59	45	69
Percentage	75%	7%	6%	2%	6%	64%	10%	11%	5%	7%	34%	12%	18%	15%	20%	46%	13%	13%	10%	16%

Global responses to questions asking about the impacts of COVID-19 on lung cancer diagnosis

Do you think you've had COVID-19 symptoms?

	Yes, and I have been tested and the test said I had COVID-19	Yes, and I have been tested but the test said I did not have COVID-19	Yes, but I have not been tested	No, I haven't had symptoms	I don't know
Total	58	67	12	307	20
Percentage	13%	14%	3%	66%	4%

Which of the following best represents your COVID-19 vaccination status?

	I have been vaccinated against COVID-19	I haven't had a COVID-19 vaccination yet, but I have an appointment for my vaccination	I want to have a COVID-19 vaccination but I haven't been invited for a vaccination yet	I have chosen not to have the COVID-19 vaccine	I have chosen not to have the COVID-19 vaccine at this time, but I might consider it in the future	I'm unable to receive the COVID-19 vaccine due to allergies or other health issues
Total	431	4	4	11	5	3
Percentage	94%	1%	1%	2%	1%	1%