

# The emotional impact of lung cancer: what do patients experience and where do they turn for support?

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

September 2021

### Background

The Global Lung Cancer Coalition (GLCC) is a partnership of 42 non-governmental organisations across 30 nations, dedicated to improving outcomes for lung cancer patients. Our members collaborate and campaign to improve lung cancer patients' experience of their treatment and care, both at a national level and globally.

To do this we need to understand what lung cancer patients experience, from the point of their diagnosis and as they progress through their treatment and care. Through our network of members, we have run two global surveys, one in 2020 and one in 2021, to ask patients around the world about their lung cancer journeys. We are grateful to every patient and carer who responded.

### The emotional impact of a lung cancer diagnosis

A lung cancer diagnosis will bring up many emotions, both for the patient and for those around them. People may have understandable fears and anxieties about their health, their treatment and prognosis, as well as the impact that their diagnosis will have on their loved ones. They may also face stigma or feel ashamed, due to lung cancer's association with smoking.

It is important that we understand the emotional impact of a lung cancer diagnosis so that we can advocate for patients to have access to services to support their emotional, as well as their physical, health and wellbeing.

We asked questions in our 2021 survey to explore the emotions that people experience as they go through their lung cancer journey and also where they seek help, whether the treatment team from the hospital, a patient support organisation, or friends and family.

### Key findings and calls to action

**A lung cancer diagnosis comes with a huge emotional burden. High quality holistic lung cancer care should meet patients' physical and emotional needs.** Not all patients realise that they can ask their medical team for emotional support. Patients should be encouraged to discuss this with their medical teams so they can be signposted to professionals and to services who can help them.

**Family and friends are the main source of emotional support for many patients.** As such, caregivers and loved ones supporting someone through a lung cancer diagnosis may themselves have need of information or emotional support.

## What are the emotional effects of a lung cancer diagnosis?

We asked respondents to tell us about how their diagnosis has affected them emotionally. A choice of ten responses was given, from positive emotions such as feeling hopeful for the future, to more neutral and 'just getting on with it', and negative feelings of loneliness isolation, fear and shame.

For each of the emotions, respondents were able to indicate whether they are feeling that emotion now, have felt it in the past, or have never felt it before. This would allow further analysis at a country level to see if patients' emotions change over time, for example, when they have just been diagnosed, are having treatment, or have finished treatment.

Tables 1a and 1b in the appendix show the range of emotions that people living with lung cancer are experiencing.

We were encouraged that, despite their diagnosis, in most countries a substantial proportion of respondents said they are currently feeling hopeful for the future and positive about life. In most countries, a significant proportion of respondents also said that they are feeling physically and mentally well now.

However, large proportions of respondents in most countries told us they are feeling worried or depressed about their future, anxious about treatment or fearful about relapse. Some respondents also said they are feeling lonely or isolated, and a small proportion in most countries said they were feeling, or had felt, ashamed of having lung cancer. The GLCC believes that no patient should experience stigma or shame, no matter the cause of their disease.

The survey findings also show that patients' emotional worries go beyond themselves, with significant proportions of respondents in most countries saying that they worried about the impact of their diagnosis on their family.

### **We encourage all countries to examine these findings and to consider:**

- If they are representative of the lung cancer patient population in their country
- What more can be done to support people with lung cancer with the emotional impact of their diagnosis, recognising that people's feelings – and support needs – may change over time

## Who do patients turn to for help with the emotional impact of lung cancer?

No-one should face a lung cancer diagnosis alone. We wanted to know where people turn for support with the emotional impact of their diagnosis. We gave people four options: treatment team, friends / family, patient organisations or other (to which they could add a comment). We then asked them if they had asked these groups for emotional support:

- Always
- Mostly
- Sometimes
- Not at all – I haven't needed to
- Not at all – I don't feel comfortable
- Not at all – I didn't know I could
- Not applicable

The results to this question are in table 2a – 2d.

The findings show that friends and family are an important source of emotional support for most respondents in all countries. In most countries, larger proportions of patients chose friends and family as those they would always or mostly turn to for support, than their treatment team or patient support groups, who they were more likely to go to sometimes.

While it is encouraging to see that many people have a network of loved ones they can reach out to, some people do not and may need to be signposted to other sources of emotional support. We also recognise that there will be an emotional impact on patients' caregivers and loved ones, who may themselves need access to information or emotional support.

Of note, a significant proportion of respondents in most countries said they either didn't feel comfortable with, or didn't know they could, contact their treatment team for emotional support. The same was true for patient support organisations. High quality holistic lung cancer care should meet people's emotional, as well as their physical, needs. It is important that people living with lung cancer feel able to talk to their treatment team about the emotional impact of their diagnosis, and that they can be signposted to different support options.

Respondents were also able to also select 'other' as an option. Selecting this response, some examples of the other people reached out to include other lung cancer patients, a counsellor and religious guidance.

### **We encourage all countries to examine these findings and to consider:**

- If they are representative of the lung cancer patient population in their country
- What actions can be taken by treatment teams to ensure that all lung cancer patients know they can speak to them about their emotional support needs
- What information and support can be provided to caregivers and loved ones supporting lung cancer patients

## Acknowledgments

We would like to thank all the patients and carers who took the time to respond to the surveys. We would also like to acknowledge the contributions of the working group of members who devised the survey questions and supported analysis of the responses: Jackie Fenemore, Lung Cancer Nursing UK; Bernard Gaspar and Javi Mayans, Asociación Española de Afectados por el Cáncer de Pulmón; Micaela Daniels and Lauren Pretorius, Campaigning for Cancer; Win Boerckel, Cancer Care; Maureen Rigney, GO2 Foundation for Lung Cancer; Aoife McNamara, Irish Cancer Society; Merel Hennink, Longkanker Nederland.

## Contact us

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 study and the work of the GLCC please visit: [www.lungcancercoalition.org](http://www.lungcancercoalition.org) or email our secretariat at: [glcc@roycastle.org](mailto:glcc@roycastle.org)

## Appendix

**Table 1a: responses to the question “Please tell us how your diagnosis has affected you emotionally”**

	Hopeful for the future / positive about life			I feel mentally and physically well			Just getting on with it			Worried or depressed about my health and future			Feeling lonely / isolated		
	I feel like this now	I have felt like this	I have never felt like this	I feel like this now	I have felt like this	I have never felt like this	I feel like this now	I have felt like this	I have never felt like this	I feel like this now	I have felt like this	I have never felt like this	I feel like this now	I have felt like this	I have never felt like this
Taiwan n=473	38%	39%	24%	48%	29%	23%	59%	31%	11%	50%	17%	33%	14%	9%	77%
Netherlands n= 170	51%	28%	21%	52%	38%	11%	35%	40%	26%	51%	36%	13%	27%	19%	54%
USA n= 129	60%	36%	4%	54%	41%	5%	38%	47%	15%	26%	65%	9%	16%	48%	36%
Italy n= 100	37%	36%	27%	35%	41%	25%	47%	26%	28%	38%	41%	22%	26%	25%	48%
Denmark n= 63	68%	19%	14%	61%	28%	11%	55%	26%	19%	42%	39%	19%	26%	21%	53%
Brazil n= 53	54%	27%	19%	54%	26%	20%	37%	39%	24%	33%	47%	20%	8%	22%	71%
UK n= 50	32%	52%	16%	42%	48%	10%	76%	18%	6%	26%	66%	8%	12%	68%	20%
Canada n= 48	55%	32%	14%	35%	53%	12%	41%	39%	20%	23%	57%	20%	20%	42%	38%
Spain n= 42	69%	26%	5%	51%	41%	8%	80%	15%	5%	13%	75%	13%	13%	33%	55%
Ireland n= 20	59%	24%	18%	50%	38%	13%	38%	63%	0%	35%	65%	0%	18%	59%	24%
Portugal n= 21	67%	27%	7%	59%	29%	12%	56%	31%	13%	44%	39%	17%	13%	0%	88%
Australia n= 11	36%	55%	9%	27%	64%	9%	60%	40%	0%	30%	60%	10%	40%	40%	20%
Mexico n= 5	80%	20%	0%	40%	60%	0%	80%	20%	0%	20%	80%	0%	20%	40%	40%
South Africa n= 4	25%	50%	25%	25%	25%	50%	100%	0%	0%	25%	25%	50%	25%	25%	50%
Bulgaria n= 1	100%	0%	0%	100%	0%	0%	100%	0%	0%	0%	0%	100%	0%	0%	100%
Sweden n= 1	100%	0%	0%	100%	0%	0%	100%	0%	0%	0%	100%	0%	0%	0%	100%
Greece n= 1	0%	100%	0%	0%	100%	0%	0%	100%	0%	0%	100%	0%	0%	100%	0%
Iceland n= 1	100%	0%	0%	100%	0%	0%	0%	0%	100%	0%	100%	0%	0%	0%	100%

**Table 1b: responses to the question “Please tell us how your diagnosis has affected you emotionally”**

	Feeling ashamed			Worried about the impact on of lung cancer on my family			Anxious about treatment and potential side effects			Fearful of relapse			Worried about the financial impact of my lung cancer on me / my family		
	I feel like this now	I have felt like this	I have never felt like this	I feel like this now	I have felt like this	I have never felt like this	I feel like this now	I have felt like this	I have never felt like this	I feel like this now	I have felt like this	I have never felt like this	I feel like this now	I have felt like this	I have never felt like this
Taiwan n=473	7%	5%	88%	53%	25%	22%	50%	24%	26%	53%	33%	14%	52%	32%	16%
Netherlands n= 170	4%	7%	89%	54%	26%	20%	28%	46%	26%	69%	12%	19%	21%	18%	61%
USA n= 129	4%	24%	72%	41%	46%	13%	25%	67%	9%	55%	33%	12%	31%	35%	34%
Italy n= 100	7%	14%	78%	42%	42%	16%	41%	40%	20%	61%	26%	13%	30%	17%	53%
Denmark n= 63	2%	6%	93%	42%	45%	13%	32%	46%	21%	60%	24%	16%	18%	22%	60%
Brazil n= 53	8%	20%	72%	35%	43%	22%	40%	44%	15%	40%	32%	28%	24%	48%	28%
UK n= 50	2%	26%	72%	39%	57%	4%	24%	70%	6%	50%	36%	14%	12%	50%	38%
Canada n= 48	5%	31%	64%	47%	45%	9%	29%	60%	11%	49%	33%	19%	28%	33%	40%
Spain n= 42	5%	18%	77%	40%	45%	14%	15%	64%	21%	35%	53%	13%	15%	40%	45%
Ireland n= 20	13%	6%	81%	22%	67%	11%	39%	61%	0%	47%	53%	0%	18%	59%	24%
Portugal n= 21	0%	7%	93%	39%	50%	11%	29%	47%	24%	65%	18%	18%	31%	31%	38%
Australia n= 11	0%	40%	60%	50%	40%	10%	40%	40%	20%	36%	45%	18%	30%	30%	40%
Mexico n= 5	20%	0%	80%	20%	80%	0%	20%	60%	20%	60%	40%	0%	60%	20%	20%
South Africa n= 4	25%	0%	75%	75%	25%	0%	25%	50%	25%	75%	25%	0%	25%	75%	0%
Bulgaria n= 1	0%	0%	100%	0%	0%	100%	100%	0%	0%	100%	0%	0%	0%	0%	100%
Sweden n= 1	0%	0%	100%	0%	100%	0%	0%	100%	0%	100%	0%	0%	0%	100%	0%
Greece n= 1	0%	100%	0%	0%	100%	0%	0%	100%	0%	0%	100%	0%	0%	100%	0%
Iceland n= 1	0%	0%	100%	0%	100%	0%	0%	0%	100%	0%	100%	0%	0%	0%	100%



**Table 2a: responses to “Whom do you go to if you’re looking for support with the emotional side effects of your diagnosis?” – treatment team**

	Always	Mostly	Sometimes	Not at all – I haven’t needed to	Not at all – I don’t feel comfortable	Not at all – I didn’t know I could	Not applicable
Taiwan n= 471	16%	15%	33%	10%	9%	10%	8%
Netherlands n= 170	7%	8%	44%	17%	4%	9%	12%
USA n= 128	4%	9%	42%	17%	19%	7%	2%
Italy n= 99	15%	11%	26%	5%	13%	10%	20%
Denmark n= 64	7%	12%	29%	19%	2%	14%	17%
Brazil n= 53	35%	23%	25%	4%	2%	6%	6%
UK n= 50	4%	2%	36%	11%	30%	15%	2%
Canada n= 48	0%	7%	32%	16%	20%	16%	9%
Spain n= 42	21%	9%	32%	12%	15%	9%	3%
Ireland n= 21	10%	0%	25%	15%	20%	30%	0%
Portugal n= 21	47%	13%	20%	7%	13%	0%	0%
Australia n= 10	55%	27%	0%	9%	0%	9%	0%
Mexico n= 5	20%	0%	20%	0%	20%	20%	20%
South Africa n= 4	33%	0%	33%	0%	33%	0%	0%
Bulgaria n= 1	100%	0%	0%	0%	0%	0%	0%
Sweden n= 1	0%	0%	100%	0%	0%	0%	0%
Greece n= 1	0%	100%	0%	0%	0%	0%	0%
Iceland n= 1	0%	0%	0%	0%	0%	0%	100%

**Table 2b: responses to “Whom do you go to if you’re looking for support with the emotional side effects of your diagnosis?” – friends and family**

	Always	Mostly	Sometimes	Not at all – I haven’t needed to	Not at all – I don’t feel comfortable	Not at all – I didn’t know I could	Not applicable
Taiwan n= 471	30%	28%	31%	5%	2%	2%	2%
Netherlands n= 170	24%	23%	40%	4%	4%	1%	4%
USA n= 128	32%	27%	28%	3%	7%	0%	2%
Italy n= 99	43%	23%	24%	1%	3%	0%	5%
Denmark n= 64	39%	26%	21%	5%	2%	0%	7%
Brazil n= 53	49%	23%	17%	2%	8%	0%	2%
UK n= 50	26%	34%	28%	0%	12%	0%	0%
Canada n= 48	41%	28%	20%	0%	7%	0%	4%
Spain n= 42	40%	36%	19%	2%	0%	0%	2%
Ireland n= 21	60%	35%	5%	0%	0%	0%	0%
Portugal n= 21	65%	25%	5%	5%	0%	0%	0%
Australia n= 10	10%	20%	30%	10%	20%	0%	10%
Mexico n= 5	40%	40%	20%	0%	0%	0%	0%
South Africa n= 4	50%	25%	25%	0%	0%	0%	0%
Bulgaria n= 1	100%	0%	0%	0%	0%	0%	0%
Sweden n= 1	100%	0%	0%	0%	0%	0%	0%
Greece n= 1	0%	0%	0%	0%	0%	0%	0%
Iceland n= 1	0%	0%	0%	0%	0%	0%	0%

**Table 2c: responses to “Whom do you go to if you’re looking for support with the emotional side effects of your diagnosis?” – patient support group**

	Always	Mostly	Sometimes	Not at all – I haven’t needed to	Not at all – I don’t feel comfortable	Not at all – I didn’t know I could	Not applicable
Taiwan n= 471	17%	22%	37%	4%	7%	9%	4%
Netherlands n= 170	3%	12%	40%	17%	8%	6%	14%
USA n= 128	12%	15%	31%	12%	12%	3%	15%
Italy n= 99	4%	6%	23%	15%	10%	11%	32%
Denmark n= 64	7%	6%	24%	27%	2%	13%	22%
Brazil n= 53	13%	2%	15%	6%	10%	23%	31%
UK n= 50	11%	14%	36%	5%	11%	5%	18%
Canada n= 48	20%	11%	27%	14%	7%	5%	16%
Spain n= 42	3%	8%	28%	19%	11%	19%	11%
Ireland n= 21	6%	0%	6%	25%	19%	38%	6%
Portugal n= 21	7%	0%	0%	60%	7%	7%	20%
Australia n= 10	0%	11%	22%	22%	22%	22%	0%
Mexico n= 5	0%	20%	40%	0%	0%	20%	20%
South Africa n= 4	67%	0%	0%	0%	0%	0%	33%
Bulgaria n= 1	0%	0%	100%	0%	0%	0%	0%
Sweden n= 1	0%	0%	100%	0%	0%	0%	0%
Greece n= 1	0%	0%	0%	100%	0%	0%	0%
Iceland n= 1	0%	0%	0%	0%	0%	0%	0%

**Table 2d: responses to “Whom do you go to if you’re looking for support with the emotional side effects of your diagnosis?” – other**

	‘Other’ response selected
Taiwan n= 471	1%
Netherlands n= 170	0%
USA n= 128	8%
Italy n= 99	0%
Denmark n= 64	0%
Brazil n= 53	0%
UK n= 50	16%
Canada n= 48	11%
Spain n= 42	0%
Ireland n= 21	10%
Portugal n= 21	0%
Australia n= 10	20%
Mexico n= 5	0%
South Africa n= 4	0%
Bulgaria n= 1	0%
Sweden n= 1	0%
Greece n= 1	0%
Iceland n= 1	0%