



GLOBAL LUNG CANCER
COALITION

THE COVID-19 PANDEMIC THE IMPACT ON LUNG CANCER PATIENTS

Insights from the Global Lung Cancer Coalition's
2021 patient experience survey

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Introduction

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

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

The pandemic had – and continues to have – a profound impact on healthcare systems around the world. Systems, services, and teams had to change drastically to sustain levels of support for patients. Many of the respiratory healthcare experts who would usually support lung cancer patients were deployed to also care for patients with COVID. Our member organisations had to change too, supporting lung cancer patients with pressing 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 undertook a new patient experience survey, again using our member networks to share it with lung cancer patients and their caregivers.

We repeated the survey questions that we asked in 2020 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 global findings, compared findings with 2020 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. Again, we have published bespoke national reports for the participating countries (except those where there were only a very few responses). The national reports are available on the GLCC's website at: <https://www.lungcancercoalition.org/surveys/2021-patient-experience-survey/>

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 to 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 countries: Argentina, Australia, Brazil, Bulgaria, Canada, Denmark, Greece, Iceland, Ireland, Israel, Italy, Mexico, the Netherlands, Portugal, South Africa, Spain, Sweden, Taiwan, the UK, and the USA.

In total, 1,291 lung cancer patients or their carers completed the survey between February and April 2021.

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

1. **Demographics and diagnosis** – used for identifying patient populations by gender, age at diagnosis, type of lung cancer, and time since diagnosis
2. **Interventions** – to understand what testing and treatments people have had since their diagnosis
3. **Experiences** – to assess how involved people feel in decision-making about their care, whether they felt treated with dignity and respect, and how they describe themselves in the light of their experience (for example as a patient or a survivor)
4. **Emotional and physical impacts of lung cancer diagnosis** – to determine how people have been affected emotionally and physically by their diagnosis, and from whom they seek support 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 and where they look for information

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

For some questions we did not receive any responses from patients in some countries. Where this is the case, it is marked with a hyphen.

A breakdown of the responses received per country is set out in Figure 1.

This year, while more people overall filled in the survey, 42% of responses were recorded in Taiwan alone.

Figure 1: number of responses to the 2021 and 2020 patient experience surveys, by country

Country	Number of responses to 2021 survey	Number of responses to 2020 survey
Taiwan	536	-
Netherlands	175	152
USA	132	56
Italy	105	-
Denmark	66	56
Brazil	57	138
UK	54	158
Canada	49	52
Spain	43	69
Ireland	24	42
Portugal	24	16
Australia	11	-
Mexico	6	41
South Africa	5	-
Bulgaria	1	15
Sweden	1	-
Greece	1	-
Iceland	1	-
Israel	0	-
Argentina	0	5

In many countries we had fewer responses in 2021 than we did in 2020. This may be due to member organisations having less time to distribute and follow-up the survey as they responded to patient needs during COVID-19.

Insights: 2021 and 2020 survey comparisons

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.

Figure 2: Number and percentage of respondents, results for 2021

Country	I am a patient	I am a carer
Taiwan n= 536	50%	50%
Netherlands n= 175	87%	10%
USA n=131	95%	5%
Italy n= 105	68%	32%
Denmark n= 64	89%	11%
Brazil n= 57	75%	25%
UK n= 53	89%	11%
Canada n= 49	88%	12%
Spain n=43	84%	16%
Ireland n= 24	71%	29%
Portugal n= 24	88%	13%
Australia n= 11	100%	0%
Mexico n= 6	67%	33%
South Africa n= 5	40%	60%
Bulgaria n=1	100%	0%
Sweden n= 1	100%	0%
Greece n=1	0%	100%
Iceland n= 1	100%	0%

The results show that, in most countries, most responses were from lung cancer patients themselves, with a smaller proportion of responses from carers. The GLCC is grateful to every patient and carer who participated and shared their experience.

Gender

Respondents were asked about their gender. Findings are set out in Figure 3 below.

Figure 3: Number and percentage of respondents by gender, results for 2021

	Female	Male	Gender neutral	Prefer not to say	None of the above, I describe myself as...
Taiwan n= 536	82%	18%	0%	0%	0%
Netherlands n= 175	86%	14%	0%	0%	0%
USA n= 132	79%	21%	0%	0%	0%
Italy n= 104	84%	15%	1%	0%	0%
Denmark n= 65	72%	26%	0%	2%	0%
Brazil n= 57	79%	21%	0%	0%	0%
UK n= 54	83%	17%	0%	0%	0%
Canada n= 49	82%	18%	0%	0%	0%
Spain n= 43	72%	28%	0%	0%	0%
Ireland n= 24	71%	29%	0%	0%	0%
Portugal n= 24	71%	25%	0%	4%	0%
Australia n= 11	73%	27%	0%	0%	0%
Mexico n= 5	40%	60%	0%	0%	0%
South Africa n= 5	80%	20%	0%	0%	0%
Bulgaria n=1	0%	100%	0%	0%	0%
Sweden n=1	100%	0%	0%	0%	0%
Greece n=1	100%	0%	0%	0%	0%
Iceland n=1	100%	0%	0%	0%	0%

Similarly to last year's survey, most respondents were from women.

Diagnosis

Type of lung cancer

Respondents were asked which type of lung cancer they had. 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, accounting for 80-85% of all lung cancers.ⁱ The majority respondents to our 2021 and 2020 surveys had non-small cell lung cancer, as set out in Figure 4.

Figure 4: Type of lung cancer among respondents, results for 2021 and 2020

	Small cell lung cancer		Non-small cell lung cancer		Pancoast tumour		Mesothelioma		I don't know	
	2021	2020	2021	2020	2021	2020	2021	2020	2021	2020
Taiwan n= 529	4%	-	92%	-	0.4%	-	0%	-	4%	-
Netherlands n= 173/151	8%	11%	84%	81	2%	1%	0%	0%	6%	7%
USA n= 130/53	3%	15%	95%	79%	1%	0%	1%	0%	1%	6%
Italy n= 105	4%	-	91%	-	0%	-	1%	-	4%	-
Denmark n=63/24	13%	13%	73%	67%	3%	0%	0%	4%	11%	17%
Brazil n= 54/138	26%	13%	63%	63%	0%	1%	0%	1%	19%	21%
UK n= 54/156	0%	6%	98%	81%	2%	1%	0%	0%	0%	12%
Canada n= 48/51	6%	4%	79%	78%	0%	0%	0%	2%	15%	16%
Spain n= 42/69	10%	6%	81%	78%	2%	1%	2%	1%	5%	13%
Ireland n= 23/42	4%	24%	57%	60%	0%	0%	0%	10%	39%	7%
Portugal n= 24/14	13%	0%	75%	93%	4%	0%	0%	0%	8%	7%
Australia n= 11/39	0%	5%	91%	87%	0%	3%	0%	3%	9%	3%
Mexico n= 5/41	0%	7%	67%	59%	0%	0%	0%	0%	33%	34%
South Africa n= 4	0%	-	75%	-	0%	-	0%	-	25%	-
Bulgaria n= 1/15	0%	20%	0%	53%	0%	0%	0%	0%	100%	27%
Sweden n= 1	0%	-	100%	-	0%	-	0%	-	0%	-
Greece n= 1	0%	-	100%	-	0%	-	0%	-	0%	-
Iceland n= 1	0%	-	100%	-	0%	-	0%	-	0%	-

Some patients said they do not know which type of lung cancer they had or have. The type of lung cancer a patient has will affect their treatment options. This can, in turn, can contribute to a better understanding of their treatment choices and help them feel more involved in decisions about their care.

The GLCC would like to see every patient being aware of their type of lung cancer, as the first step in understanding their cancer and what treatment options may be available to them. Further survey work could be conducted to determine whether the experience of the respondents reflects that of the wider lung cancer patient population in each country.

Age at diagnosis

Respondents were asked how old they were when they received their diagnosis. Lung cancer mainly occurs in older people, and most respondents to our 2021 and 2020 surveys were over the age of 45 when they received their diagnosis.

Figure 5: Age profile of respondents, results for 2021 and 2020

	0 – 14		15 – 39		40 – 44		45 – 49		50 – 54		55 – 59		60 – 64		65 – 69		70+	
	2021	2020	2021	2020	2021	2020	2021	2020	2021	2020	2021	2020	2021	2020	2021	2020	2021	2020
Taiwan n= 532	0%	-	5%	-	12%	-	11%	-	15%	-	17%	-	16%	-	11%	-	12%	-
Netherlands n= 175/152	0%	0%	2%	3%	3%	4%	14%	16%	25%	26%	22%	17%	16%	16%	8%	7%	9%	10%
USA n= 132/53	0%	0%	8%	2%	4%	6%	4%	4%	17%	4%	14%	17%	19%	28%	15%	25%	20%	15%
Italy n= 105	1%	-	4%	-	7%	-	11%	-	17%	-	14%	-	16%	-	14%	-	15%	-
Denmark n= 66/24	0%	0%	0%	4%	2%	0%	2%	8%	8%	8%	23%	21%	17%	21%	21%	25%	29%	13%
Brazil n= 56/138	0%	1%	18%	19%	7%	7%	14%	9%	9%	16%	21%	20%	13%	11%	5%	7%	13%	9%
UK n= 54/158	0%	1%	4%	3%	6%	5%	9%	13%	17%	12%	15%	18%	19%	20%	19%	13%	13%	14%
Canada n= 48/49	0%	0%	0%	0%	8%	10%	10%	8%	17%	16%	15%	16%	23%	10%	17%	18%	8%	16%
Spain n= 42/68	0%	0%	19%	6%	7%	6%	14%	13%	19%	16%	21%	29%	7%	7%	0%	10%	12%	12%
Ireland n= 23/42	4%	0%	17%	12%	4%	5%	17%	7%	17%	2%	0%	17%	22%	14%	9%	19%	9%	24%
Portugal n= 24/16	0%	6%	17%	0%	8%	0%	25%	6%	8%	25%	17%	25%	8%	13%	13%	19%	4%	6%
Australia n= 11/39	0%	0%	9%	5%	9%	13%	0%	8%	0%	10%	36%	28%	18%	13%	9%	5%	18%	18%
Mexico n= 6/41	0%	2%	0%	7%	0%	7%	33%	7%	33%	20%	33%	20%	0%	15%	0%	10%	0%	12%
South Africa n= 4	0%	-	50%	-	0%	-	0%	-	0%	-	0%	-	25%	-	0%	-	25%	-

Figure 5: Age profile of respondents, results for 2021 and 2020 – continued

	0 – 14		15 – 39		40 – 44		45 – 49		50 – 54		55 – 59		60 – 64		65 – 69		70+	
	2021	2020	2021	2020	2021	2020	2021	2020	2021	2020	2021	2020	2021	2020	2021	2020	2021	2020
Bulgaria n= 1/15	0%	0%	0%	13%	0%	13%	0%	7%	0%	27%	0%	20%	100%	7%	0%	13%	0%	0%
Sweden n= 1	0%	-	0%	-	0%	-	0%	-	100%	-	0%	-	0%	-	0%	-	0%	-
Greece n= 1	0%	-	0%	-	0%	-	0%	-	0%	-	100%	-	0%	-	0%	-	0%	-
Iceland n= 1	0%	-	0%	-	0%	-	0%	-	0%	-	100%	-	0%	-	0%	-	0%	-

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 Most respondents noted that they were diagnosed in the last five years, with a small number who didn't know when they were diagnosed. For 2020, respondents could indicate whether they were diagnosed before or during the COVID-19 pandemic, so individual countries could use the data to examine whether there were differences in patients' experience of treatment and care depending on whether they were diagnosed before or during the pandemic.

Figure 6: Year of diagnosis amongst respondents, results for 2021 and 2020

	2021	2020 – during COVID-19	2020 – before COVID-19	2019		2018		2017		2016		Before 2016		I don't know	
	2021	2021	2021	2021	2020	2021	2020	2021	2020	2021	2020	2021	2020	2021	2020
Taiwan n=534	3%	27%	6%	24%	-	18%	-	9%	-	6%	-	8%	-	0%	-
Netherlands n= 175/152	4%	29%	3%	22%	26%	15%	23%	9%	16%	5%	10%	11%	24%	0%	0%
USA n= 132/53	3%	17%	4%	11%	43%	15%	26%	13%	15%	8%	2%	29%	13%	0%	0%
Italy n= 105	2%	22%	3%	25%	-	14%	-	15%	-	5%	-	14%	-	0%	-
Denmark n= 66/24	0%	17%	3%	20%	29%	9%	17%	12%	17%	9%	17%	29	16%	2%	4%
Brazil n= 56/138	9%	30%	9%	25%	41%	13%	16%	2%	14%	4%	10%	9%	17%	0%	1%
UK n= 54/156	2%	19%	7%	17%	22%	26%	19%	11%	18%	4%	12%	15%	29%	0%	0%
Canada n= 48/49	10%	24%	4%	22%	35%	8%	12%	4%	14%	6%	4%	18%	31%	2%	4%
Spain n= 43/69	0%	16%	5%	16%	32%	19%	25%	19%	16%	16%	13%	9%	13%	0%	1%
Ireland n= 23/42	22%	52%	0%	0%	29%	13%	21%	0%	19%	9%	10%	4%	21%	0%	0%
Portugal n= 24/16	13%	25%	8%	8%	38%	21%	6%	4%	13%	8%	19%	13%	25%	0%	0%
Australia n= 11/39	0%	27%	0%	27%	15%	27%	21%	9%	23%	0%	10%	9%	31%	0%	0%

Figure 6: Year of diagnosis amongst respondents, results for 2021 and 2020 – continued

	2021	2020 – during COVID-19	2020 – before COVID-19	2019		2018		2017		2016		Before 2016		I don't know	
	2021	2021	2021	2021	2020	2021	2020	2021	2020	2021	2020	2021	2020	2021	2020
Mexico n= 6/41	0%	17%	0%	17%	34%	17%	27%	0%	10%	33%	20%	17%	10%	0%	0%
South Africa n= 4	0%	50%	25%	25%	-	0%	-	0%	-	0%	-	0%	-	0%	-
Bulgaria n= 1/14	0%	100%	0%	0%	43%	0%	0%	0%	14%	0%	14%	0%	21	0%	7%
Sweden n= 1	0%	0%	0%	0%	-	0%	-	100%	-	0%	-	0%	-	0%	-
Greece n=1	0%	0%	0%	100%	-	0%	-	0%	-	0%	-	0%	-	0%	-
Iceland n= 1	0%	100%	0%	0%	-	0%	-	0%	-	0%	-	0%	-	0%	-

Delay in diagnosis

Detection of cancer at an earlier stage means treatment is more likely to be successful so improving earlier detection is critical to improving survival rates. This year, people were asked if they felt that there was an unnecessary delay in getting their diagnosis. This question was added to learn about the potential impact that COVID-19 may have had on people who tried to get their symptoms checked out or were waiting for test results to come back. Participants could tick more than one option.

Figure 7: Would you say there was an unnecessary delay in getting your diagnosis? Results for 2021

	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
Taiwan n= 535	14%	7%	7%	64%	7%
Netherlands n= 175	24%	9%	9%	62%	1%
USA n= 131	8%	15%	11%	71%	3%
Italy n= 105	6%	14%	16%	59%	7%
Denmark n= 65	12%	5%	9%	71%	3%
Brazil n= 56	14%	11%	7%	64%	4%
UK n= 54	19%	17%	11%	54%	6%
Canada n= 49	16%	20%	16%	51%	14%
Spain n= 42	17%	10%	10%	69%	2%
Ireland n= 24	21%	13%	13%	50%	4%
Portugal n= 24	13%	8%	4%	75%	0%
Australia n= 11	0%	9%	18%	64%	18%
Mexico n= 6	17%	17%	17%	50%	0%
South Africa n= 4	25%	25%	25%	50%	0%
Bulgaria n= 1	0%	0%	0%	100%	0%
Sweden n= 1	0%	100%	0%	0%	0%
Greece n= 1	0%	0%	0%	100%	0%
Iceland n= 1	0%	0%	0%	100%	0%

The results show that, while most respondents in most countries were satisfied with how long it took to get their diagnosis, there were significant proportions of patients who thought there it took too long for them to see someone to get symptoms checked, to get tested or to receive their results.

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.

Figure 8: Did you have any biomarker testing? Results for 2021

	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
Taiwan n=533	44%	17%	25%	11%	3%
Netherlands n= 175	54%	21%	18%	5%	2%
USA n= 131	76%	10%	5%	7%	2%
Italy n= 105	71%	9%	11%	8%	1%
Denmark n= 65	40%	23%	23%	9%	5%
Brazil n= 56	32%	18%	30%	16%	4%
UK n= 54	46%	19%	31%	4%	0%
Canada n= 49	54%	4%	23%	13%	6%
Spain n= 43	58%	9%	12%	19%	2%
Ireland n= 24	21%	13%	46%	13%	8%
Portugal n= 24	33%	38%	25%	4%	0%
Australia n= 11	55%	9%	18%	9%	9%
Mexico n= 6	17%	17%	33%	33%	0%
South Africa n= 4	50%	50%	0%	0%	0%
Bulgaria n= 1	0%	0%	0%	100%	0%
Sweden n= 1	100%	0%	0%	0%	0%
Greece n= 1	100%	0%	0%	0%	0%
Iceland n= 1	0%	100%	0%	0%	0%

While it is encouraging to see that, in most countries, a substantial proportion of respondents know they have had a biomarker test, they do not always know the results. There are also substantial proportions of patients who are not sure if they've had biomarker testing or who know they have not and would like a test. We recognise that our survey includes respondents who were diagnosed many years ago and who may have completed treatment. However, we believe all newly diagnosed patients should have the opportunity of biomarker testing and should know their results, to enable them to be involved in decision-making around their treatment options.

Interventions

Respondent profile

Respondents were asked where they were in their cancer journey and could choose from five options. The findings show that, in most countries, most respondents were currently having treatment, with a substantial proportion having finished treatment. A small proportion of patients in some countries said they were unable to have treatment or chose not to. Further research could be done at a national level to explore the reasons for this. Responses to this question will likely impact the way people view themselves; this is fully explored in a later question.

Figure 9: Which of the following best describes you? Results for 2021

	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
Taiwan n= 530	3%	79%	17%	0.4%	1%
Netherlands n= 175	2%	62%	34%	1%	1%
USA n= 132	1%	68%	30%	1%	1%
Italy n= 101	4%	75%	21%	0%	0%
Denmark n= 63	0%	46%	52%	0%	2%
Brazil n= 56	5%	77%	18%	0%	0%
UK n= 53	0%	60%	34%	0%	6%
Canada n= 48	6%	51%	35%	2%	6%
Spain n= 42	0%	71%	26%	0%	2%
Ireland n= 22	18%	41%	27%	0%	14%
Portugal n= 23	8%	65%	26%	0%	0%
Australia n= 11	0%	55%	45%	0%	0%
Mexico n= 6	0%	83%	17%	0%	0%
South Africa n= 4	0%	75%	25%	0%	0%
Bulgaria n= 1	100%	0%	0%	0%	0%
Sweden n= 1	0%	0%	100%	0%	0%
Greece n= 1	0%	0%	0%	0%	100%
Iceland n= 1	0%	0%	100%	0%	0%

Treatment

With research in lung cancer treatment advancing at a fast pace, treatment options are increasing for patients. We asked respondents to select from a list of treatments all those they had received (Figure 10a). Respondents could also choose 'other' and specify which other forms of treatment they had received.

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

	Surgery		Radiotherapy		Chemotherapy		Immunotherapy		Targeted therapies		Symptom management		No treatment		Other	
	2021	2020	2021	2020	2021	2020	2021	2020	2021	2020	2021	2020	2021	2020	2021	2020
Taiwan n= 533	42%	-	37%	-	47%	-	13%	-	68%	-	48%	-	2%	-	1%	-
Netherlands n= 174/151	29%	33%	53%	50%	60%	53%	50%	26%	29%	36%	21%	34%	2%	2%	4%	8%
USA n= 132/53	45%	32%	55%	47%	55%	75%	27%	47%	52%	15%	28%	49%	2%	0%	2%	2%
Italy n= 104	30%	-	36%	-	44%	-	32%	-	41%	-	22%	-	2%	-	5%	-
Denmark n= 66/24	45%	33%	45%	38%	62%	79%	41%	29%	12%	4%	15%	42%	2%	0%	8%	8%
Brazil n= 56/136	21%	30%	45%	35%	79%	66%	30%	27%	25%	18%	18%	30%	4%	6%	2%	7%
UK n= 54/156	43%	45%	31%	35%	44%	56%	30%	19%	35%	33%	33%	24%	4%	1%	9%	4%
Canada n= 49/48	33%	40%	37%	38%	43%	40%	35%	23%	33%	27%	31%	29%	6%	6%	8%	4%
Spain n= 43/67	33%	37%	53%	54%	67%	73%	40%	40%	40%	18%	16%	22%	0%	1%	0%	4%
Ireland n= 24/39	29%	28%	17%	38%	29%	59%	13%	13%	21%	26%	13%	28%	13%	13%	17%	0%
Portugal n= 24/16	46%	56%	21%	25%	50%	81%	33%	25%	25%	0%	4%	19%	16%	0%	0%	0%
Australia n= 11/39	27%	38%	82%	67%	73%	54%	36%	23%	55%	44%	45%	38%	0%	0%	9%	3%
Mexico n= 6/40	50%	23%	50%	23%	100%	63%	0%	13%	17%	55%	67%	35%	0%	0%	17%	8%

Figure 10a: Types of treatment respondents received, results for 2021 and 2020 - continued

	Surgery		Radiotherapy		Chemotherapy		Immunotherapy		Targeted therapies		Symptom management		No treatment		Other	
	2021	2020	2021	2020	2021	2020	2021	2020	2021	2020	2021	2020	2021	2020	2021	2020
South Africa n= 4	0%	-	100%	-	50%	-	25%	-	50%	-	75%	-	0%	-	0%	-
Bulgaria n= 1/15	0%	40%	0%	13%	0%	73%	0%	27%	0%	7%	0%	7%	100%	13%	0%	7%
Sweden n= 1	100%	-	100%	-	100%	-	0%	-	0%	-	0%	-	0%	-	0%	-
Greece n= 1	0%	-	100%	-	100%	-	100%	-	0%	-	100%	-	0%	-	0%	-
Iceland n= 1	100%	-	0%	-	0%	-	0%	-	0%	-	0%	-	0%	-	0%	-

Surgery remains the most effective way of treating lung cancer but is only an option for patients diagnosed early. Improvements in early diagnosis will mean that more patients should be eligible for treatment.

This year, we wanted to learn more about the reasons why some patients did not receive any treatment. Respondents who chose ‘no treatment’ were invited to answer an additional question, with five options to choose from (Figure 10b).

Figure 10b: Responses from respondents who did not receive any treatment, results for 2021

	I have not received any other treatment because I have just been diagnosed	I have not received any other treatment, but I am due to start	I have not received any other treatment because COVID-19 has delayed it	I have not received any other treatment because I chose not to	I have not received any other treatment because it is not available to me
Taiwan n=536	0.4%	1%	1%	0%	0%
Netherlands n= 174	2%	2%	1%	18%	1%
USA n= 128	0%	1%	3%	13%	9%
Italy n= 104	0%	2%	0%	0%	0%
Denmark n= 66	2%	0%	0%	0%	0%
Brazil n= 56	0%	2%	2%	0%	0%
UK n= 54	2%	0%	4%	6%	6%
Canada n= 49	4%	0%	0%	2%	0%
Spain n= 0	-	-	-	-	-
Ireland n= 24	4%	4%	4%	0%	0%
Portugal n= 24	13%	4%	0%	0%	0%
Australia n= 0	-	-	-	-	-
Mexico n= 0	-	-	-	-	-
South Africa n= 0	-	-	-	-	-
Bulgaria n= 0	-	-	-	-	-
Sweden n= 0	-	-	-	-	-
Greece n= 0	-	-	-	-	-
Iceland n= 0	-	-	-	-	-

The findings show that some patients were newly diagnosed and were waiting for treatment to start, but there were small proportions of patients who said that COVID-19 had delayed their treatment or that treatment was not available. Additional national research would be needed to understand this further.

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 have not received additional forms of support. As in 2020, respondents also had the option to select 'other' and indicate other forms of support they had received.

Figure 11a: Types of support respondents received, results for 2021 and 2020

	Psychosocial support / counselling		Physical therapy / pulmonary rehabilitation		Occupational therapy		Dietary advice		Lifestyle advice	
	2021	2020	2021	2020	2021	2020	2021	2020	2021	2020
Taiwan n= 527	13%	-	9%	-	1%	-	29%	-	12%	-
Netherlands n= 174/115	30%	49%	34%	48%	5%	30%	24%	6%	2%	6%
USA n= 132/41	30%	49%	16%	32%	3%	2%	38%	42%	12%	39%
Italy n= 99	19%	-	9%	-	0%	-	20%	-	18%	-
Denmark n= 60 / 15	15%	33%	20%	33%	0%	46%	22%	0%	7%	7%
Brazil n= 55/118	49%	57%	18%	36%	0%	47%	36%	20%	11%	1%
UK n= 53/102	38%	39%	17%	21%	4%	15%	13%	32%	8%	14%
Canada n= 49/31	31%	23%	6%	19%	0%	13%	25%	23%	8%	26%
Spain n= 42/44	45%	59%	17%	25%	0%	0%	19%	18%	12%	18%
Ireland n= 23/29	26%	24%	0%	24%	0%	7%	17%	48%	9%	14%
Portugal n= 22/12	5%	33%	32%	50%	0%	67%	32%	25%	5%	0%
Australia n= 11/32	27%	47%	45%	34%	0%	47%	18%	19%	0%	13%
Mexico n= 6/37	50%	24%	67%	46%	0%	0%	33%	35%	17%	11%
South Africa n= 4	25%	-	0%	-	0%	-	0%	-	25%	-
Bulgaria n= 1/14	0%	29%	0%	14%	0%	36%	0%	50%	100%	0%
Sweden n= 1	100%	-	100%	-	0%	-	100%	-	0%	-
Greece n= 1	100%	-	0%	-	0%	-	0%	-	0%	-
Iceland n= 1	0%	-	0%	-	0%	-	0%	-	0%	-

Figure 11b: Types of support respondents received, results for 2021 and 2020

	Financial advice		Return to work advice		Smoking cessation	Support group	No support	Other	
	2021	2020	2021	2020	2021	2021	2021	2021	2020
Taiwan n= 527	1%	-	1%	-	7%	51%	20%	6%	-
Netherlands n= 174/115	1%	2%	3%	7%	2%	36%	25%	17%	15%
USA n= 132/41	6%	20%	2%	5%	3%	26%	9%	9%	12%
Italy n= 99	1%	-	1%	-	4%	4%	37%	17%	-
Denmark n= 60 / 15	8%	0%	3%	0%	5%	13%	25%	30%	20%
Brazil n= 55/118	4%	3%	0%	1%	0%	5%	25%	13%	16%
UK n= 53/102	11%	29%	4%	12%	0%	40%	17%	15%	22%
Canada n= 49/31	6%	19%	4%	10%	2%	52%	31%	17%	16%
Spain n= 42/44	2%	2%	7%	5%	5%	2%	34%	12%	27%
Ireland n= 23/29	4%	0%	0%	10%	9%	9%	44%	4%	31%
Portugal n= 22/12	0%	0%	0%	0%	9%	0%	41%	5%	0%
Australia n= 11/32	0%	3%	9%	6%	0%	45%	27%	18%	19%
Mexico n= 6/37	0%	5%	0%	0%	0%	17%	17%	0%	0%
South Africa n= 4	0%	-	0%	-	50%	50%	25%	0%	-
Bulgaria n= 1/14	0%	7%	0%	7%	0%	0%	0%	0%	14%
Sweden n= 1	0%	-	0%	-	0%	100%	0%	0%	-
Greece n= 1	0%	-	0%	-	0%	0%	0%	0%	-
Iceland n= 1	0%	-	0%	-	0%	0%	100%	0%	-

Further work at a national level could be undertaken to explore:

- How useful people found the additional forms of support that they received, and if they would recommend this to other patients.
- What other types of support people would have liked to have been offered

A lung cancer diagnosis can be devastating, and it is important that every patients is supported through this journey. There is, however, a significant proportion of respondents in most countries who noted they didn't receive any support. We asked these respondents an additional question as to why that was the case, with five options for them to choose from. The findings are set out in Figure 11b.

Figure 11c: Responses from respondents who did not receive any form of support, results for 2021

	I have not received any other support because I have just been diagnosed	I have not received any other support, but I am due to start	I have not received any other support because COVID-19 has delayed it	I have not received any other support because I chose not to	I have not received any other support because it is not available to me
Taiwan n=536	2%	2%	0.4%	2%	14%
Netherlands n= 174	2%	2%	1%	18%	1%
USA n= 132	0%	1%	3%	13%	9%
Italy n= 99	3%	3%	4%	13%	14%
Denmark n= 60	7%	0%	7%	12%	3%
Brazil n= 55	0%	4%	4%	9%	9%
UK n= 53	2%	0%	4%	6%	6%
Canada n= 49	4%	0%	4%	6%	17%
Spain n= 42	5%	5%	2%	17%	5%
Ireland n= 23	9%	4%	9%	0%	22%
Portugal n= 22	14%	0%	0%	14%	14%
Australia n= 11	0%	0%	0%	18%	9%
Mexico n= 6	17%	0%	0%	0%	0%
South Africa n= 4	-	-	-	-	-
Bulgaria n= 1	-	-	-	-	-
Sweden n= 1	-	-	-	-	-
Greece n= 1	-	-	-	-	-
Iceland n= 1	0%	0%	0%	0%	100%

Further work at a national level could be undertaken to explore:

- Whether people who did not received additional support because of COVID-19 were offered it at a later point
- What support people would have liked to have been offered

Respondents' 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. We wanted to understand whether and to what extent lung cancer patients feel involved in making decisions about their treatment and care.

In 2020, respondents could only choose from 'Yes', 'No', 'No, but I didn't want to be involved' and 'No, but my caregiver was involved'.

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'.

Figure 12: Responses from respondents regarding how they were included in decisions about their treatment and care, 2021 results

Country	Yes, I've been fully involved	Yes, I've been involved most of the time	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
Taiwan n= 536	57%	21%	10%	6%	2%	4%
Netherlands n= 175	75%	13%	5%	6%	1%	1%
USA n= 129	66%	18%	11%	5%	0%	1%
Italy n= 105	34%	26%	15%	17%	4%	4%
Denmark n= 66	47%	24%	9%	14%	2%	5%
Brazil n= 56	61%	14%	7%	7%	4%	7%
UK n= 54	48%	22%	19%	7%	2%	2%
Canada n= 48	49%	27%	12%	12%	0%	0%
Spain n= 43	40%	19%	26%	12%	2%	2%
Ireland n= 24	42%	17%	21%	21%	0%	0%
Portugal n= 24	54%	29%	8%	8%	0%	0%
Australia n= 10	60%	30%	0%	10%	0%	0%
Mexico n= 6	33%	17%	33%	0%	0%	17%
South Africa n= 4	75%	25%	0%	0%	0%	0%
Bulgaria n= 1	0%	0%	100%	0%	0%	0%
Sweden n= 1	0%	100%	0%	0%	0%	0%
Greece n= 1	0%	0%	100%	0%	0%	0%
Iceland n= 1	0%	100%	0%	0%	0%	0%

The results show that every country can do more to increase the proportion of lung cancer patients who feel fully involved in decision-making around their treatment and care.

In most countries, there was a proportion of respondents who felt they were not involved in decisions around their treatment and care but who wanted to be involved. It also shows that, while some of the respondents feel fully involved in decision-making, others were only mostly or sometimes involved. Further work could be undertaken at a national level to explore:

- Whether these findings reflect the experiences of the wider lung cancer patient population
- Why some people were only involved sometimes when others felt fully or mostly involved
- What can be done 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. Considering 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.

Figure 13: Proportion of patients feeling treated with dignity and respect by their treatment team, results for 2021 and 2020

	Always		Mostly		Sometimes		Never	
	2021	2020	2021	2020	2021	2020	2021	2020
Taiwan n= 532	73%	-	22%	-	4%	-	1%	-
Netherlands n= 174/149	83%	70%	11%	23%	5%	5%	1%	1%
USA n= 132/ 53	78%	75%	19%	23%	3%	2%	0%	0%
Italy n= 104	68%	-	14%	-	13%	-	4%	-
Denmark n= 66 /23	64%	57%	33%	35%	3%	9%	0%	0%
Brazil n= 55/131	84%	76%	13%	17%	2%	5%	2%	2%
UK n= 53/155	72%	65%	21%	23%	6%	11%	2%	1%
Canada n= 49/46	71%	65%	20%	28%	6%	4%	2%	2%
Spain n= 43/67	81%	75%	16%	20%	2%	6%	0%	0%
Ireland n= 24/32	54%	57%	29%	30%	4%	11%	13%	3%
Portugal n=24/16	92%	100%	8%	0%	0%	0%	0%	0%
Australia n= 11/38	82%	66%	18%	26%	0%	8%	0%	0%
Mexico n= 6/41	67%	83%	33%	17%	0%	0%	0%	0%
South Africa n= 4	75%	-	25%	-	0%	-	0%	-
Bulgaria n= 1/15	0%	53%	0%	0%	0%	27%	100%	20%
Sweden n= 1	0%	-	100%	-	0%	-	0%	-
Greece n= 1	0%	-	0%	-	100%	-	0%	-
Iceland n= 1	0%	-	100%	-	0%	-	0%	-

The results show that more can be done in every country to make sure that lung cancer patients feel they are always treated with dignity and respect by their treatment team.

While the largest proportion of respondents in every country said they were always treated with dignity and respect, there were significant proportions in most countries who said this was the case mostly or only sometimes. In some countries respondents told us their treatment team never treated them with dignity and respect.

Further work could be undertaken at a national level to explore:

- Whether these reflects the experiences of the wider lung cancer patient population
- How the proportion of lung cancer 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. It is important to understand how people want to be described. Most of the options were repeated from the 2020 survey, with some new options provided following feedback.

Figure 14a: Proportion of patients who described themselves as one of the following

	Living with lung cancer		Patient		Surviving with lung cancer		Lung cancer survivor		Overcomer		Survivor		Advocate		Thrifer		Other	
	2021	2020	2021	2020	2021	2020	2021	2020	2021	2020	2021	2020	2021	2020	2021	2020	2021	2020
Taiwan n= 474	36%	-	12%	-	3%	-	37%	-	2%	-	8%	-	0%	-	4%	-	2%	-
Netherlands n= 169/147	46%	66%	21%	44%	10%	12%	9%	20%	3%	3%	10%	12%	4%	6%	3%	43%	10%	7%
USA n= 129/53	54%	57%	65%	51%	27%	23%	49%	28%	11%	8%	29%	15%	24%	9%	20%	15%	5%	8%
Italy n= 100	24%	-	19%	-	17%	-	6%	-	-	-	4%	-	-	-	4%	-	5%	-
Denmark n= 64/23	42%	35%	27%	39%	14%	9%	19%	30%	3%	4%	8%	26%	2%	0%	19%	0%	20%	9%
Brazil n= 53/129	23%	35%	32%	36%	11%	24%	15%	16%	32%	20%	4%	10%	17%	15%	9%	29%	0%	18%
UK n= 50/154	64%	46%	44%	31%	14%	16%	20%	28%	2%	4%	10%	17%	22%	11%	4%	6%	14%	9%
Canada n= 49/45	50%	47%	50%	31%	21%	11%	25%	27%	6%	4%	13%	22%	29%	29%	19%	13%	8%	18%
Spain n= 42/67	45%	42%	31%	42%	14%	19%	17%	12%	2%	1%	2%	3%	2%	1%	17%	12%	5%	6%
Ireland n= 21/32	29%	34%	24%	16%	5%	22%	19%	22%	0%	6%	14%	16%	10%	9%	14%	0%	29%	22%
Portugal n= 21/14	19%	21%	14%	7%	19%	29%	29%	21%	24%	29%	10%	7%	0%	0%	29%	14%	10%	21%
Australia n= 11/38	55%	53%	64%	45%	0%	18%	36%	34%	0%	5%	9%	8%	27%	21%	0%	11%	18%	11%
Mexico n= 6/41	0%	20%	20%	29%	20%	24%	20%	12%	0%	2%	0%	7%	0%	12%	20%	7%	0%	17%
South Africa n= 5	40%	-	20%	-	60%	-	20%	-	20%	-	20%	-	20%	-	0%	-	0%	-
Bulgaria n= 1/15	0%	40%	0%	40%	100%	27%	0%	13%	0%	13%	0%	20%	0%	0%	0%	0%	0%	0%
Sweden n= 1	0%	-	100%	-	0%	-	0%	-	0%	-	0%	-	100%	-	0%	-	0%	-
Greece n= 1	0%	-	0%	-	0%	-	0%	-	0%	-	0%	-	100%	-	0%	-	0%	-
Iceland n= 1	100%	-	0%	-	0%	-	0%	-	0%	-	0%	-	0%	-	0%	-	0%	-

Often cancer is described using language around war, patients are ‘fighting’ or ‘battling’ their disease. We wanted to understand whether patients identify with this language, and in the 2021 survey included new options to find out whether they would describe themselves using this kind of language. The results are set out in figure 14b.

Figure 14b: Proportion of patients who described themselves as one of the following (2021 only)

	Battling lung cancer	At war with lung cancer	Fighter	Warrior	Fighting lung cancer
Taiwan n= 474	11%	8%	5%	6%	37%
Netherlands n= 169/147	7%	3%	14%	9%	8%
USA n= 129/53	12%	12%	27%	18%	27%
Italy n= 100	6%	15%	12%	10%	22%
Denmark n= 64/23	9%	3%	16%	2%	3%
Brazil n= 53/129	13%	8%	15%	36%	15%
UK n= 50/154	4%	4%	8%	2%	12%
Canada n= 49/45	8%	2%	25%	21%	19%
Spain n= 42/67	0%	5%	17%	5%	21%
Ireland n= 21/32	10%	0%	5%	0%	5%
Portugal n= 21/14	10%	10%	19%	19%	10%
Australia n= 11/38	9%	18%	18%	9%	45%
Mexico n= 6/41	20%	0%	0%	40%	0%
South Africa n= 5	40%	40%	40%	20%	40%
Bulgaria n= 1/15	0%	0%	0%	0%	0%
Sweden n= 1	0%	0%	0%	0%	0%
Greece n= 1	0%	0%	0%	0%	0%
Iceland n= 1	0%	0%	0%	0%	0%

The results to this question demonstrates that respondents use a wide range of language to describe themselves and some options are more popular in some countries than others. Further work could be undertaken to examine:

- Whether people’s experience of care and point in their journey affects the way they see and describe 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 lung cancer diagnosis will have a profound impact for patients' emotional health and wellbeing, as well as affecting their caregivers and loved ones. Common feelings can include distress, depression, anxiety and may involve loss of self-esteem and feelings of isolation. A 2019 study found that about one third of patients newly diagnosed with the most common form of lung cancer have moderate to severe symptoms of depression.ⁱⁱⁱ It is important to recognise these changes to ensure the right emotional support is offered to people diagnosed with lung cancer.

This year, the GLCC decided to ask people questions to understand how their diagnosis has affected them both emotionally and physically, and where they turned for support.

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, and asked respondents to indicate whether the statement applied to them now, in the past, or never.

The results are set out in tables 15a and 15b and show the wide range of emotions experienced by lung cancer patients, as well as indicating how these can change over time.

Further studies could explore:

- How experience of care and interaction with a treatment team influences the way people feel about their diagnosis as they progress through their journey
- How different forms of support and information impact people's emotional wellbeing

Figure 15a: How diagnosis affected respondents emotionally, results for 2021

	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%

Figure 15b: How diagnosis affected respondents emotionally, results for 2021

	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%

Where do people turn for emotional support?

We also asked lung cancer patients whom they go to when looking for support with the emotional impact of their diagnosis. People could choose from four options: their treatment team, family and friends, a patient support group and 'other' to which they could add information.

Figure 16a: Where do people turn for support with the emotional impact of their 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%

Figure 16b: Where do people turn for support with the emotional impact of their 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%

Figure 16c: Where do people turn for support with the emotional impact of their 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%

Figure 16d: Where do people turn for support with the emotional impact of their 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%

Examples of other forms of support given included Facebook groups, specialist nurse, counsellors or spiritual support.

The findings indicate the importance of different sources of emotional support, as lung cancer patients turn to treatment teams, to friends and family and to patient support groups. However, in most countries, the largest proportion of patients turn to friends and family most frequently.

We noted that a significant proportion of respondents in most countries said they did not know that they could or would not feel comfortable, turning to their treatment team for emotional support.

Further studies could explore:

- Why some people diagnosed with lung cancer said they would not ask their treatment team for emotional support
- What support be offered to family and friends, given that they are an important source of emotional support for many lung cancer patients

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. To simplify the data, the results have been aggregated and an average of the responses from 1 to 5 have been taken. As such, the higher the number in the column below, the more people from that country stated it was a serious concern.

Figure 17: What are the physical effects people have experienced due to their lung cancer and its treatment, 2021 results

	Pain	Breath- lessness	Fatigue	Nausea / vomiting	Sleepless ness	Loss of appetite	Weight loss	Weight gain	Fluid retention	Bowel problems	Hair loss	Skin problems	Vision problems
Taiwan n=	2.78	2.04	2.91	2.11	2.65	2.53	2.24	2.03	1.82	1.34	2.25	2.82	1.88
Netherlands n=	2.5	2.99	3.89	2.2	2.92	2.4	2.17	2.54	2.05	2.65	2.4	2.61	2.04
USA n=	2.89	2.88	3.67	2	2.79	2.13	2	2.22	2.03	2.81	2.24	2.6	1.9
Italy n=	2.56	2.84	3.62	2.22	2.92	2.22	2.14	2.44	2.45	2.98	2.19	2.91	2.51
Denmark n=	3.06	2.6	3.59	2.07	2.76	2.07	1.92	2.23	1.74	2.22	2.28	2.26	1.91
Brazil n=	3.06	2.6	3.38	2.16	2.7	2.54	2.58	2.24	2.31	2.81	2.83	2.43	1.88
UK n=	2.96	2.79	3.5	2.54	2.98	2.5	2.13	2.55	2.23	3.04	2.02	2.61	1.69
Canada n=	3.07	2.89	3.63	2.07	2.87	2.04	1.8	2.37	1.87	2.04	1.8	2.02	1.85
Spain n=	2.44	2.88	2.9	2.34	2.85	2.2	2.2	2.59	2.17	2.54	2.5	2.33	2.05
Ireland n=	2.95	2.55	3.4	2.28	2.75	2.5	1.89	1.31	1.38	2.53	1.94	2.19	1.81
Portugal n=	2.37	2.2	3.35	2.06	2.71	1.89	1.9	2.74	2.61	3	2.11	2.5	2
Australia n=	2.45	2.36	3.5	1.73	2.55	1.91	1.73	2.18	2.18	3	2.64	2	2.45
Mexico n=	3.2	3.6	3.4	3.2	2.2	2.2	3.2	2.2	1.8	2.6	4.2	2.6	2.2
South Africa n=	3.25	3.5	4	2	2.75	3.5	3.25	2	2.75	2.75	3.75	3.25	2.75
Bulgaria n= 1	1	1	2	2	1	2	3	4	1	1	1	3	1
Sweden n= 1	3	2	5	3	2	1	1	5	1	2	1	2	1
Greece n= 1	5	3	5	3	3	3	3	3	3	5	5	4	3
Iceland n= 1	3	4	4	1	3	3	4	1	1	1	1	1	1

The findings indicate the range of physical effects that lung cancer patients are experiencing. Pain, fatigue, sleeplessness and breathlessness tended to be the physical effects with the biggest impact for most of the respondents.

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

Respondents were asked whom they go to when they are looking for support with the physical effects of their lung cancer. As with the question on emotional impact, people could choose from their treatment team, family and friends, patient support group or 'other'. In addition, patients could indicate how often they reached out to those people.

Figure 18a: Whom do you go to if you're looking for support with the physical 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= 470	45%	28%	17%	2%	0.4%	2%	5%
Netherlands n= 170	29%	26%	35%	4%	1%	2%	3%
USA n= 128	46%	25%	17%	5%	2%	1%	4%
Italy n= 98	44%	16%	22%	2%	5%	3%	7%
Denmark n= 64	27%	28%	15%	3%	0%	10%	17%
Brazil n= 52	48%	19%	23%	0%	0%	6%	4%
UK n= 49	37%	33%	14%	6%	6%	2%	2%
Canada n= 47	36%	18%	22%	9%	0%	7%	9%
Spain n= 42	46%	20%	20%	10%	0%	0%	5%
Ireland n= 20	35%	18%	29%	0%	0%	18%	0%
Portugal n= 21	45%	30%	10%	15%	0%	0%	0%
Australia n= 11	55%	27%	0%	9%	0%	9%	0%
Mexico n= 5	20%	0%	40%	20%	0%	20%	0%
South Africa n= 4	33%	33%	33%	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%	100%	0%	0%	0%	0%
Iceland n= 1	0%	0%	0%	0%	0%	0%	100%

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

	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= 470	32%	24%	29%	7%	2%	2%	5%
Netherlands n= 170	15%	11%	50%	12%	4%	2%	6%
USA n= 128	17%	17%	41%	12%	6%	2%	5%
Italy n= 98	34%	18%	32%	6%	2%	0%	7%
Denmark n= 64	25%	20%	24%	8%	0%	0%	22%
Brazil n= 52	50%	12%	20%	2%	6%	0%	10%
UK n= 49	11%	9%	48%	11%	11%	0%	9%
Canada n= 47	24%	10%	43%	7%	10%	2%	5%
Spain n= 42	18%	10%	25%	13%	5%	0%	30%
Ireland n= 20	47%	16%	37%	0%	0%	0%	0%
Portugal n= 21	42%	21%	21%	11%	0%	0%	5%
Australia n= 11	10%	20%	30%	10%	20%	0%	10%
Mexico n= 5	60%	20%	0%	20%	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	0%	0%	100%	0%	0%	0%	0%
Greece n= 1	0%	0%	0%	0%	0%	0%	0%
Iceland n= 1	100%	0%	0%	0%	0%	0%	0%

Figure 18c: Whom do you go to if you're looking for support with the physical 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= 470	22%	22%	34%	5%	5%	7%	5%
Netherlands n= 170	2%	13%	33%	21%	6%	5%	19%
USA n= 128	11%	10%	26%	21%	12%	3%	17%
Italy n= 98	1%	6%	24%	13%	9%	9%	40%
Denmark n= 64	7%	2%	23%	21%	0%	18%	29%
Brazil n= 52	8%	2%	13%	6%	10%	21%	40%
UK n= 49	9%	12%	35%	7%	5%	5%	28%
Canada n= 47	5%	12%	39%	20%	5%	2%	17%
Spain n= 42	0%	8%	30%	16%	11%	22%	14%
Ireland n= 20	0%	0%	0%	33%	13%	27%	27%
Portugal n= 21	0%	0%	7%	64%	7%	7%	14%
Australia n= 11	0%	11%	22%	22%	22%	22%	0%
Mexico n= 5	0%	20%	40%	0%	0%	20%	20%
South Africa n= 4	33%	33%	0%	0%	0%	0%	33%
Bulgaria n= 1	0%	0%	100%	0%	0%	0%	0%
Sweden n= 1	0%	0%	0%	0%	0%	100%	0%
Greece n= 1	0%	0%	0%	0%	0%	0%	0%
Iceland n= 1	0%	0%	0%	100%	0%	0%	0%

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

	'Other' response selected
Taiwan n= 470	0.4%
Netherlands n= 170	0%
USA n= 128	4%
Italy n= 98	0%
Denmark n= 64	0%
Brazil n= 52	0%
UK n= 49	6%
Canada n= 47	4%
Spain n= 42	0%
Ireland n= 20	0%
Portugal n= 21	0%
Australia n= 11	18%
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%

Examples of other forms of support chosen by patients included yoga, meditation, Chinese medicine, and support from other patients.

From the results of this question, it is evident that respondents were more likely to turn to their treatment team for support with physical impact of their lung cancer, but friends and family and patient support groups remain important sources of support for many patients.

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. We were 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. Findings are set out in Figure 19.

The largest proportion of respondents in most of the countries said that there had been no difference in how easy or hard it was to contact their treatment team, and some had found it easier. However, a significant proportion of respondents in most countries had found it harder to contact their treatment team, and some patients had held back from contact because they thought their team was so busy.

A large proportion of respondents in most countries said their treatment had continued as normal. However, a small proportion of respondents in some countries said treatment had been delayed or cancelled – a concern given the seriousness and urgency of a cancer diagnosis.

While a larger proportion of respondents said they continued to attend appointments during the pandemic, a small proportion of respondents in most countries had been reluctant to attend for fear of infection, and a few patients said they had missed appointments because of this.

In most countries, respondents indicated that face-to-face appointments had been swapped for 'virtual' i.e. video or telephone appointments. The effectiveness / popularity of this shift to virtual appointments is explored in later questions.

Some patients said they had been offered new services, including online information and support groups and home delivery of medicines.

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

	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
Taiwan n= 450	6%	48%	1%	4%	49%	2%
Netherlands n= 169	10%	55%	5%	5%	37%	9%
USA n= 124	4%	60%	11%	6%	49%	6%
Italy n= 94	7%	45%	11%	4%	54%	4%
Denmark n= 60	2%	58%	7%	5%	48%	12%
Brazil n= 51	6%	49%	8%	0%	55%	4%
UK n= 47	2%	43%	26%	21%	43%	11%
Canada n= 47	6%	30%	15%	11%	36%	13%
Spain n= 42	5%	48%	14%	10%	60%	7%
Ireland n= 19	11%	21%	16%	11%	11%	11%
Portugal n= 20	0%	55%	5%	15%	50%	0%
Australia n= 10	20%	40%	10%	10%	50%	0%
Mexico n= 5	20%	20%	40%	0%	60%	40%
South Africa n= 4	0%	75%	25%	0%	50%	0%
Bulgaria n= 1	-	-	-	-	-	-
Sweden n= 1	0%	100%	0%	0%	100%	0%
Greece n= 1	0%	0%	100%	0%	0%	0%
Iceland n= 1	0%	0%	0%	0%	0%	0%

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

	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
Taiwan n= 450	7%	33%	3%	0.4%	0%	0.2%
Netherlands n= 169	10%	54%	1%	2%	24%	3%
USA n= 124	7%	53%	8%	1%	39%	8%
Italy n= 94	6%	33%	6%	1%	2%	4%
Denmark n= 60	8%	55%	0%	0%	38%	3%
Brazil n= 51	2%	61%	2%	0%	14%	2%
UK n= 47	6%	49%	4%	4%	85%	9%
Canada n= 47	11%	32%	15%	4%	68%	13%
Spain n= 42	2%	48%	2%	0%	31%	2%
Ireland n= 19	11%	26%	11%	0%	32%	0%
Portugal n= 20	5%	45%	15%	0%	10%	0%
Australia n= 10	0%	50%	0%	0%	40%	20%
Mexico n= 5	0%	60%	20%	20%	0%	0%
South Africa n= 4	0%	75%	25%	0%	0%	0%
Bulgaria n= 1	-	-	-	-	-	-
Sweden n= 1	0%	100%	0%	0%	0%	0%
Greece n= 1	0%	0%	0%	0%	0%	0%
Iceland n= 1	100%	0%	0%	0%	0%	0%

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. As with the previous question which asked respondents to rank the impact of certain emotions. The results have been aggregated and an average of the responses from 1 to 5 have been taken. As such, the higher the number in the column below, the more people from that country stated it was a serious concern for them. The results in Figure 20 below demonstrate the impact of COVID-19 on the wellbeing of those diagnosed with lung cancer.

Figure 20: 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

	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	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
Taiwan n= 440	1.75	1.48	1.63	1.51	1.41	1.67
Netherlands n= 169	1.73	1.46	1.97	1.4	1.36	1.58
USA n= 124	1.57	1.39	1.81	1.46	1.28	1.76
Italy n= 92	1.88	2.04	1.96	1.7	1.63	2.06
Denmark n= 57	1.46	1.52	1.59	1.32	1.36	1.36
Brazil n= 51	1.75	1.73	1.73	1.65	1.59	2.71
UK n= 46	1.8	2.17	2.46	2	1.52	1.89
Canada n= 48	1.91	2	2.43	1.91	1.66	2.16
Spain n= 41	1.75	1.75	1.89	1.49	1.34	1.58
Ireland n= 20	2.65	2.56	2.79	2.8	1.89	2.63
Portugal n= 17	2.41	2.07	2.07	2.2	1.5	1.94
Australia n= 10	1.5	1.5	1.3	1	1	1.7
Mexico n= 5	2.6	2.2	2.6	2.4	1.6	2.6
South Africa n= 4	2	1.75	2	2	2	2
Bulgaria n= 1	-	-	-	-	-	-
Sweden n= 1	2	1	3	1	1	2
Greece n= 1	4	4	4	4	4	-
Iceland n= 1	1	1	1	1	1	1

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 to maintain support for patients when face-to-face options were not as easily available. New technologies and telehealth are now increasingly used in many countries 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.

Figure 21: 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

	Telephone	Video	In person	No, I have not been in contact with my treatment team at all, but I wanted to	No, I have not been in contact with my treatment team at all, but I haven't needed / wanted to
Taiwan n= 445	11%	1%	68%	4%	22%
Netherlands n= 168	75%	14%	86%	1%	3%
USA n= 124	65%	47%	81%	0%	3%
Italy n= 95	40%	4%	67%	11%	6%
Denmark n= 61	62%	0%	70%	5%	13%
Brazil n= 51	41%	14%	92%	2%	0%
UK n= 48	94%	17%	67%	0%	2%
Canada n= 48	81%	13%	60%	8%	10%
Spain n= 42	60%	0%	88%	0%	5%
Ireland n= 20	60%	5%	80%	5%	0%
Portugal n= 19	32%	0%	84%	5%	0%
Australia n= 10	90%	20%	90%	0%	0%
Mexico n= 5	20%	0%	80%	20%	0%
South Africa n= 4	0%	0%	75%	0%	25%
Bulgaria n= 1	-	-	-	-	-
Sweden n= 1	100%	100%	100%	0%	0%
Greece n= 1	100%	0%	0%	0%	0%
Iceland n= 1	0%	0%	0%	100%	0%

The results show that the majority patients in most countries have continued to see treatment teams in person. Telephone and video appointments have also been used through the pandemic, but video was less common apart from in the USA where nearly half (47%) of respondents said this was an option for them. Patients' opinions of virtual consultations are explored in further questions.

In most countries there was a small proportion of respondents who said they have not been in contact with their treatment teams but wanted to. It is essential that patients can contact their treatment teams when they need to, and all patients should be encouraged to seek help when they need it.

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 could not speak to their treatment team.

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

	In person is the only option and I am worried about infection	In person is the only option and I can't travel	A video call has been offered but I don't have a computer / smartphone	A video call has been offered but I don't know how	A phone call has been offered but I can't hear well on a phone call	A phone call has been offered but I don't want to do a phone call	Other
Taiwan n= 16	50%	19%	0%	0%	6%	0%	33%
Netherlands n= 2	50%	0%	0%	0%	0%	0%	50%
USA n= 0	-	-	-	-	-	-	-
Italy n= 7	14%	14%	14%	0%	0%	0%	57%
Denmark n= 3	0%	33%	0%	0%	0%	0%	67%
Brazil n= 1	0%	0%	0%	0%	0%	0%	100%
UK n= 0	-	-	-	-	-	-	-
Canada n= 3	33%	0%	0%	0%	0%	33%	33%
Spain n= 0	-	-	-	-	-	-	-
Ireland n= 2	0%	0%	0%	0%	0%	0%	100%
Portugal n=	0%	0%	0%	0%	0%	0%	0%
Australia n= 0	-	-	-	-	-	-	-
Mexico n= 1	100%	0%	0%	0%	0%	0%	0%
South Africa n= 0	-	-	-	-	-	-	-
Bulgaria n= 0	-	-	-	-	-	-	-
Sweden n= 0	-	-	-	-	-	-	-
Greece n= 0	-	-	-	-	-	-	-
Iceland n= 1	0%	0%	0%	0%	0%	0%	100%

The results show the range of reasons why people were not able to speak to their treatment teams. The most common responses were that in-person was the only option and patients were either reluctant to attend for fear of infection or unable to travel.

What do people think of video or telephone consultations?

For respondents who had said they contacted their treatment team by video or telephone, we asked what their opinion was of using these methods. People could choose more than one option.

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

	I found it quicker	I found it helpful as I don't have to travel to hospital as much	I prefer face-to-face appointments	I found it more difficult to understand my treatment team / make myself understood	I don't like it and I want to stop as soon as possible
Taiwan n= 56	41%	43%	29%	11%	0%
Netherlands n= 127	13%	50%	57%	6%	3%
USA n= 93	18%	52%	63%	3%	6%
Italy n= 40	25%	45%	50%	5%	10%
Denmark n= 38	18%	24%	55%	3%	0%
Brazil n= 21	24%	52%	33%	10%	0%
UK n= 45	24%	33%	73%	16%	9%
Canada n= 39	26%	59%	49%	13%	5%
Spain n= 25	20%	56%	48%	8%	8%
Ireland n= 13	31%	54%	54%	0%	0%
Portugal n= 7	14%	29%	86%	0%	43%
Australia n= 9	11%	22%	100%	11%	0%
Mexico n= 1	100%	0%	100%	0%	0%
South Africa n= 0	-	-	-	-	-
Bulgaria n=	-	-	-	-	-
Sweden n= 1	0%	0%	100%	0%	0%
Greece n= 0	-	-	-	-	-
Iceland n= 0	-	-	-	-	-

While many respondents noted the benefits of speaking to their treatment team via phone / video, in terms of speed or not having to travel, a large proportion of respondents in most countries prefer face-to-face appointments.

Some respondents said they had difficulties with understanding their treatment team or making themselves understood over the telephone or on a video call. Only a small proportion of respondents said they wanted to stop having virtual appointments (except in Portugal, where a larger proportion of respondents indicated that was the case).

As healthcare systems begin to recover from COVID-19, it is essential that a range of contact methods are offered to patients, recognising that people have different needs.

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

Respondents were asked how they would like to have a conversation with their treatment team when finding out their diagnosis, at the first consultation, regular check-ups, if there was a change to treatment and when they are worried about something. The results show that most respondents in most countries prefer face-to-face in all situations. However, telephone was acceptable for a larger proportion of patients if they are worried about something – potentially because this may be quicker to arrange than an in-person appointment.

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

	Finding out about the diagnosis				The first consultation				Regular check ups			
	Video	Phone	Face-to-face	I'm not sure	Video	Phone	Face-to-face	I'm not sure	Video	Phone	Face-to-face	I'm not sure
Taiwan n= 440	8%	12%	88%	6%	5%	8%	89%	4%	11%	11%	89%	2%
Netherlands n= 169	1%	4%	94%	1%	0%	1%	99%	0%	7%	21%	72%	1%
USA n= 124	12%	15%	90%	2%	4%	2%	97%	1%	34%	17%	80%	1%
Italy n= 94	6%	1%	92%	1%	5%	1%	92%	2%	9%	7%	84%	1%
Denmark n= 59	0%	3%	93%	3%	0%	2%	98%	0%	3%	17%	69%	10%
Brazil n= 51	4%	4%	86%	6%	4%	0%	92%	4%	14%	2%	80%	4%
UK n= 48	0%	2%	98%	0%	2%	0%	100%	0%	23%	35%	54%	4%
Canada n= 47	4%	15%	87%	2%	4%	4%	91%	2%	23%	36%	57%	2%
Spain n= 42	0%	2%	95%	5%	0%	0%	98%	2%	17%	24%	71%	0%
Ireland n= 20	5%	5%	100%	0%	0%	0%	100%	0%	22%	33%	78%	6%
Portugal n= 19	5%	0%	100%	0%	6%	0%	100%	0%	6%	11%	83%	6%
Australia n= 10	0%	0%	100%	0%	0%	0%	100%	0%	20%	50%	90%	0%
Mexico n= 5	20%	40%	40%	0%	20%	20%	60%	0%	20%	0%	80%	0%
South Africa n= 4	0%	0%	100%	0%	0%	0%	100%	0%	0%	0%	100%	0%
Bulgaria n= 1	-	-	-	-	-	-	-	-	-	-	-	-
Sweden n= 1	0%	0%	100%	0%	0%	0%	100%	0%	100%	0%	0%	0%
Greece n= 1	100%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%	0%
Iceland n= 1	0%	0%	100%	0%	0%	0%	100%	0%	0%	0%	100%	0%

Figure 24b: How would you like to have a conversation with the treatment team in the following situations? (Tick all that apply). Results for 2021

	If there is a change to treatment				If I'm worried about something			
	Video	Phone	Face-to-face	I'm not sure	Video	Phone	Face-to-face	I'm not sure
Taiwan n= 440	9%	10%	87%	3%	10%	26%	74%	5%
Netherlands n= 169	2%	5%	90%	3%	4%	34%	60%	2%
USA n= 124	21%	14%	86%	2%	36%	36%	61%	5%
Italy n= 94	7%	8%	85%	1%	7%	32%	59%	2%
Denmark n= 59	0%	2%	97%	2%	3%	38%	48%	10%
Brazil n= 51	4%	6%	82%	8%	10%	24%	55%	12%
UK n= 48	19%	17%	77%	4%	10%	48%	67%	2%
Canada n= 47	11%	23%	77%	0%	17%	45%	55%	0%
Spain n= 42	5%	0%	95%	2%	14%	36%	67%	0%
Ireland n= 20	11%	21%	84%	5%	16%	53%	53%	11%
Portugal n= 19	6%	6%	94%	0%	22%	28%	78%	0%
Australia n= 10	10%	20%	90%	10%	20%	50%	90%	0%
Mexico n= 5	20%	20%	80%	0%	20%	60%	20%	0%
South Africa n= 4	0%	0%	100%	0%	0%	50%	75%	0%
Bulgaria n= 1	-	-	-	-	-	-	-	-
Sweden n= 1	0%	0%	100%	0%	100%	100%	0%	0%
Greece n= 1	0%	0%	0%	0%	0%	0%	0%	0%
Iceland n= 1	0%	0%	100%	0%	0%	0%	100%	0%

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.

Sources of information

The GLCC wanted to find out where people with lung cancer would look for information. Respondents could choose from seven options, with an 'other' option to allow respondents to specify other sources.

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

	Treatment team			Patient support organisation			Other people with lung cancer			Friends or family		
	I have / will	I didn't know I could	I don't want to	I have / will	I didn't know I could	I don't want to	I have / will	I didn't know I could	I don't want to	I have / will	I didn't know I could	I don't want to
Taiwan n= 442	79%	18%	3%	86%	11%	3%	84%	13%	3%	81%	8%	11%
Netherlands n= 169	88%	5%	7%	64%	12%	24%	70%	7%	23%	63%	0%	37%
USA n= 123	98%	0%	3%	81%	2%	17%	82%	3%	15%	74%	2%	24%
Italy n= 91	89%	9%	2%	59%	23%	19%	62%	17%	21%	74%	1%	24%
Denmark n= 58	91%	3%	5%	61%	14%	25%	67%	6%	27%	54%	2%	44%
Brazil n= 49	88%	2%	6%	52%	13%	9%	58%	20%	9%	74%	19%	6%
UK n= 48	94%	4%	2%	81%	4%	15%	80%	4%	16%	49%	2%	49%
Canada n= 46	87%	13%	0%	75%	10%	15%	81%	12%	7%	77%	5%	19%
Spain n= 42	97%	2%	0%	83%	5%	13%	79%	5%	16%	59%	0%	41%
Ireland n= 20	80%	20%	0%	50%	44%	6%	50%	19%	31%	94%	0%	6%
Portugal n= 19	100%	0%	0%	46%	8%	46%	56%	13%	31%	93%	0%	7%
Australia n= 10	80%	20%	0%	50%	10%	40%	50%	20%	30%	60%	0%	40%
Mexico n= 5	80%	20%	0%	80%	20%	0%	80%	0%	20%	80%	0%	20%
South Africa n= 4	50%	50%	0%	75%	25%	0%	75%	25%	0%	75%	25%	0%
Bulgaria n= 1	-	-	-	-	-	-	-	-	-	-	-	-
Sweden n= 1	100%	0%	0%	100%	0%	0%	100%	0%	0%	100%	0%	0%
Greece n= 1	-	-	-	-	-	-	-	-	-	-	-	-
Iceland n= 1	0%	100%	0%	0%	0%	100%	0%	0%	100%	0%	0%	100%

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

	The internet			Social media			Pharmaceutical company		
	I have / will	I didn't know I could	I don't want to	I have / will	I didn't know I could	I don't want to	I have / will	I didn't know I could	I don't want to
Taiwan n= 442	93%	4%	2%	90%	6%	3%	44%	41%	15%
Netherlands n= 169	79%	0%	21%	58%	2%	40%	21%	17%	61%
USA n= 123	83%	2%	16%	54%	2%	44%	61%	6%	33%
Italy n= 91	72%	2%	26%	68%	3%	30%	35%	30%	35%
Denmark n= 58	73%	0%	27%	40%	2%	57%	27%	17%	56%
Brazil n= 49	75%	13%	4%	63%	21%	10%	33%	23%	13%
UK n= 48	81%	4%	15%	53%	0%	47%	30%	26%	43%
Canada n=	79%	2%	19%	64%	2%	33%	50%	18%	33%
Spain n=	54%	0%	46%	40%	0%	59%	43%	11%	46%
Ireland n=	65%	0%	35%	21%	7%	71%	14%	14%	71%
Portugal n=	56%	0%	44%	43%	0%	57%	31%	15%	54%
Australia n=	90%	0%	10%	70%	0%	30%	60%	20%	20%
Mexico n=	80%	0%	20%	20%	40%	40%	20%	60%	20%
South Africa n=	75%	25%	0%	75%	25%	0%	25%	75%	0%
Bulgaria n= 1	-	-	-	-	-	-	-	-	-
Sweden n= 1	100%	0%	0%	100%	0%	0%	100%	0%	0%
Greece n= 1	-	-	-	-	-	-	-	-	-
Iceland n= 1	100%	0%	0%	100%	0%	0%	0%	0%	100%

The results indicate that many respondents have sought, or would be open to receiving, information from a range of different sources. This indicates the importance of having good signposting so that patients can easily find the high-quality, reliable information they need. Further studies could explore:

- The reasons why people chose certain options and not others
- What kinds of information people want from different sources
- How organisations can signpost patients to places where they can 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, and whether they preferred conversations or information that they can refer to again later.

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

	A conversation in person	A conversation over the phone	A conversation on video call	Something I can read e.g. a leaflet / booklet	Something I can view online e.g. a website / social media	Something I can listen to e.g. a podcast	Something I can watch e.g. a video
Taiwan n= 439	54%	21%	12%	42%	80%	37%	41%
Netherlands n= 167	62%	23%	13%	54%	59%	10%	30%
USA n= 121	87%	63%	61%	69%	69%	34%	60%
Italy n= 92	83%	20%	18%	21%	35%	7%	24%
Denmark n= 59	85%	46%	14%	42%	44%	14%	25%
Brazil n= 49	41%	24%	27%	31%	55%	18%	47%
UK n= 49	84%	61%	35%	61%	61%	16%	39%
Canada n= 47	74%	64%	38%	55%	62%	32%	49%
Spain n= 42	88%	14%	17%	31%	45%	10%	29%
Ireland n= 19	89%	58%	32%	68%	32%	21%	21%
Portugal n= 19	79%	32%	16%	16%	16%	11%	11%
Australia n= 10	90%	40%	50%	70%	90%	40%	40%
Mexico n= 5	60%	40%	20%	20%	20%	0%	20%
South Africa n= 4	75%	50%	50%	50%	75%	50%	75%
Bulgaria n= 0	-	-	-	-	-	-	-
Sweden n= 1	100%	100%	100%	100%	100%	100%	100%
Greece n= 0	-	-	-	-	-	-	-
Iceland n= 1	100%	0%	100%	100%	100%	0%	100%

The results demonstrate that respondents want to receive information in different formats, but in person conversations and materials to view online or read were the most popular options in most countries.

Further work could be undertaken to explore whether the type of information being conveyed affects people's preferred formats for receiving it.

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 study and the work of the GLCC please visit our website at www.lungcancercoalition.org or email our secretariat at: glcc@roycastle.org

References

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