

Contact and communication during COVID-19: insights from the Global Lung Cancer Coalition's 2021 patient experience survey

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Background

The Global Lung Cancer Coalition (GLCC) is a partnership of 42 patient 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 importance of communication between patients and their treatment team

Lung cancer is an aggressive disease and, as soon as a diagnosis is made, patients need to have rapid access to high quality treatment and care. Patients and their families will have to take in new and often complex information about their diagnosis, its implications and potential treatment options. At the same time, the treatment team needs to listen to and understand each patient's individual situation, preferences, hopes and fears, so that their needs can be met in a holistic way.

Good communication between patient and treatment team is essential. But the COVID-19 pandemic changed the way that treatment teams were able to communicate with patients. For example, many hospitals switched to telephone or video consultations in an effort to maintain support for patients but without having to bring them into hospital for a face-to-face consultation. The GLCC used its 2021 patient experience survey to explore how COVID-19 had changed communication between patients and their treatment team, and what they thought about video or telephone consultations.

Key findings and calls to action

Despite services being stretched, most patients were still able to contact their treatment team when they needed to. However, **some patients noted they found it more difficult to contact their treatment team or held back in doing so because of the pandemic.** All patients should be encouraged to still contact their medical team when they need them, and be able to access the advice and support they need.

As healthcare systems recover from COVID-19, patients' perspectives on virtual consultations must be considered to ensure they work for everyone. Most lung cancer patients responding to the survey said they prefer face-to-face appointments in all situations. While some patients saw advantages to telephone or video options, others found them difficult and wanted to stop as soon as possible.

How easy did patients find it to contact their treatment teams during COVID-19?

We wanted to ask patients how easy or difficult they found it to contact their treatment team during COVID-19. We set out a number of statements to explore this, as well as to ask whether patients had continued to see their treatment team in-person or had virtual consultations. People could select the options that best described their experience. Findings are set out in Tables 1a – 1b in the appendix.

The findings show that 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, perhaps because of the introduction of telephone or video options.

However, a significant proportion of respondents in most countries said they had found it harder to contact their treatment team, and some patients had even 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 urgency of a lung 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 said they had been reluctant to attend for fear of infection, and a few patients said they had missed appointments because of this. We note that the survey was run before most countries had been able to offer vaccinations against COVID-19, so the level of anxiety may be different now.

In most countries, respondents indicated that face-to-face appointments had been swapped for 'virtual' i.e. video or telephone appointments. Patients' views on this shift to virtual appointments is explored later in this briefing. Some patients said they had been offered new services, including online information and support groups and home delivery of medicines.

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 reassure patients that they should seek help from their treatment teams when they need it, and not hold back from doing so because their team is busy
- Whether patients are still afraid to attend face-to-face appointments for fear of infection and, if so, how they can be reassured and supported
- The impact of delays to lung cancer treatment, and how services can be supported to recover as quickly as possible

How did lung cancer patients contact their treatment teams during COVID-19?

We also asked patients how they had been in contact with their treatment team during the pandemic, giving telephone, video and in-person as options (they could choose more than one). We also gave options for patients who had not been in touch with their treatment team to tell us whether they would have liked to or whether this was because they didn't need to.

Responses to this question are in table 2a in the appendix. 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 be. All patients should be able to contact their treatment teams when they need to. We asked these patients why they had not been in contact with their treatment team, giving possible reasons and an 'other' option. Answers are in table 2b in the appendix.

There was only a small number of responses to this question but the most common answers for lack of contact were that in-person was the only option and either the fear of infection was too great or that travelling was not possible. A few patients gave other reasons including having multiple teams passing responsibility for their care, not feeling that their concerns are being taken seriously and no contact at all from their treatment team

What do lung cancer patients think of virtual consultations?

We asked those respondents who said they had a consultation with their treatment team via phone or video call, what they thought about it. People could choose more than one option. The responses to this question can be found in table 3 in the appendix.

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 recover from COVID-19, patients' perspectives on virtual consultations must be considered to ensure they work for everyone, with in-person alternatives available for those who find speaking to their team via video or telephone difficult.

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

While there may be instances that conducting appointments via telephone or video is mutually beneficial to patient and clinician, there may be instances where this is not the case. We gave respondents a range of scenarios and asked them if they would be comfortable speaking to their treatment team via video, telephone or in-person. These scenarios consisted of:

- The diagnosis
- The first consultation
- Regular catch ups
- Change to treatment
- If they were worried about something.

The results to this question can be found in tables 4a and 4b of the appendix. Responses to finding out the diagnosis and the first consultation were almost exclusively face-to-face. Receiving a lung cancer diagnosis can be anxiety inducing and having to do so alone is clearly extremely daunting for many. Regular check-ups and changing treatment were also favoured in a face-to-face format, although more people did say they would be comfortable having these conversations virtually.

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

- If they are representative of the lung cancer patient population in their country
- How to ensure that every patient feels comfortable in the way they are able to contact and communicate with their treatment team, whether in-person or virtually

Acknowledgments

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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 or email our secretariat at: glcc@roycastle.org

Appendix

Table 1a: responses to the question “Which of the following describes your experience during COVID-19?”

	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%

Table 1b: responses to the question “Which of the following describes your experience during COVID-19?”

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

Table 2a: responses to the question “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?”

	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%

Table 3: responses to the question “What is your opinion on contacting your treatment team by video or telephone?”

	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	-	-	-	-	-

Table 4a: responses to the question “How would you like to have a conversation with the treatment team in the following situations?”

	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%

Table 4b: responses to the question “How would you like to have a conversation with the treatment team in the following situations?”

	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%