

Delays to lung cancer diagnosis: 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 has responded.

The importance of early diagnosis in lung cancer

The earlier lung cancer is suspected and the faster the patient is diagnosed, the better their chance of having successful treatment and living for longer. Most countries do not yet have lung cancer screening programmes in place, although many are considering introducing them. At present, therefore, early diagnosis depends on people being aware of possible symptoms of lung cancer, presenting to their doctor for investigations, and being referred quickly for tests to confirm the diagnosis. Any delays during this process could compromise someone's chances of survival.

We wanted to understand more about patients' experiences of diagnosis. During the COVID-19 pandemic, with healthcare services under pressure, we know that some patients have found it harder to get appointments or may indeed have held back from seeking help even when they had symptoms they were worried about.

In our 2021 survey, we asked new questions to find out if lung cancer patients were satisfied with the time it took to receive their diagnosis or whether they thought there was any delay at any point. This could have been a delay in seeing someone to get symptoms checked, to the testing process, to receiving their test results.

Key finding and call to action

Not all lung cancer patients are experiencing a smooth diagnostic pathway. Although a majority of patients in all countries are satisfied with the time it took to get their diagnosis, the survey findings indicate that nearly every country has a proportion of respondents who believe there was an unnecessary delay to their diagnosis. **No country has room for complacency on early diagnosis, and every country can work to improve early detection, rapid referral and diagnosis pathways.** We also urge all countries to consider, if they are not already, **introducing a national lung cancer screening programme** to identify people with lung cancer even before they may have symptoms.

Do lung cancer patients feel they could have been diagnosed sooner?

In the GLCC patient experience survey for 2021, we asked patients if they felt that there was an unnecessary delay in getting their diagnosis. Asking this question again in future surveys may help to indicate the impact that the COVID-19 pandemic has had on the speed of lung cancer diagnosis and how quickly services have been able to recover.

The table below sets out their responses. Please note that respondents could choose more than one option, and, in some countries, the small number of responses affects the percentages.

Table 1: survey responses to the question ‘Would you say there was an unnecessary delay in getting your diagnosis?’

	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%

Encouragingly, the responses demonstrate that there is a majority of patients in all countries who are satisfied with the time it took to get their diagnosis. Portugal received the highest number of respondents who were satisfied with the time it took to receive their diagnosis at 75% (discounting those countries who only received one response) followed by the USA and Denmark on 71%.

However, the results also show that more can be done in every country to make sure that lung cancer patients are diagnosed without delay.

Even in the best performing countries, there are significant proportions of respondents who were dissatisfied with the time it took to receive their diagnosis. Respondents said they experienced delays in different parts of the pathway, from first seeing someone to discuss symptoms, to getting tested, and in waiting for test results.

Efforts must be made to ensure that every person coming forward with symptoms can be quickly assessed and have rapid access to investigations, with quick reporting of results to reduce the anxiety of waiting for a confirmed diagnosis and allow appropriate treatment to start.

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 can be done to reduce the delays noted by patients responding to this survey
- Consider, if they are not already, the value of introducing national lung cancer screening programmes, to identify people at the earliest stages and before they may even have symptoms

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, the UK, and the 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